

BURNING NIGHTS CRPS SUPPORT

England & Wales · Charity number 1166522

Details

Status Registered

Legal form CIO

Registered 2016-04-13

Register [View on the Charity Commission register](#)

Contact

Address 1 Alder Brook
Chinley
High Peak
SK23 6DN

Phone 01663795055

Email news@burningnightscrps.org

Website <http://www.burningnightscrps.org>

Activities

Objects: 1) TO PROMOTE AND PROTECT THE HEALTH OF SUFFERERS OF COMPLEX REGIONAL PAIN SYNDROME (CRPS), THEIR FAMILIES AND CARERS BY THE PROVISION OF INFORMATION, ADVICE AND SUPPORT INCLUDING RAISING AWARENESS OF ALL ASPECTS OF CRPS AMONGST THE PUBLIC IN GENERAL BUT IN PARTICULAR THOSE INVOLVED IN THE DIAGNOSIS, TREATMENT AND CARE OF THOSE SUFFERING FROM CRPS; AND2) TO ASSIST AND SUPPORT RESEARCH INTO CRPS, ITS CAUSES, TREATMENT AND CURE AND TO ENSURE THE USEFUL RESULTS OF SUCH RESEARCH ARE PUBLISHED.

Activities: Burning Nights CRPS works to improve life for those affected by Complex Regional Pain Syndrome (CRPS) as well as healthcare, legal & the public. We offer Counselling & Therapy Service, Befriending Scheme, online support groups, annual conference, Helpline, general support, information & more. We provide awareness training, seminars & conferences for healthcare professionals and students.

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£81,784	£93,983	-	-
2024-03-31	£62,673	£91,533	-	-
2023-03-31	£64,836	£80,052	-	-
2022-03-31	£84,469	£59,669	-	-
2021-03-31	£54,286	£25,179	-	-

Trustees

Name	Role	Appointed
VICTORIA ABBOTT-FLEMING MBE	Chair	2015-05-01
ALTAF PATEL		2016-01-01
Lisa Davis		2017-08-01
Rachel O'Brien		2024-09-24
Richard Anthony Ingham		2022-11-22

Accounts

Report of the Trustees and
Unaudited Financial Statements for the Year Ended 31 March 2025
for
Burning Nights CRPS

Contents of the Financial Statements
for the Year Ended 31 March 2025

	Page
Report of the Trustees	1 to 21
Independent Examiner's Report	22
Statement of Financial Activities	23
Balance Sheet	24
Notes to the Financial Statements	25 to 30
Detailed Statement of Financial Activities	31 to 32

The trustees present their report with the financial statements of the charity for the year ended 31 March 2025. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Summary of the objects of the charity

The purposes and objectives of Burning Nights CRPS Support, as in our governing document, remain central to everything we do. They are:

- To promote and protect the health of people living with Complex Regional Pain Syndrome (CRPS), along with their families and carers, through the provision of information, advice and emotional and practical support. This includes raising awareness of all aspects of CRPS among the public and, importantly, among those involved in the diagnosis, treatment and care of people living with CRPS.
- To assist and support research into CRPS-its causes, treatments, management and potential cure-and to ensure that the useful results of such research are shared and published for the public benefit.

In line with these aims and objectives, we provide a wide range of support services for anyone impacted by CRPS, including those living with CRPS, their families, loved ones and carers, including mental health support through our online Counselling & Psychotherapy Service for adults, children and young people aged 5 and over. We also offer emotional support through our Befriending Service plus a telephone helpline, live web chat, online support groups, an active community forum, educational information and a range of wellbeing and community-based activities.

We support both adults and children, recognising that CRPS can impact individuals of any age. We also provide dedicated support for families, young carers, and close friends, as a diagnosis of CRPS can have a profound ripple effect on everyone surrounding the person living with the condition.

These charitable purposes guide all our work, ensuring that the services we deliver, the awareness we raise, and the research we support directly contribute to improving the lives and wellbeing of the CRPS community.

OBJECTIVES AND ACTIVITIES

Objectives, strategies and activities

We want to begin by expressing our sincere gratitude to everyone who has been part of Burning Nights CRPS Support this year—our incredible volunteers, Trustees, supporters, fundraisers, members, partners and the wider community. It is only because of your dedication, compassion and belief in our aims and objectives that we are able to continue providing vital support and champion much-needed change for people living with Complex Regional Pain Syndrome (CRPS) and their families.

Whether you've helped run our support services, shared your lived experience to raise awareness, taken part in our events, joined our webinars, contributed to our magazine, or simply cheered on our fundraisers from the sidelines—every single act of support makes a profound difference. You help ensure that no one affected by CRPS feels alone.

We also want to extend a special thank you to our extraordinary fundraisers, who once again have gone above and beyond this year. Your energy, creativity and determination continue to power our charity forward and allow us to keep offering the services our community relies on so deeply.

Complex Regional Pain Syndrome (CRPS) continues to have a profound impact on the lives of people across the UK. It is a severe, often invisible condition that can lead to significant physical, emotional and social challenges. Many people describe feeling isolated, misunderstood, and unsure where to turn for reliable information or compassionate support.

Burning Nights CRPS Support exists to change that experience. As a national, patient-led charity, our work is grounded in lived experience and guided by the voices of people directly affected by CRPS, alongside their families and carers. Throughout the year 2024-2025, we have remained committed to improving understanding of the condition, reducing isolation, and providing accessible support services for all those who need them.

Our activities span three key areas:

- **Support:** delivering direct services such as counselling and psychotherapy, support groups, the helpline, befriending and peer-led initiatives.
- **Information:** providing clear, trustworthy resources to help people navigate life with CRPS and make informed decisions about their care.
- **Awareness:** and Advocacy: amplifying the patient and carer voice to influence policy, improve care pathways and raise awareness across health, social care and the wider public.

Through these key areas, we work to ensure that anyone affected by CRPS can access the understanding, connection and hope they deserve. Although CRPS is a rare and complex condition, we remain committed to ensuring that no one has to face it alone.

In planning and delivering our activities, the trustees had full regard to the Charity Commission's guidance on public benefit. Our work remains focused on supporting people impacted by CRPS, reducing isolation, providing accurate information and ensuring our services are accessible to all.

During the year, our main activities and projects included:

Providing direct support for people with CRPS, their families, close friends and carers through our:

- telephone helpline
- live web chat service
- email support
- online community forum
- social media support
- and peer-led online support groups

OBJECTIVES AND ACTIVITIES

Delivering ongoing mental health and emotional support, including our:

- CRPS Counselling & Psychotherapy Service for adults, children, and young people aged 5+
- Virtual Befriending Service offering one-to-one weekly support calls for up to 12 sessions.

Running regular wellbeing activities such as Zentangle sessions, which followed on from our previous Wellbeing Wednesday project and continued to offer accessible wellbeing support for our community.

Producing educational information, updating and publishing new resources, providing CRPS awareness materials and distributing printed literature to hospitals, clinics and community groups across the UK.

Hosting educational events, including our annual CRPS Patients & Carers Information Day, with expert speakers and opportunities for attendees to learn about condition management, research developments and support options.

Launching and starting to deliver a new series of 10 monthly CRPS Education webinars in partnership with Healthsec Rehab, offering high-quality, patient-centred information on pain, mobility, rehabilitation, mental wellbeing, self-management and practical strategies for day-to-day life with CRPS. These webinars have been well received by our members and wider community, with all sessions recorded and made available for ongoing access.

Continuing to build our membership scheme, including the biannual publication of The Warriors Lifeline magazine, which features research updates, personal stories, wellbeing content and educational articles to support the community.

Maintaining and expanding our online presence, continuing to grow our social media following, share CRPS information and research and respond to individual support queries across multiple platforms.

Supporting research, including ongoing involvement in Public and Patient Involvement and Engagement (PPIE) across numerous CRPS and chronic pain studies in the UK and internationally. This included contributing to the Pain-at-Work Toolkit trial, HOPE-AO for pain in older people, the OptiMeth Trial for CRPS, and promoting research participation opportunities to our community.

Raising awareness, delivering talks, attending exhibitions, taking part in campaigning and advocacy work, and engaging with healthcare professionals, policymakers and students to improve understanding of CRPS and the challenges individuals face.

Providing information and community resources, including our website with regularly updated content, educational sections for healthcare professionals and students, a dedicated resource library, and ongoing improvements to content clarity and accessibility.

Engaging our supporters through fundraising activities, challenge events, community initiatives, corporate partnerships and trust and foundation applications to sustain our services.

All of these activities were carried out to advance the charitable purposes of Burning Nights CRPS Support for the public benefit. During a time when many in the CRPS community continue to face long NHS waiting times, gaps in treatment pathways and limited access to mental health support, our services-most of which are free to access-remain a vital source of help, information and connection.

Public benefit

The Trustees have had regard to the Charity Commission's guidance on public benefit.

OBJECTIVES AND ACTIVITIES

Volunteers

Our volunteers continue to be at the heart of Burning Nights CRPS Support. Their contribution is central to our ability to provide national support to people living with Complex Regional Pain Syndrome (CRPS) and those who care for them. This year, volunteers generously gave their time, skills and lived experience across every area of the charity, from counselling and befriending to helpline support, awareness-raising, events, research involvement and governance.

During the year, we held 17 volunteer inductions and welcomed 51 new volunteers into the organisation. By the end of the year, we had 62 active volunteers, each playing a meaningful role in delivering our services and supporting our community.

With the launch of our new e-learning platform, volunteers were able to access consistent, high-quality training that strengthened their confidence and capability in their roles. All volunteers completed core modules in Equality, Diversity & Inclusion (EDI), confidentiality, neurodiversity, GDPR, and CRPS awareness. Volunteers in public-facing or client-support positions undertook further specialist training in mental health awareness, suicide awareness, suicide prevention, self-harm guidance and safeguarding, ensuring they could offer safe, sensitive and appropriate support.

In addition to mandatory training, volunteers also had access to a library of more than 300 further courses, supporting their ongoing learning, wellbeing and professional development.

The dedication and compassion of our volunteers made a significant difference to the lives of people affected by CRPS. Their commitment enabled us to expand our reach, strengthen the quality of our services and ensure that no one has to face CRPS alone.

We extend our deepest gratitude to our extraordinary volunteers. Your unwavering commitment to our mission is truly inspiring and your generous donation of time and skills is profoundly appreciated. Without your support, we wouldn't be where we are today. Thank you for everything you do!

ACHIEVEMENTS AND PERFORMANCE

Charitable activities

During 2024-2025, Burning Nights CRPS Support continued to provide vital support, information and community connection to people impacted by Complex Regional Pain Syndrome (CRPS). This year saw a continued rise in demand for our services, reflecting both the scarcity of CRPS-informed support within statutory services and the growing recognition of our charity as a trusted and accessible source of help.

Across all our services that are mainly volunteer-led we directly supported 4,394 people, and when including our newsletters, reached 8,049 individuals. Each statistic represents a person - often distressed, isolated, or newly diagnosed - reaching out for understanding, reassurance and guidance. The difference our work has made is evident through the feedback, impact quotes and emotional testimonies we received throughout the year.

Below is an overview of our main achievements and the measurable difference they have made to patients living with CRPS, their families, carers and close friends.

Direct Support Services: Being There When It Matters Most

People living with CRPS commonly report feeling dismissed, misunderstood or left without guidance. Our direct support services continue to fill this gap, providing accessible and empathetic support for anyone who needs it.

Our support services remain the centre of Burning Nights CRPS Support, and we are incredibly grateful to all our volunteers who work tirelessly to provide these support services for those who need them.

Our highlights this year:

- Answered 242 live web chats
- Responded to 1,268 emails
- Answered 449 helpline calls which totalled almost 47 hours of support

These services are often the first point of contact for people newly diagnosed, facing a flare-up, or dealing with overwhelming pain, fear, or uncertainty. We frequently support people who have nowhere else to turn.

Impact we made:

- Provided real-time emotional de-escalation
- Helped people to prepare for medical appointments
- Supported people to better communicate with healthcare professionals
- Guided families and carers struggling to understand CRPS
- Reduced isolation and anxiety at critical moments

Beneficiary voices:

"Thank you so much... This was the most helpful conversation I've had to date." - T.A., Live Chat (Aug 2024)

"You've been very helpful - I'm not freaking out so much anymore." - K.M., Live Chat (Sept 2024)

"Your replies... got me back on track." - Jen (2024)

Counselling & Psychotherapy Service: Life-Changing Mental Health Support

Mental health is one of the most significant unmet needs for people impacted by CRPS, whether that's someone living with the condition, a family member or carer. Many face trauma, fear, isolation and depression - often compounded by long NHS waiting lists and clinicians unfamiliar with CRPS.

Burning Nights CRPS

Report of the Trustees for the Year Ended 31 March 2025

During this year we were delighted to receive National Lottery funding to fund a Clinical Lead for 10 hours per week. The Clinical Lead started in her post in February 2025 and she has really started to improve the service even more than it was.

Our therapy service offers up to 20, one-hour sessions per client for those aged 12 and over, for those under 12s we offer 10, 45-minute sessions, ensuring depth, continuity and sustained emotional support.

Our highlights this year:

- 189 active clients received therapy
- 520 specialist pain management related therapy sessions were delivered by 10 volunteer qualified and trained counsellors and therapists, with 4 clinical supervisors

Impact we made:

- Reduced anxiety, panic and distress
- Improved coping strategies for pain and flare-up cycles
- Strengthened emotional resilience
- Reduced suicidal ideation
- Positive impacts on family relationships and daily functioning

Beneficiary voices:

"The service has genuinely changed my life for the better... My counsellor set me up for life." - AD (2024-25)

"I've had counselling before, but never experienced a positive effect like I have this time." - MC (2024-25)

"I am so grateful... This has been life-changing for me." - WP (2024-25)

"My life... took a positive turn when I discovered Burning Nights CRPS Support." - JMB (2024)

This service continues to prevent mental health in the CRPS community, reduce loneliness and provide tools for long-term psychological wellbeing.

Befriending Service: Reducing Loneliness and Isolation

For many with CRPS, pain forces a retreat from everyday life. Families and carers can become frustrated and lonely. The Befriending Service offers 12 weekly calls or Zoom video calls and they allow for supportive conversations with trained lived experience volunteers who understand the condition and its emotional impact.

Our highlights this year:

- 10 new clients began befriending
- 106 befriending sessions delivered
- 5 volunteer befrienders with lived experience of CRPS

Impact we made:

- Reduced social isolation
- Reduced level of loneliness
- Increased confidence and emotional stability
- Provided a safe space to talk openly about difficult emotions

Beneficiary voices:

"Feeling so scared... but she made me feel not so alone and very understood." - EH (2024-25)

"It is a great service, especially when you can build up a good relationship with the befriender. [Befriender] was flexible when I was too ill to take the call and made sure she informed me of when the next call would be. She always remembered previous conversations and would often refer back to them in the following calls. I do wish to say thank you to [befriender] and to Burning Nights CRPS." - WE (2024-2025)

Support Groups: Creating Connection and Community

Our online peer-led support groups continue to be one of the most important ways we bring the CRPS community together. These groups offer a safe, understanding and non-judgemental space where people living with CRPS-and those who care for them-can talk openly about their experiences, ask questions, and gain emotional strength from others who truly understand what they are going through.

Our highlights this year:

- 204 attendees joined our support groups
- 12 support groups were held
- Almost 34.5 hours of shared peer support were delivered

These sessions were run by trained volunteers with lived experience, supported by safeguarding oversight and clear group guidelines to ensure that every participant felt emotionally safe and respected.

Our online support groups serve a wide range of people across the UK and internationally. Many attendees join after receiving a new diagnosis, feeling frightened, confused or unsupported. Others attend during a flare-up or at points where the emotional impact of CRPS becomes overwhelming. For carers and family members, the groups provide space to understand the condition better and learn how to support their loved one while also looking after their own wellbeing.

Each session includes a mixture of facilitated discussion, shared lived experience, signposting to reliable resources and mutual encouragement.

Common themes discussed:

- Managing pain and symptoms
- Dealing with the reactions of family, friends, schools and employers
- The emotional burden of chronic illness
- Maximising the effectiveness of doctor appointments
- Finding CRPS specialists and other healthcare professionals and seeking recommendation

Many participants describe our support groups as a lifeline-often the only place where they feel believed, Validated and surrounded by people who genuinely understand their challenges.

The positive outcomes reported by attendees demonstrate the importance of these sessions. People told us they felt:

- significantly less alone
- more confident in managing their condition
- better informed about CRPS and treatment options
- empowered to advocate for themselves in healthcare settings
- connected to a community that genuinely understands them

Our support groups also help to prevent crisis escalation by giving participants a space to express distress early, seek guidance, and develop stronger coping strategies. This not only benefits individuals and their families, but also reduces pressure on wider health and social care services.

As demand for emotional and peer support continues to rise-particularly among people struggling with delayed diagnosis, long NHS waiting lists, and difficulties accessing specialist care-we remain committed to expanding and strengthening our support group provision. These sessions continue to offer connection, comfort, and hope to people who may otherwise feel invisible or unheard.

Burning Nights CRPS

Report of the Trustees for the Year Ended 31 March 2025

These groups provide a sense of belonging and validation that beneficiaries often struggle to find elsewhere.

Impact feedback:

"Thank you from the bottom of my heart... The help I get from this group and all the lovely people within it helps me immensely." - SA (Sept 2025)

Wellbeing and Online Events: Supporting Whole-Person Health

This year, our wellbeing programme continued to play a vital role in supporting the emotional, mental and creative wellbeing of people living with CRPS. For many within our community, chronic pain affects far more than the body-it disrupts identity, confidence, sleep, relationships and the ability to engage in everyday life. Our wellbeing activities are designed to offer moments of calm, connection and creativity in the midst of overwhelming symptoms and uncertainty.

We continued to offer holistic wellbeing activities and accessible online learning events. Our focus this year were Zentangle groups led by a certified Zentangle Instructor.

Zentangle is a mindful, accessible drawing method that encourages relaxation, focus, and self-expression. These sessions were intentionally created to support people who struggle with high pain levels, anxiety, fatigue, or reduced mobility by offering a gentle, adaptable activity that can be done seated, lying down, or with one hand-making it especially suitable for many people with CRPS.

Our highlights this year:

- 146 wellbeing attendees
- 21 wellbeing events

Many participants joined these sessions at times when they felt overwhelmed, stuck in flare-ups, or emotionally drained. The calm, structured nature of Zentangle helped people to regulate their nervous system, find moments of presence and experience small but meaningful achievements-often in contrast to the loss of control many feel due to CRPS.

During the classes, participants were encouraged to slow their breathing, follow simple patterns and allow their mind to settle. The format also allowed time for gentle conversation and connection with others, which participants repeatedly told us helped them feel grounded and less alone.

Beneficiary voice:

"Thank you so, so much. This was a 'pure joy' activity that brought me back to the present moment." - V, Zentangle Class (April 2024)

CRPS Education: Webinars including launch of the 10-Month Webinar Series with Healthsec Rehab

Aside from 2 (open to all) webinars that we ran during the year, a major new achievement this year was launching our exclusive members' only 10-month CRPS Education Webinar series in conjunction with Healthsec Rehab. Healthsec Rehab is a rehabilitation company that supports veterans and the public with conditions including CRPS.

Following on from a members focus group where we discussed what topics the members wanted from the education series, we devised a series of webinars that covered all the main topics and the subjects within each topic. We began those webinars in February 2025.

This programme has significantly strengthened our educational offer, covering rehabilitation, pacing, flare-up management, mobility, mental health and family/carers communication.

Our highlights this year for the Members' CRPS Education Series

- 4 members' only events

Burning Nights CRPS

Report of the Trustees for the Year Ended 31 March 2025

- 53 members' webinar attendees

Our highlights for our open access online education webinars:

- 2 webinars
- 109 open access attendees

Impact we've made:

- Increased understanding of CRPS and its management
- Improved confidence in communicating with healthcare teams
- Better emotional coping for both patients and families
- Reduced fear related to flare-ups and disease progression

Beneficiary voices:

"Thank you It was incredibly informative and exactly what I needed to understand more about the treatment." - MW (Scrambler Therapy Webinar, April 2024)

"The recent presentation events for members only have been really useful and it is a great way perhaps (I hope!) of attracting new members. The focus on one topic at a time is great." Jan, Annual Feedback Survey 2024-2025

Annual CRPS Conference / Patient & Carer Information Day 2024

One of the highlights of our year was our Annual CRPS Patient & Carer Information Day, which took place at the Hilton Northampton on 16 November 2024. This event continues to be one of the most valued parts of our calendar, bringing together people living with CRPS, their families, carers, and supporters for a full day of learning, connection, and shared experience.

The event welcomed 62 attendees from across the UK, many of whom had never previously met anyone else living with CRPS. For newly diagnosed individuals and long-term patients alike, the day provided a rare opportunity to feel understood, supported, and part of a wider community that truly "gets it." Carers and family members told us how invaluable it was to learn alongside their loved ones, helping them better understand the condition and how to support those they care for.

The programme included expert-led talks covering a range of essential topics, such as pain management, psychological support, rehabilitation strategies, current research and lived-experience insights. Attendees had the chance to engage directly with specialists and exhibitors, to ask questions and receive practical guidance that they could take away and use in their day-to-day lives.

Alongside the educational sessions in the first part of the day, the remainder of the event provided time for informal discussions, peer connection and emotional support. Many attendees told us that simply being in a room with others facing similar challenges made them feel less alone and more hopeful about the future.

Feedback from the day highlighted several key benefits:

- Improved understanding of CRPS and how to manage symptoms
- Increased confidence when speaking with healthcare providers
- Reduced feelings of isolation
- A stronger sense of empowerment and control
- Greater support for carers and families
- Opportunities to meet and connect with others facing similar challenges

For many, the event was described as "reassuring," and "comforting," offering both practical knowledge and emotional renewal. As one attendee shared afterwards, "It's the first time I've felt truly seen and heard since my diagnosis."

The success of the Northampton event reflects the vital need for in-person, CRPS-informed education and connection. It remains a key part of how we deliver public benefit, empower patients and carers, and ensure that no one affected by CRPS has to navigate this condition alone.

Main highlights:

- 62 attendees, including patients, carers, families and professionals
- 100% would recommend the information day

During the day we were delighted to announce that the Victoria Ellen Williams Award for Outstanding Contribution was awarded to a special volunteer who had supported the charity with responding to comments on social media.

These in person events play a crucial role in reducing isolation, improving knowledge and providing direct access to expert perspectives.

Beneficiary voices:

"Great to hear all the information available, the speakers and to also meet up with new people who totally get what you're going through. No need to explain what's wrong!" Anon, CRPS patient

"It was a very informative day that we got a lot of benefit from. My son was very down in the weeks before but now he has spoken to people and sees that he is not alone, he is much happier and has realised that he really needs to push for the support he needs." Parent of a CRPS Patient

ACHIEVEMENTS AND PERFORMANCE

Awareness and Professional Education: Improving Understanding in Society

Improving understanding of CRPS among healthcare professionals remained a key priority this year. We delivered six CRPS awareness sessions around the U.K. and online, totalling almost 10 hours of training to physiotherapists, rehabilitation teams, healthcare students and military recovery services.

These sessions helped clinicians recognise CRPS earlier, understand the lived experience and provide more compassionate, person-centred care. Feedback was highly positive, with professionals reporting greater confidence and clearer insight into how to support patients and families.

This work strengthens care pathways, reduces delays in diagnosis, and contributes to long-term improvements in how CRPS is understood and managed across the health and rehabilitation sectors.

Our highlights this year:

- 6 groups,
- Delivered almost 10 hours of training

Our awareness training covers key topics such as:

- early signs and symptoms of CRPS
- diagnostic considerations and common misconceptions
- the lived experience of CRPS, including psychological and social impact
- flare-up patterns and triggers
- communication approaches that reduce distress and build trust
- pacing, mobility and rehabilitation considerations
- the importance of supporting carers and family members
- safeguarding and mental health concerns specific to CRPS

Each session combines medical insight with lived experience, ensuring professionals hear directly from someone who understands both the science and the daily realities of the condition. This combination-often missing from clinical training-helps professionals rethink their assumptions, adjust their communication, and deepen their empathy.

Feedback from the sessions was overwhelmingly positive, with professionals reporting increased confidence in recognising CRPS earlier and a stronger understanding of how to support patients holistically. Many attendees told us the training was the first time they had received structured education on CRPS, despite years of clinical experience.

Beneficiary voices from professionals:

"Your presentation style was well received... We look forward to seeing you again." - Physio Team (May 2024)

"Thank you so much... That is a real help to better understand the condition." - Physio Participant (March 2025)

These sessions have a long-term social impact by improving care pathways and reducing diagnostic delays.

Online Reach, Community Engagement and Information

Our online presence continues to be one of the most important ways people find us, access information and receive emotional support. For many individuals living with CRPS-especially those who are housebound, shielding, experiencing mobility limitations, or unable to attend in-person appointments-digital support is their primary connection to the outside world.

ACHIEVEMENTS AND PERFORMANCE

This year, **1,662 people received one-to-one support through our social media** channels, where we responded to messages, signposted to services, provided reassurance during flare-ups and helped people navigate difficult conversations with healthcare professionals. Many beneficiaries reach out during moments of crisis or late at night when other services are unavailable, making our digital responsiveness vital.

Our website remains a trusted and widely referenced resource for CRPS information internationally. We continued to update our educational content, add new articles, expand guidance for healthcare professionals, and ensure our information is accessible, clear and grounded in lived experience. Website visitors frequently tell us that they discovered the name of their condition through our pages or finally felt "seen" after reading about symptoms that had been dismissed or misunderstood for years.

Through our monthly newsletters, reaching **3,655 subscribers**, we provided clinical updates, wellbeing resources, research opportunities, lived-experience stories, guidance for managing CRPS and community announcements. These newsletters help keep people connected to a supportive and informed community, particularly those who may not be active on social media or able to join live sessions.

We also continued to grow our online community presence across multiple platforms, using social media to:

- raise awareness of CRPS
- challenge misconceptions
- share stories and experiences
- promote our services
- highlight research and clinical trials
- provide comfort and encouragement during flare-ups

Our highlights this year:

- **67,027 followers** across all our social media channels (Facebook, X, Instagram, Pinterest, YouTube, LinkedIn and TikTok)
- **1,662 people received one-to-one support** through social media
- **3,655 newsletters subscribers**
- Our website remained a major source of accessible CRPS information - **157,230 sessions on our website and 94,675 engaged sessions**
- **351,375 page views on our website**

Our digital work continues to reduce isolation, ensure people can access reliable CRPS information, and provide vital emotional support to those who may otherwise feel forgotten, misunderstood, or invisible.

Impact voices:

"Your posts helped me believe in myself and not be ashamed about my pain." - Lara K. (2024)

"When I found your account I started crying... finally someone speaking about my disease." - @sandra_bzk (June 2024)

"You are a beacon of light in the darkness." - Julia (2024)

Campaigning and Political Engagement

Alongside our support services, raising the profile of CRPS and championing the needs of those affected remains a central part of our work. Throughout 2024-2025, we continued our commitment to campaigning and advocacy to ensure that people living with CRPS have their voices heard within policy, healthcare, and public health decision-making.

ACHIEVEMENTS AND PERFORMANCE

We engaged directly with local politicians across the UK, highlighting the challenges faced by people with CRPS—including delayed diagnosis, lack of specialist services, limited mental health support, and the profound impact the condition has on families and carers. By sharing lived-experience insights, evidence from our helpline and counselling services and the stories of those we support, we helped bring CRPS to the attention of those who influence local and national health priorities.

In Scotland, we continued to play an active role in national chronic pain policy development. We contributed to the Scottish Cross-Party Parliamentary Group for Chronic Pain, offering lived-experience perspectives and raising awareness of the specific needs of people with CRPS within broader pain pathways. Our involvement ensures that CRPS remains visible within ongoing discussions about improving access to treatment, mental health provision and equitable pain care across Scotland.

We also participated in short-life working groups linked to the development of new chronic pain guidelines in Scotland. Our contribution helped shape guidance on patient experience, accessibility and communication for those living with chronic pain conditions. Additionally, we remained engaged with the Third Sector Chronic Pain Network, working collaboratively with other health charities to amplify patient voices and champion improvements across the pain landscape.

Research, PPIE and Advocacy

Burning Nights CRPS Support continued to play an influential and respected role in CRPS and chronic pain research throughout 2024-2025. As a charity rooted in lived experience, we prioritise research that is meaningful, accessible and genuinely shaped by the voices of people living with CRPS, as well as their carers and families.

This year, we contributed to multiple UK and international studies, offering insight, co-design support and Patient and Public Involvement and Engagement (PPIE) leadership across a range of projects. Our involvement helps ensure that research moves beyond academic settings and reflects the real-world experiences, challenges, and needs of those affected by CRPS.

Our work has included:

- supporting NIHR-funded trials related to chronic pain
- contributing to the Pain-at-Work Toolkit evaluation
- involvement in the OptiMeth Trial for CRPS
- promoting accessible research opportunities to our community
- advising on study design, participant materials, ethics and dissemination plans
- ensuring that CRPS research reflects patient priorities and lived-experience realities

We also worked closely with researchers to ensure they adopt accessible communication methods, use patient-friendly language and incorporate feedback from people with CRPS throughout every stage of their projects.

By championing meaningful PPIE, we help influence:

- more person-centred study designs
- improved recruitment and retention of participants
- stronger, more relevant outcomes
- clearer dissemination of findings to the public
- increased visibility of CRPS and chronic pain within academic and clinical research communities

Our involvement in research also brings wider societal benefits by shaping future treatment pathways, raising awareness among employers and clinicians and ensuring new evidence reaches communities that need it most.

ACHIEVEMENTS AND PERFORMANCE

This year, we saw increasing recognition of the crucial role lived experience plays in advancing CRPS understanding. Our continued commitment to accessible, inclusive, and ethically grounded PPIE ensures that people with CRPS-and their carers-are not just participants in research, but partners and co-creators in shaping the future of care.

Our Supporters

We continued to benefit greatly from the dedication of our supporter fundraisers and we thank each and every one of them for showing their support to the charity no matter how they choose to fundraise for us. This year, individuals and community groups took on challenge events, organised sponsored activities, hosted awareness events and raised funds in creative and meaningful ways. Their commitment not only generated essential income for our services but also played a crucial role in raising the profile of CRPS within their communities. Many supporters shared their personal stories publicly for the first time or used their fundraising platforms to educate others about the condition-helping to break stigma, build understanding, and reach people who may be struggling in silence.

We fundraise in a wide variety of ways while also raising as much awareness of Complex Regional Pain Syndrome (CRPS) as possible. Our fundraising activities continue to grow each year, thanks to the dedication and passion of our incredible supporters, volunteers, and partners. Our main fundraising activities include:

- Sponsored challenge events, including places in large national runs and personal endurance challenges taken on by supporters including places in the Great North Run
- Supporting individuals and groups to run their own fundraising initiatives, from bake sales and coffee mornings to sponsored activities, workplace events, and in-memory collections
- Applications to charitable trusts, foundations, and grant-giving organisations, enabling us to fund core services such as counselling, befriending and helpline support
- Email fundraising appeals sent to supporters who have opted in to receive updates
- Social media fundraising campaigns and awareness drives across multiple platforms
- Corporate support, including payroll giving, employee fundraising, matched giving and partnerships with carefully selected organisations

We are incredibly grateful to our community of supporters whose generosity makes our work possible. This year, supporters across the UK took part in a wide range of challenge events, personal fundraisers, and community activities, raising both essential income and crucial awareness of CRPS-a condition still widely misunderstood.

Our supporter-led fundraising continued to grow, with individuals organising sponsored walks, marathons, half-marathons, abseils, group hikes, bake sales, workplace events, and creative awareness activities. From large team challenges to intimate local events, supporters once again found meaningful ways to stand with people affected by CRPS.

We were deeply moved by the dedication of fundraisers who shared their personal stories publicly to raise awareness and donations. For many, fundraising is not only a way to support the charity, but a way to honour a loved one, commemorate a personal journey, or give back to a service that has supported them through the most difficult periods of their lives.

We also continued to receive incredible support from workplaces and corporate teams. Businesses took part in sponsored challenges, dress-down days, bake sales, and awareness events-helping us raise the profile of CRPS within their organisations while generating vital funds for our services.

As a supporter-led charity, we recognise that every pound raised directly contributes to sustaining our helpline, email support, counselling and psychotherapy service, befriending programme, online support groups, wellbeing sessions, and our ongoing campaign to ensure that no one with CRPS feels alone.

We remain committed to fundraising in an honest, transparent, and respectful way. We safeguard privacy, and will never sell or share data with third parties.

ACHIEVEMENTS AND PERFORMANCE

Burning Nights CRPS Support does not use external professional fundraisers. Where appropriate, and in line with legal requirements, we establish Commercial Participator Agreements with sole traders or businesses fundraising for us, ensuring transparency and compliance. We also monitor fundraising activity by reviewing messaging, products and promotional materials to ensure they meet charity standards and uphold our values.

We are immensely grateful to every individual, group, company and funder who supported us this year. Your generosity helps us continue offering life-changing support to those living with CRPS, their families, and their carers-when they need us most.

Supporting Our Volunteers

Throughout the year, we continued to invest in our incredible team of volunteers, whose dedication and compassion underpin everything we do for the CRPS community. Our volunteers play a vital role in providing peer support, delivering services, raising awareness, and helping people feel less alone in what can be an overwhelming and isolating condition.

This year we launched our new online training and e-learning platform, ensuring every volunteer receives consistent, accessible and high-quality training. All volunteers completed our core modules, which covered the essential foundations of Equality, Diversity & Inclusion (EDI), confidentiality, neurodiversity awareness, and GDPR. To strengthen understanding of the condition itself, every volunteer also took part in our CRPS awareness training, delivered through an engaging video followed by a short knowledge check.

Volunteers in forward-facing or client-support roles received additional specialist training through the platform, including mental health awareness, suicide awareness, suicide prevention, self-harm guidance and safeguarding. These sessions were designed to help volunteers feel confident, prepared and supported when engaging with individuals and families during moments of vulnerability.

In addition to our mandatory modules, volunteers were given access to a library of over 300 further courses, enabling them to build new skills, grow in their roles and develop professionally at their own pace.

We also welcomed, inducted and trained 50 new volunteers throughout the year, providing them with tailored onboarding, training and ongoing support. We held 17 inductions during the year. At the end of the year we had 62 active volunteers. Their commitment makes a profound difference to the lives of people affected by CRPS, and we remain extremely grateful for the time, passion and care they bring to our charity.

All volunteers and staff are required to follow Burning Nights CRPS Support's safeguarding policy, which ensures that at risk and vulnerable adults and children are protected across every aspect of our work.

We are incredibly grateful for the unwavering support of our donors and volunteers. Their generosity is what allows us to navigate these challenging times and make a positive impact on the lives of those affected by CRPS. We encourage our entire community to continue their fundraising efforts and support our work. Together, we can overcome these obstacles and build a brighter future for the CRPS community.

Acknowledgements

Every service delivered, every session held and every conversation offered contributed to reduced isolation, improved wellbeing, earlier support and greater understanding of CRPS across society.

We could not do the work we do without the dedication, compassion and expertise generously given by our volunteers, staff, fundraisers, corporate partners, speakers, health professionals and clinical advisors. Every one of them plays a vital role in helping us reach, support and empower people affected by Complex Regional Pain Syndrome (CRPS). We extend our heartfelt thanks to each person who has stood alongside us this year and contributed to our mission.

ACHIEVEMENTS AND PERFORMANCE

A special note of gratitude goes to all of our volunteers who give their time to support the CRPS community through all of our services and our wider operational and awareness-raising activities. Their empathy, professionalism and insight ensure that no one has to face CRPS alone.

We would also like to thank everyone who took part in challenge events or community fundraising, or who organised their own activities to raise vital funds for the charity. Your determination, creativity and generosity help sustain our services and enable us to reach more people than ever before.

A very heartfelt thank you goes to those who bravely shared their personal stories in the media and across our platforms. We know how emotionally demanding and vulnerable this can feel, yet your courage helps raise awareness, reduce stigma and ensure others feel seen, heard and understood.

We recognise the significant barriers and inequalities many people with CRPS face when trying to access care, diagnosis, mental health support, or rehabilitation. We are committed to addressing these inequalities and championing the voices of those most marginalised or underserved within chronic pain pathways. We are deeply grateful to the organisations, advocates, and allies who stand with us in this work.

As always, our achievements are truly a team effort. Our volunteers, members, trustees, clinical supervisors, counsellors, corporate partners, researchers, healthcare professionals, families, carers, and supporters all form the backbone of Burning Nights CRPS Support. Your collective passion and commitment drive meaningful change for a community that urgently needs understanding, compassion, and accessible support.

We are immensely grateful for the continued and new support of the funders listed below. We also extend our sincere thanks to every individual, group, and organisation who has made a donation, shared our work with others, or encouraged someone to reach out for help. Your generosity and belief in our mission enable us to continue being a lifeline for people affected by CRPS.

With sincere gratitude and thanks to our funders during 2024-2025

- Clothworkers Trust
- E C Graham (Cumbria) Trust
- Nationwide
- St. James Place (local)
- The National Lottery Awards for All

Get Involved

The more people working together the stronger we are and the louder our voice. We have a range of ways you can get involved, for more information please check out our website: <https://www.burningnightscrps.org/get-involved/>

If you would like to hear what we are up to throughout the year, sign up for our regular e-newsletter.

ACHIEVEMENTS AND PERFORMANCE

The charity's principal sources of funds (including any fundraising)

Burning Nights CRPS Support is funded through a diverse range of income streams which together enable us to deliver our essential services, expand our reach, and respond to the increasing needs of the CRPS community. As with many charities especially within the health sector, we continue to operate in a challenging financial climate, shaped by rising operational costs and reduced public giving. Despite this, our supporters, funders and partners have enabled us to sustain and develop our work throughout the year.

Our income is generated through a combination of:

- Grants from charitable trusts and foundations, which remain a vital source of funding for our core services, including counselling and psychotherapy, befriending, helpline support, volunteer training, wellbeing activities and digital resources.
- Fundraising and community-led events, with supporters organising and participating in sponsored walks, runs, abseils, challenge events and local fundraising activities.
- Corporate support, including payroll giving, workplace fundraising, matched funding, pro bono partnerships, and donations from organisations with an interest in pain management, rehabilitation, and disability support.
- Individual donations, including regular giving, one-off gifts, in-memory donations, birthday fundraisers, and response to seasonal appeals.
- Membership income from our growing paid membership scheme, which offers supporters exclusive benefits such as access to our magazine The Warriors Lifeline, priority webinars, wellbeing sessions, and member-only updates. (Membership does not confer voting rights.)
- Sales from our online shop, offering branded merchandise and CRPS awareness items, with all proceeds reinvested into our support services.

Like many small charities, we felt the impact of the cost-of-living crisis, which affected both individual giving and event fundraising. In response, we continued to strengthen and diversify our income portfolio by:

- increasing applications to trusts and foundations
- expanding legacy giving and payroll giving promotion
- strengthening relationships with corporate partners
- developing new community fundraising opportunities
- engaging more deeply with members and supporters through targeted appeals

We are particularly grateful for the ongoing support of our corporate partners, including law firms who participate in our small legal panel and commit to annual donations. We also continue to receive support from companies and organisations in the health, rehabilitation, and mobility sectors, whose contributions help sustain our specialist services.

Despite the financial challenges faced across the charity sector, Burning Nights CRPS Support remains committed to delivering high-quality, accessible support to those affected by Complex Regional Pain Syndrome. Our diverse income base is essential to ensuring the stability of our services, and we are deeply appreciative of every grant, donation, membership, and fundraising effort that makes our work possible.

FINANCIAL REVIEW

Investment policy and objectives

It is the policy of the charity to maintain Reserves for both restricted and unrestricted funds in cash.

The charity has not yet accumulated sufficient funds to consider establishing a formal Investment Policy.

Reserves policy

It is the policy of the charity to maintain unrestricted funds, which are free reserves of the charity, at a level of 6 months of the resources expended. At this level the Trustees feel that in the event of a significant drop in funding, they would be able to continue the current activities of the charity for a limited period and discharge all financial and contractual liabilities. It would obviously be necessary to consider how funding would be replaced and/or activities changed.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its Constitution adopted 20th October 2015, and constitutes a Charitable Incorporated Organisation.

Recruitment and appointment of new trustees

The charity appoints trustees in line with the processes set out in its Constitution, ensuring transparency, good governance and alignment with the charity's values and charitable purposes.

Under the Constitution, trustees may be appointed by the existing Board and must be formally approved by a minimum of three (3) current trustees. Except for the founding trustees, all trustees serve a three-year term and are eligible for reappointment for a further three-year term, subject to approval at a quorate trustee meeting or at the Annual General Meeting (AGM). Trustees must retire or be reappointed every three years to ensure both continuity and the regular introduction of new skills and perspectives.

There are no external bodies or individuals with the right to appoint trustees. All appointments are made internally by the Board of Trustees.

When recruiting for new trustees, the charity follows a structured and robust process. Prospective trustees are invited to apply through an open recruitment process, where they must submit a CV, cover letter, and two referees, in line with our Trustee Recruitment Pack. Applicants are assessed on their skills, experience, commitment to the charity's aims, understanding of governance responsibilities, and their ability to contribute constructively to strategic decision-making.

As part of our safeguarding standards, all trustees must complete DBS checks and the required Trustee Eligibility and Fit & Proper Person declarations.

New trustees are selected carefully to ensure they reflect the values of Burning Nights CRPS Support, bring relevant expertise (for example in legal, financial, clinical, academic, or lived-experience areas) and enhance the Board's collective skills. As of March 2025, 80% of our Board have a chronic illness, whether that is CRPS, chronic pain or another chronic illness. This continues to be invaluable in shaping the charity's direction.

This structured approach ensures that the Board remains diverse, skilled and committed to strong governance, while upholding the requirements of the Constitution and the long-term needs of the charity.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

Burning Nights CRPS Support is a Charitable Incorporated Organisation (CIO) governed by a Board of Trustees. The Board holds overall responsibility for strategic direction, governance, financial oversight and ensuring the charity meets its legal and regulatory obligations. Trustees bring a mix of professional expertise and lived experience of CRPS and meet every two months, with additional decisions taken between meetings as needed.

The Chair of Trustees leads the day-to-day operations of the charity under delegated authority from the Board. This includes oversight of safeguarding, service delivery, finance, volunteer management, policy implementation and partnership development.

Operational activity is delivered through a predominantly volunteer-led model supported by specialist professionals.

During the reporting year, the charity was supported by a large team of volunteers, including 4 to 5 Volunteer Coordinator volunteers who assisted with volunteer recruitment, induction, safeguarding requirements, rota management and ongoing volunteer support.

In February 2025, the Clinical Lead started her role thanks to the National Lottery. She has the oversight of the counselling and therapy team including therapists and supervisors.

All volunteers receive appropriate induction, safeguarding training (repeated annually), GDPR guidance and role-specific development. Professional external support is commissioned where required, such as accountancy.

The wider membership community engages with the charity through services, events and feedback. However, the members have no legal voting rights within our charity.

Externally the charity is a member of Pain UK, which is an umbrella organisation for pain charities like ours.

We are also a member of the Third Sector Network in Scotland as well as a member of the Cross-Party Group for Chronic Pain in Scotland. We regularly attend meetings of both groups.

These relationships, while essential, are not classified as related parties under the Statement of Recommended Practice (SORP).

STRUCTURE, GOVERNANCE AND MANAGEMENT

Induction and training of new trustees

Burning Nights CRPS Support is committed to ensuring that every trustee feels confident, informed, and well-equipped to carry out their responsibilities. We recognise that strong governance begins with a supportive and thorough induction, followed by access to ongoing training and development.

Trustees' Induction

All new trustees receive a comprehensive induction programme that introduces them to the charity's mission, values, and strategic objectives. This includes:

- An overview of our Constitution, charitable purposes, and governance structure.
- A briefing on the duties and legal responsibilities of trustees, drawing on Charity Commission guidance.
- A review of key organisational policies such as safeguarding, financial controls, confidentiality, GDPR, Equality, Diversity & Inclusion (EDI), and conflicts of interest.
- An introduction to the charity's services, projects, volunteer structure, and operational procedures.
- A CRPS awareness induction, ensuring all trustees understand the lived experience of the community we support.

Trustees are also provided with copies of the Trustee Recruitment Pack, the latest Annual Report and Accounts, recent Board minutes, and the strategic priorities for the year.

Mandatory documentation and checks

In line with our Constitution and safeguarding commitments, all new trustees must complete:

- Trustee Eligibility Declaration and Fit & Proper Person Declaration
- A full conflict of interest disclosure
- A DBS check prior to formal appointment

Trustees' Training and ongoing development

Trustees are encouraged to engage in regular training to strengthen their governance skills and keep up to date with best practice. Our procedures include:

- Annual safeguarding training (adults and children), mandatory for all trustees
- Annual GDPR and confidentiality refreshers
- Access to Charity Commission webinars, guidance and sector updates
- Opportunities for trustees to join relevant external training (charity finance, risk management, HR, governance, fundraising regulation, etc.)
- Other training sessions on organisational priorities and developments, particularly in areas such as CRPS awareness, research involvement, mental health and service delivery

Support and collective responsibility

We offer an open and supportive environment where trustees can ask questions, seek guidance and learn from each other. The Chair provides additional support to new trustees during their early months and all trustees receive regular updates on operational matters, safeguarding, financial reporting and strategic developments. Trustees Meetings are held every 2 (two) months to ensure everyone is up to date on what is going on within the organisation.

Policies such as safeguarding, financial management and confidentiality are reviewed on a two-year cycle, with trustees involved in the review process to ensure policies remain current and aligned with legal and regulatory requirements.

By offering a structured induction, clear expectations and ongoing training opportunities, we ensure that every trustee is empowered to contribute effectively, uphold good governance and support the charity's mission to improve life for all those impacted by Complex Regional Pain Syndrome (CRPS).

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1166522

Principal address

1 Alder Brook
Chinley
High Peak
Derbyshire
SK23 6DN

Trustees

Mrs V Abbott - Fleming MBE
Mr R A Ingham
Miss L Davis
Mr A Patel
Mr T Craig Lowe Trustee (resigned 15/7/2024)
Ms R O'Brein Trustee (appointed 24/9/2024)

Independent Examiner

S&W Partners (Leeds) Limited
Accountants
3rd Floor
56 Wellington Street
Leeds
West Yorkshire
LS1 2EE

Approved by order of the board of trustees on 15 January 2026 and signed on its behalf by:



Trustee

Independent Examiner's Report to the Trustees of
Burning Nights CRPS

I report to the trustees on my examination of the accounts of Burning Nights CRPS for the year ended 31 March 2025, which comprise the Statement of Financial Activities, the Balance Sheet, the Statement of Cash Flows, and the notes to the accounts, including significant accounting policies.

Respective responsibilities of trustees and examiner and basis of report

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination, I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.


Matthew Barton (Jan 16, 2026 12:25:44 GMT)

Matthew Barton BA (Hons) FCA CTA

S&W Partners (Leeds) Limited
Accountants
3rd Floor
56 Wellington Street
Leeds
West Yorkshire
LS1 2EE

Date: 16/01/2026.....

Burning Nights CRPS

Statement of Financial Activities
for the Year Ended 31 March 2025

	Notes	Unrestricted fund £	Restricted funds £	2025 Total funds £	2024 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	50,830	26,447	77,277	56,741
Other trading activities	3	3,995	-	3,995	5,174
Other income	4	512	-	512	758
Total		<u>55,337</u>	<u>26,447</u>	<u>81,784</u>	<u>62,673</u>
EXPENDITURE ON					
Raising funds		10,829	2,882	13,711	16,366
Charitable activities	5				
Charitable activities		<u>63,569</u>	<u>16,703</u>	<u>80,272</u>	<u>75,167</u>
Total		<u>74,398</u>	<u>19,585</u>	<u>93,983</u>	<u>91,533</u>
NET INCOME/(EXPENDITURE)		(19,061)	6,862	(12,199)	(28,860)
RECONCILIATION OF FUNDS					
Total funds brought forward		50,496	10,627	61,123	89,983
TOTAL FUNDS CARRIED FORWARD		<u>31,435</u>	<u>17,489</u>	<u>48,924</u>	<u>61,123</u>
CONTINUING OPERATIONS					
All income and expenditure has arisen from continuing activities.					

Burning Nights CRPS

Balance Sheet
31 March 2025

	Notes	Unrestricted fund £	Restricted funds £	2025 Total funds £	2024 Total funds £
FIXED ASSETS					
Intangible assets	10	3,214	-	3,214	8,022
CURRENT ASSETS					
Stocks	12	2,727	-	2,727	2,411
Cash at bank		29,554	17,490	47,044	54,440
		32,281	17,490	49,771	56,851
CREDITORS					
Amounts falling due within one year	13	(4,061)	-	(4,061)	(3,750)
NET CURRENT ASSETS		28,220	17,490	45,710	53,101
TOTAL ASSETS LESS CURRENT LIABILITIES		31,434	17,490	48,924	61,123
NET ASSETS		31,434	17,490	48,924	61,123
FUNDS	14				
Unrestricted funds				31,434	50,496
Restricted funds				17,490	10,627
TOTAL FUNDS				48,924	61,123

The financial statements were approved by the Board of Trustees and authorised for issue on 15 January 2026 and were signed on its behalf by:



Trustee

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the Charity, which is a public benefit company under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102)' Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102' The Financial Reporting Standard applicable in the UK and Republic of Ireland and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

The Charity has taken advantage of the following disclosure exemption in preparing these financial statements as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirement of Section 7 Statement of Cash Flows.

The charity has taken advantage of the following disclosure exemption in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Intangible fixed assets

Amortisation is charged at the following annual rates in order to write off each asset over its estimated useful life.

Website - 25% Straight line

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Furniture and equipment - 25% Straight line

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Taxation

The charity is exempt from tax on its charitable activities.

Pension costs and other post-retirement benefits

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

Notes to the Financial Statements - continued
for the Year Ended 31 March 2025

2. DONATIONS AND LEGACIES

	2025	2024
	£	£
Donations	45,607	42,417
Gift aid	2,737	993
Grants	26,448	11,894
Income from membership	2,485	1,437
	<u>77,277</u>	<u>56,741</u>

Grants received, included in the above, are as follows:

	2025	2024
	£	£
Other grants	<u>26,448</u>	<u>11,894</u>

3. OTHER TRADING ACTIVITIES

	2025	2024
	£	£
Sales of goods and services	<u>3,995</u>	<u>5,174</u>

4. OTHER INCOME

	2025	2024
	£	£
Other income	<u>512</u>	<u>758</u>

5. EXPENDITURE ON CHARITABLE ACTIVITIES

	Direct Costs (see note 6)	Support costs	Totals
	£	£	£
Charitable activities	<u>16,152</u>	<u>64,120</u>	<u>80,272</u>

6. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2025	2024
	£	£
Trustees' expenses	2,106	4,024
Travel expenses	740	835
Conference expenses	7,829	8,714
Staff training	5,477	4,081
	<u>16,152</u>	<u>17,654</u>

7. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2025 nor for the year ended 31 March 2024.

Trustees' expenses

	2025 £	2024 £
Trustees' expenses	2,106	4,024

The trustee expenses were paid to 3 trustees for training and travel costs during the year.

8. STAFF COSTS

	2025 £	2024 £
Wages and salaries	22,000	26,625
Other pension costs	473	580
	<u>22,473</u>	<u>27,205</u>

The average monthly number of employees during the year was as follows:

	2025	2024
Staff	<u>1</u>	<u>1</u>

No employees received emoluments in excess of £60,000.

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	44,847	11,894	56,741
Other trading activities	5,174	-	5,174
Other income	758	-	758
Total	<u>50,779</u>	<u>11,894</u>	<u>62,673</u>
EXPENDITURE ON			
Raising funds	16,366	-	16,366
Charitable activities			
Charitable activities	73,900	1,267	75,167
Total	<u>90,266</u>	<u>1,267</u>	<u>91,533</u>
NET INCOME/(EXPENDITURE)	(39,487)	10,627	(28,860)
RECONCILIATION OF FUNDS			
Total funds brought forward	89,983	-	89,983

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Total funds £
TOTAL FUNDS CARRIED FORWARD	50,496	10,627	61,123

10. INTANGIBLE FIXED ASSETS

	Website £
COST	
At 1 April 2024 and 31 March 2025	19,229
AMORTISATION	
At 1 April 2024	11,207
Charge for year	4,808
At 31 March 2025	16,015
NET BOOK VALUE	
At 31 March 2025	3,214
At 31 March 2024	8,022

11. TANGIBLE FIXED ASSETS

	Furniture and equipment £
COST	
At 1 April 2024 and 31 March 2025	744
DEPRECIATION	
At 1 April 2024 and 31 March 2025	744
NET BOOK VALUE	
At 31 March 2025	-
At 31 March 2024	-

12. STOCKS

	2025 £	2024 £
Stocks	2,727	2,411

Notes to the Financial Statements - continued
for the Year Ended 31 March 2025

13. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025 £	2024 £
Trade creditors	1,062	336
Taxation and social security	659	704
Other creditors	2,340	2,710
	<u>4,061</u>	<u>3,750</u>

14. MOVEMENT IN FUNDS

	At 1/4/24 £	Net movement in funds £	At 31/3/25 £
Unrestricted funds			
General fund	50,496	(19,062)	31,434
Restricted funds			
Nationwide colleagues	9,894	(8,085)	1,809
E C Graham's Charitable Settlement	-	2,400	2,400
The National Lottery	-	13,008	13,008
E C Graham Charitable Trust	733	(735)	(2)
SJP	-	275	275
	<u>10,627</u>	<u>6,863</u>	<u>17,490</u>
TOTAL FUNDS	<u>61,123</u>	<u>(12,199)</u>	<u>48,924</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	55,337	(74,399)	(19,062)
Restricted funds			
Nationwide colleagues	-	(8,085)	(8,085)
E C Graham's Charitable Settlement	3,000	(600)	2,400
The National Lottery	17,047	(4,039)	13,008
E C Graham Charitable Trust	-	(735)	(735)
Clockworker's Trust	4,900	(4,900)	-
SJP	1,500	(1,225)	275
	<u>26,447</u>	<u>(19,584)</u>	<u>6,863</u>
TOTAL FUNDS	<u>81,784</u>	<u>(93,983)</u>	<u>(12,199)</u>

Notes to the Financial Statements - continued
for the Year Ended 31 March 2025

14. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/23 £	Net movement in funds £	At 31/3/24 £
Unrestricted funds			
General fund	89,983	(39,487)	50,496
Restricted funds			
Nationwide colleagues	-	9,894	9,894
E C Graham's Charitable Settlement	-	733	733
	-	10,627	10,627
TOTAL FUNDS	89,983	(28,860)	61,123

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	50,779	(90,266)	(39,487)
Restricted funds			
Nationwide colleagues	9,894	-	9,894
E C Graham's Charitable Settlement	2,000	(1,267)	733
	11,894	(1,267)	10,627
TOTAL FUNDS	62,673	(91,533)	(28,860)

15. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2025.

Accounts

REGISTERED CHARITY NUMBER: 1166522

Report of the Trustees and
Unaudited Financial Statements for the Year Ended 31 March 2024
for
Burning Nights CRPS Support

Burning Nights CRPS Support

Contents of the Financial Statements
for the Year Ended 31 March 2024

	Page
Report of the Trustees	1 to 21
Statement of Trustees' Responsibilities	22
Independent Examiner's Report	23
Statement of Financial Activities	24
Balance Sheet	25 to 26
Notes to the Financial Statements	27 to 34
Detailed Statement of Financial Activities	35 to 36

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

The trustees present their report with the financial statements of the charity for the year ended 31 March 2024. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Summary of the objects of the charity

The purposes and objectives of the charity are as follows:

1) to promote and protect the health of sufferers (patients) of Complex Regional Pain Syndrome (CRPS), their families and carers by the provision of information, advice and support including raising awareness of all aspects of CRPS amongst the public in general but in particular those involved in the diagnosis, treatment and care of those suffering from (living with) CRPS; and

2) to assist and support research into CRPS, its causes, treatment and cure and to ensure the useful results of such research are published

Within our aims and objectives, we offer a range of support services including mental health support such as a Befriending Service, Counselling & Psychotherapy Service for anyone affected by CRPS aged 5 and over i.e. for both children under 18 and adults, telephone helpline, live web chat, online community forum, support groups and more.

We provide services to both adults and children since Complex Regional Pain Syndrome can affect anyone at any age as well as providing services to families as having a CRPS diagnosis can be a ripple effect to those around them.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

OBJECTIVES AND ACTIVITIES

Objectives, strategies and activities

Burning Nights CRPS Support is a national charity working to improve the lives of those impacted by Complex Regional Pain Syndrome (CRPS).

Our mission is dedicated to enhancing the quality of life for people with Complex Regional Pain Syndrome (CRPS) and their immediate circle. We aim to provide support and resources not only for those with CRPS but also for their caregivers, families, and friends.

Our objective is to expand our services and the literature we provide to empower individuals to understand and manage their condition, learn to become their own advocates and offer support where necessary. We understand the challenges CRPS poses for caregivers, families, and friends, and we are committed to providing them with information so they can also understand their loved one's condition and support them in their roles as caregivers.

Our commitment lies in consistently enhancing the support we provide, with the goal of improving the overall health and well-being of all involved.

Our ultimate vision for the future is a world free of Complex Regional Pain Syndrome and pain free lives.

Our mission in three words is:

Awareness. Education. Support.

This means that we want to bring together the CRPS community to ensure people whose lives have been touched by this condition are not alone.

We aim to raise awareness of Complex Regional Pain Syndrome (CRPS) and provide education so that more people across healthcare and in the public understand the condition and its debilitating effects. From education, training and campaigning to advice and support, as the UK's leading CRPS charity we are on a mission to change the way that CRPS is looked at, managed and treated.

Finally, our values are:

- **We're Stronger Together**
- **We're a community** - We all work better together so that everyone provides support for others and we are able to help people support themselves and we learn from everyone we work with.
- **We're Empowering** - We empower each other to fulfil our roles and support patients, families, and their carers, in advocating and driving for change.
- **We're Respectful** - We value everyone's unique story and journey, showing respect to supporters, patients, stakeholders, and each other.
- **We're Compassionate** - We offer assistance and guidance for individuals with CRPS and their families, providing support and reassurance that they are not facing this alone.
- **We're Empathetic** - We, as a patient and caregiver-led organisation, have volunteers with lived experience who empathise with your experiences.

Operating context

Each year, over 15,000 individuals are diagnosed with CRPS, affecting not only those with the condition but also their families. This includes both adults and children. Receiving a diagnosis of complex regional pain syndrome (CRPS) can have significant emotional and financial impacts on individuals and families dealing with the condition.

As a patient led organisation, we believe in the value of lived experience. Therefore 60% of the current Trustee board live with CRPS or chronic pain. Approximately 65% of our volunteers also have lived experience of CRPS, chronic illness or chronic pain.

OBJECTIVES AND ACTIVITIES

Having lived experience of pain within the charity is invaluable for several reasons. People who have personally navigated the complexities of chronic pain bring with them a deep, empathetic understanding to the organisation, ensuring that the charity's initiatives are genuinely aligned with the needs of those who we aim to support. Their insights have helped to tailor some of our support services and our literature. We also find that their presence can inspire hope and solidarity amongst our service users, helping to offer a compassionate community where experiences are validated, and shared challenges are met with collective strength.

Summary of Activities

In planning our activities for the year, we kept in mind the Charities Commission's guidance on public benefit at our trustees' meetings.

The purpose of the annual report is to review the charity's goals, objectives, and activities for the year, and to share with our supporters the impact their help has made. While we are extremely proud of our accomplishments, we recognise that there is still much more to be done, but we feel confident that with your help, we will achieve more each year.

The trustees provide a detailed account of the success of each key activity and highlight the positive impact the charity has made on the specific groups it was established to support. This thorough review not only showcases the tangible benefits delivered to these groups but also serves as an essential tool for the trustees to evaluate the charity's alignment with its mission.

By reviewing the outcomes of the year's work, the trustees ensure that the charity's aims, objectives, and activities continue to remain focused on its core purpose, enabling them to make informed decisions for future initiatives and strategies. This process of reflection and assessment ensures that the charity remains effective, accountable, and committed to fulfilling its mission.

Outlined below are the charity's key activities and the groups it seeks to assist.

All of these projects and services are carried out to advance the charitable purposes of Burning Nights CRPS Support for the benefit of the public, with a focus on:

- Support for everyone who've been impacted by Complex Regional Pain Syndrome whether they are patients, families, close friends, carers including young carers and relatives
- Information
- Raising awareness, providing education and campaigning
- Supporting research
- Resourcing the organisation so that we can deliver more

Due to the high cost of living crisis, the CRPS community has faced significant challenges. Many patients are experiencing long wait times for appointments with Pain Clinics and Pain Services and have limited access to pain management programmes and mental health support, particularly due to the ongoing pressures on the NHS. As a result, some individuals have struggled to obtain a diagnosis and access the treatments they urgently need.

We have made it a priority to ensure that CRPS is discussed at all levels of decision-making and among the general public, highlighting the profound impact a CRPS diagnosis can have on all aspects of life, including the lives of those around patients.

To address these gaps, we have worked diligently to continue providing various virtual support services, including regular online support groups, along with information and guidance. Our online support groups have been a vital resource for many seeking a community that listens and responds to their needs. We have also hosted webinars, expanded our CRPS Counselling and Psychotherapy Service, and continued to operate our web (live) chat service and helpline.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

OBJECTIVES AND ACTIVITIES

We take great pride in the incredible support provided by our volunteers, who have worked hard to enhance our Befriending Service and other virtual offerings, including social media outreach. With the help of our team of 51 trained volunteers, Burning Nights CRPS Support remains committed to assisting those affected by CRPS during their most challenging times.

This year, the charity's main activities in line with its mission have included:

1. Providing information and support through various channels to individuals affected by CRPS, including patients, families, and caregivers.
2. Updating and publishing educational literature.
3. Developing a membership scheme for mutual support.
4. Producing 'The Warriors Lifeline', a magazine available online and in print for a small subscription fee, with the membership scheme
5. Organising annual conference and educational webinars
6. Maintaining a website and social media presence to promote public awareness and provide support.
7. Hosting well-being events to foster community among adults and children.
8. Facilitating regular online support groups.
9. Operating a telephone information helpline and online web/live chat service for all members of the CRPS community, including patients, family members, caregivers, and friends.
10. Supporting research initiatives that will benefit individuals affected by CRPS.
11. Running an online community forum for mutual support, information sharing, and idea exchange.
12. Providing educational talks to enhance understanding and awareness of CRPS.
13. Attending exhibitions to raise public awareness.
14. Advocating for the rights and needs of those affected by CRPS, particularly patients.

Public benefit

The Trustees have had regard to the Charity Commission's guidance on public benefit.

Volunteers

Throughout 2023-2024, the dedication and compassion of our volunteers have played a crucial role in providing essential support and comfort to CRPS patients and their families. Through various platforms, including email, phone, and social media, our 51 volunteers devoted a remarkable 8,769 hours to actively listening, offering guidance, answering questions, and providing much-needed counselling.

The impact of our volunteers is immeasurable.

As a small charity, their contributions have been nothing short of invaluable. Their relentless commitment has empowered the charity to thrive and achieve significant milestones. Thanks to their selflessness, dedication, and expertise, we've been able to offer meaningful assistance to those who need it most.

Sadly, during August 2023, we were extremely saddened to hear of the very sudden and untimely death of one of our popular volunteer Befrienders, Victoria (Vicky) Ellen Williams. Vicky had such a friendly way about her that put her all befriended clients at so much ease. She really did help so many people in so many ways, just by being herself.

It was decided that we would have an annual award dedicated to Vicky - The Victoria Ellen Williams Award for Outstanding Contribution. Our sincere condolences are with Vicky's family and friends.

We extend our deepest gratitude to our extraordinary volunteers. Your unwavering commitment to our mission is truly inspiring, and your generous donation of time and skills is profoundly appreciated. Without your support, we wouldn't be where we are today. Thank you for everything you do!

ACHIEVEMENTS AND PERFORMANCE

Charitable activities

Our mission is to ensure that individuals living with Complex Regional Pain Syndrome (CRPS), along with their families and close relatives, experience the best possible quality of life despite their chronic condition. We are committed to providing support and resources not only to those diagnosed with CRPS but also to their caregivers, families, and friends.

We aim to continuously expand our services, projects and resources to help individuals understand their rights, manage their condition, and pursue their passions. We recognise the challenges that CRPS presents, not just for patients but for caregivers, families, and friends as well. Our goal is to offer high-quality information to help them navigate the complexities of CRPS and understand their roles and rights. Our mission is to unite the CRPS community, ensuring that no one touched by this condition feels alone.

We also strive to raise awareness of CRPS and provide education so that healthcare professionals and the public better understand the condition and its debilitating effects. Through education, training, advocacy, and support, we are committed to changing how CRPS is perceived, managed, and treated as the UK's leading CRPS charity.

Our core values that we believe in, are:

Stronger Together

We are a community, working collaboratively to help individuals support themselves and learn from one another.

Empowerment

We empower each other in our roles and provide patients, caregivers, and supporters with the tools to continue advocating for change.

Respect

We honour everyone's unique journey. We treat our supporters, patients, stakeholders, and colleagues with the utmost respect.

Compassion

We stand by everyone who have been impacted by CRPS, no matter whether they are patients or families and loved ones. When people come to us for help, we listen and care. No one faces this alone.

Empathy

As a patient and caregiver-led organisation, we deeply understand the struggles that those affected by CRPS endure.

Main Areas of Focus for 2023-2024:

- Support for all those affected by CRPS (patients, families, friends, and caregivers)
- Campaigning, advocacy, and raising awareness
- Providing information and education
- Supporting research and studies
- Valuing our volunteers
- Engaging with our supporters

We are dedicated to continuously improving our services, with the ultimate goal of enhancing the health and well-being of everyone impacted by CRPS.

Our vision is a world free from Complex Regional Pain Syndrome, where pain no longer limits lives.

Our mission is: CRPS: **Awareness. Education. Support.**

Support for those impacted by CRPS

We remain dedicated to supporting, assisting, and informing anyone impacted by Complex Regional Pain Syndrome (CRPS), whether they are patients, loved ones, family members, or caregivers.

ACHIEVEMENTS AND PERFORMANCE

We offer direct support through a range of services, including:

- Online Support Groups
- Telephone Helpline
- Live Web Chat
- Social Media Support
- Email Support
- Online Community Forum
- Befriending Service (virtual/online)
- Counselling & Psychotherapy Services
- Wellbeing Sessions

Our volunteer-led support services remain central to how we assist the CRPS community. The cost-of-living crisis has brought new challenges to light, including delays in diagnosis, limited treatment options, and gaps in care, which we are actively working to address and advocate for.

Here is an overview of our services and key achievements:

Online CRPS support groups

Our peer-led online support groups, facilitated by volunteers with lived experience, have continued to thrive. Hosting these groups virtually has made them more accessible, and the feedback from our community has been overwhelmingly positive. While many appreciate the convenience, we are assessing interest in possibly returning to in-person support groups.

Our main adult group has been meeting monthly, drawing regular attendance of approximately 10-20 participants. We are still however exploring options to better support children and young people with CRPS and young carers.

The group discussions have spanned topics like pain management, fatigue, the impact of CRPS on internal organs, complementary therapies, challenges related to menopause, family and friend dynamics, dental issues, and navigating loss with compassion. Throughout the year, 12 support group sessions were held, supporting 195 individuals. This year we saw an increase from last year in the number of attendees by 66.7%. Those who did participate found the service invaluable especially with them being held online.

"Thank you everyone for allowing me to listen to your experiences. These sessions are hugely important." - Support Group Member

Telephone Helpline

Our Telephone Helpline and Email Support services are cornerstones of our mission to support individuals affected by CRPS. These vital services assist not only patients but also their families, healthcare professionals, and social prescribers.

Our Helpline is a crucial resource for those seeking information, guidance, and help with navigating various issues such as accessing NHS services, securing mental health support, and managing educational needs for young people and adults with CRPS or their families. Our trained volunteers, many of whom are CRPS patients or with lived experience as carers or family members themselves, provide compassionate and knowledgeable support.

We are especially grateful to our volunteers and staff who manage the increasing volume of difficult calls, including those related to suicidal thoughts and self-harm. During 2023-2024, we responded to 439 calls, totalling 53.40 hours of support. This is an increase of 23.34% on last year's helpline calls.

To continue improving this service, we are working on recruiting additional volunteers and implementing a comprehensive training programme. Our goal is to ensure everyone who reaches out receives the highest quality of support and information.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

ACHIEVEMENTS AND PERFORMANCE

Email support

Burning Nights CRPS Support is committed to assisting individuals affected by CRPS through our Email Support system. In 2023-2024, we dealt with 1,393 queries and requests for services, addressing a wide variety of enquiries ranging from access to services to CRPS-specific information and referrals to specialist lawyers.

Our email service plays a key role in combating the isolation and loneliness that often accompany living with CRPS. By providing timely advice, education, and support, we empower patients, families, and caregivers with the resources they need to better manage the condition and enhance their quality of life.

We firmly believe that everyone affected by CRPS deserves access to the support they need, and we remain dedicated to delivering that through our email system and other channels of communication.

Live web chat

Our Live Web Chat support service has now been an additional support service for 3 years since its inception in July 2020. We introduced it as a digital alternative for individuals unable to use our other communication channels. The goal was to create an accessible, efficient solution that allows our community members to receive support quickly and conveniently, regardless of their location or circumstances.

Our Live Web Chat service is vital for people affected by CRPS as it provides immediate, accessible support when they need it most. CRPS can be isolating and overwhelming, and having a real-time platform allows people to connect with trained lived experience volunteers who can offer advice, emotional support, and practical information. For those who may find it difficult to talk on the phone or attend in-person support, live web chat offers our CRPS community a discreet, convenient way to seek help and feel understood. It ensures that people affected by CRPS can access guidance even when our other services may have closed, helping them manage their pain and mental well-being more effectively.

Since its launch, the Live Web Chat has been available six days a week (Monday to Friday, 11am-6pm, and Saturdays, 12 noon-4pm). This consistent availability has provided a reliable way for people to connect with us and receive timely assistance. Our team of trained volunteers, many of whom have lived experience with CRPS, works diligently to offer prompt, personalised support to each person who reaches out.

In 2023-2024, we provided live chat support to 240 individuals, totalling 68.17 hours of support. Although the number of individual chats decreased slightly, on average we have maintained a 1hour 37-minute average chat time. Having this service and consistent chat time does show our commitment to giving each person the time and attention they need, ensuring they receive thorough and compassionate care. We are proud of the continued success of this service and are dedicated to maintaining its high level of accessibility and effectiveness.

"Thank you so much, for real. This was the most helpful conversation I've had on this to date. I'll definitely start doing the spray on moisturiser. Thank you all so much for offering this service. :heart:"
- T.A. via Live Web Chat

Social media support

We have still maintained an active presence across seven major social media platforms: Facebook, X (formerly Twitter), Instagram, Pinterest, LinkedIn, YouTube, and TikTok. Through these platforms, we regularly share informative content, including articles, events, videos/reels, and research opportunities related to CRPS, helping us reach and support patients, their families, and caregivers.

Understanding the challenges of living with CRPS, we believe that personalised support is essential. Our trained lived experience volunteers respond to private messages and comments across these platforms, providing direct, one-on-one assistance. In the past year, we responded to 1,385 individual private messages—an increase of 8.2% from the previous year—ensuring that no one in our community feels isolated or unsupported.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

ACHIEVEMENTS AND PERFORMANCE

Our growth across social media reflects the positive impact we are making. By the end of March 2024, we saw an 8.9% increase in our online community, reaching a total of 64,533 followers and subscribers across all seven platforms. This continued growth indicates that more people are finding our content valuable and informative, and we remain committed to providing useful resources and fostering connection within the CRPS community.

Additionally, we offer a closed Facebook support group specifically for parents and guardians/carers of children and teens with CRPS. This group provides a safe, supportive space to share experiences and advice on caring for a young person with CRPS. Membership in this group has grown to 1,096 members in the past year, reflecting the increasing need for this specialised support. This has shown an increase of 36% from last year.

We feel it is important to have this closed Facebook group for Parents/Carers with Young People who have CRPS because it offers the following:

- **Emotional Support and Shared Experiences** - Parents of children with CRPS often face unique emotional challenges, such as stress, fear, and isolation. This group provides a safe space where parents and guardians can connect with others who truly understand their struggles. Sharing experiences, tips, and encouragement helps foster a sense of community and reduces feelings of loneliness.
- **Tailored Advice and Resources** - This group allows parents and guardians to exchange information specifically related to managing their child's CRPS, such as medical treatments, educational issues, or coping strategies. Members are often seen to recommend hospitals, therapies, or programs that have worked for their children, providing valuable insights that may not be available through general groups or resources.
- **Advocacy and Empowerment** - Parents/guardians of children with CRPS very often need to advocate for their child's needs in medical, educational, and social settings. This group really can and does empower parents by offering advice on how to navigate these systems, share legal rights, and provide templates or guidance for meetings with healthcare professionals or schools. This collective knowledge strengthens their ability to advocate effectively for their child/teen.

"Thank you so much to everyone in Burning Nights CRPS. I feel so better with your daily support. I feel that I'm not alone in this fight. I don't remember how I found u but I am very happy that you very important part of my life. Thank you so much" - jank_mottylik via Instagram

"Lovely tweet. @BNightsCRPS really do make you feel like you're not alone and just having other people who completely understand your pain and everything that comes along with this awful disease is comforting x" - J, via X, responding to another tweet

Online community forum

Our Online Community Forum is a key resource for supporting the CRPS community, accessible through our website. It offers a safe, moderated space for people affected by Complex Regional Pain Syndrome (CRPS) to connect, share experiences, and seek advice. Living with chronic pain can often lead to feelings of isolation and loneliness.

Unlike social media platforms, the forum provides a focused environment where users can discuss the specific challenges of living with CRPS or caring for someone with CRPS without distractions. Our Community Forum allows people to connect with others who truly understand their experiences. This shared understanding encourages emotional support, reduces feelings of isolation, and allows members to exchange practical advice, coping strategies, and personal stories in a compassionate environment. Sharing personal stories, challenges, and successes helps to promote a sense of belonging and reduces the emotional burden. Knowing that others are going through similar struggles can significantly enhance mental well-being and resilience.

CRPS patients and their families often struggle to access timely medical support or accurate information. Our Community Forum provides 24/7 access to a wealth of knowledge, with members sharing resources, treatment options, and advice on managing pain. This empowers individuals to make informed decisions about their health and care.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

ACHIEVEMENTS AND PERFORMANCE

The forum is moderated by a team of dedicated lived experience volunteers, either patients, carers, or family members. These trained volunteers ensure that all posts adhere to forum guidelines and are appropriate, fostering a respectful and helpful community. They also contribute by sharing their personal insights and offering support to others.

Currently, the forum has over 883 members, creating a robust source of shared knowledge and emotional support. We know that after our website was relaunched with the new Forum in November 2022, it required all previous members to re-register, and all existing posts were cleared. While rebuilding the forum's membership has been a challenge, we are actively working to encourage new sign-ups and engagement.

Available 24/7, the forum allows users from around the world to connect at any time. It serves as a vital platform for asking questions, exchanging advice, and accessing information. Additionally, it plays an important role and service in not only combating loneliness and isolation but it helps helping those affected by CRPS to self-manage their condition more effectively and feel less alone in their journey.

We are proud to provide this invaluable resource and remain committed to maintaining a safe, supportive, and welcoming environment for all CRPS community members.

Befriending service (online/virtual)

We are thrilled by the positive response to our Befriending Service, which has continued to expand throughout 2023-2024. With the help of four dedicated volunteer Befrienders, we have been able to offer weekly phone or video calls lasting 40-45 minutes to those living with CRPS or their families seeking support. This service has quickly become one of our most popular, with each client receiving a total of 12 sessions/calls. The key to its success lies in the lived experience of our Befrienders, who are CRPS patients, carers, or relatives, making their empathy and understanding invaluable.

As demand continues to grow, we are committed to expanding our team. In the next financial year, we plan to recruit two-four additional volunteers to meet the increasing needs of the CRPS community. The benefits of this service have been profound, including reduced symptoms, less social isolation, and improved well-being, as evidenced by pre- and post-surveys. Over the year, we provided 90 sessions, onboarded 9 new clients, and discharged 8, and we look forward to continuing this vital service to reach even more people in need of support.

We have seen a slight reduction in the number of sessions this year compared to last year, however we had some volunteer illnesses and we were reduced to only 2 active Befriender volunteers during the year which has had an impact on the number of sessions we have been able to offer during this year.

"Thank you very much to everyone from Burning Nights CRPS for doing this for us. And Big Thanks to my Befriender Vicky. She is very nice, kind, patient and friendly person who listen and help giving you an advice if she can. I'm very happy I had Vicky as my Befriender. Good luck in this Vicky " - JV, Client, CRPS Patient

CRPS counselling & psychotherapy service (online only)

Our CRPS Counselling & Psychotherapy Service, which has now been going since it was launched in March 2021, has proven to be our biggest service and most certainly a lifeline for those unable to access mental health services through the NHS. Due to the overwhelming demand, it has led us to expand the service more and more each year, now supported by seven (7) counsellors and psychotherapists plus 3 volunteer clinical supervisors. This year alone, we delivered 283 sessions compared to 460 the previous year, and we continue to see a growing waiting list. However, we lost a few volunteer therapists who went to work in private practice.

ACHIEVEMENTS AND PERFORMANCE

We offer up to 20 sessions of counselling or psychotherapy for anyone over the age of 5, with regular assessments to monitor anxiety and depression. Each session is one hour in length and is held either over the telephone or more usually online via video conferencing software ie Zoom. This is significantly more than what is typically available through public health services, allowing clients time to build trust and confidence with their therapist. In response to increasing registrations for young people under 18, we recruited 3 dedicated youth therapists. We felt it was critical that we onboarded 3 new young person therapists because offering therapy for children under 18 with Complex Regional Pain Syndrome (CRPS) is crucial because it helps them manage both the emotional and psychological toll of living with chronic pain at a young age. It provides coping strategies to reduce anxiety, depression, and isolation, improving resilience and emotional well-being during critical developmental years. It also helps for young people to be able to talk to someone other than a family member especially surrounding managing their condition at school and also coping with CRPS with family.

In 2023-2024, we onboarded 23 new clients, and our service's impact is evident. This included assessing 6 young people and eventually taking on 3 child and young people as clients. On average for those who completed the full course of 20 sessions, we saw anxiety levels have dropped from severe to mild-medium for 85% clients, with similar reductions in depression. Notably, 86% of clients felt more confident after completing the 20 sessions, 90% saw a reduction in anger, fear or frustration and 95% of clients reported a reduction in suicidal thoughts. We attribute the increasing anxiety scores we've seen over the past year to external factors like the cost-of-living crisis which we found affected 52% of our community and the lingering effects of the pandemic.

Thanks to our amazing team of volunteers-including qualified therapists, trainee therapists on placement, and clinical supervisors - this service continues to provide essential mental health support to the CRPS community.

"I am so grateful to Burning Nights for allowing me to benefit from therapy. This has been life-changing for me. My quality of life is so much better now. A million thanks to Burning Nights and my amazing therapist." - WP, CRPS Patient

"I'm up and down still but Lorna has given me hope for the first time in many years. The counselling has helped me more than any nhs or crps specialist. Someone in my position to be given hope is massive." - AH, CRPS Patient

"Just a massive thank you to all involved who made it possible, without Burning Nights I'd still be fighting for help, now I have the tools and knowledge to tackle life's journey x" - TM, CRPS Patient

Wellbeing Wednesday project

Our Wellbeing Wednesday project was launched in 2023. This project involved hosting weekly activity sessions every Wednesday, offering accessible, low-impact physical exercises for people living with chronic pain, including Complex Regional Pain Syndrome (CRPS). These online Zoom sessions featured Chair Yoga, Dance, Qigong, and meditation, making it easier for those who are housebound or bedbound to participate. It was an excellent opportunity for individuals with chronic pain to explore new activities, stay active, or even begin a journey toward physical fitness.

We began with taster sessions followed by a series of 10 weekly sessions. Each class lasted 45-60 minutes, ensuring participants weren't overly fatigued, and each session was designed for up to 35 people. Led by specialist instructors, the sessions targeted CRPS symptoms, focusing on building strength, improving coordination, and promoting overall well-being. Two volunteers assisted in each class to answer questions and address concerns related to long-term pain management.

The exercises were carefully tailored for people with CRPS and chronic pain, but also welcomed friends, family members, and individuals with mobility issues. Regular physical activity has been shown to help manage chronic pain, reduce symptoms, and improve quality of life.

The project had three main goals:

- Increase physical activity among people with CRPS, chronic pain, and their families.
- Enhance mental well-being, reducing feelings of isolation and stress, and encouraging open conversations about their condition.

- Encourage a sense of community.

These sessions were designed to inspire attendees to continue the activities on their own, ensuring lasting benefits for both mental and physical health.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

ACHIEVEMENTS AND PERFORMANCE

In addition to the physical activities, we offered Zentangle sessions-a creative form of self-help art therapy. These sessions helped participants relieve stress, boost self-confidence, and foster a social community, reducing loneliness and isolation. Zentangle complemented the physical exercises, further enhancing the overall Wellbeing Wednesday experience.

Throughout the project, we provided 25 sessions for 179 people and 11 hours of well-being classes, achieving our core aims. We extend our gratitude to the incredible instructors who made this possible: Jackie from Strictly Chair Yoga, David for the Tai Chi & Meditation sessions, and Dawn for the Zentangle classes.

However we felt that the Wellbeing Project was coming to an end, so it was decided in August 2023 that we would stop the Wellbeing Wednesday project but we would continue in 2024-2025 with Zentangle sessions as our community felt they preferred this type of session.

We will continue to look for ways to bring wellbeing sessions to support the CRPS community for their mental, emotional and physical needs.

"Thank you so, so much. We've had a tough week and this was what I call an "pure joy" activity that brought me back to the present moment. I had so much fun that my son and partner did a drawing too." - V (Zentangle class)

ACHIEVEMENTS AND PERFORMANCE

CAMPAIGNING, ADVOCACY AND AWARENESS

Our Founder and Chair isn't only the driving force behind our organisation and also holds the position of Chair for The Patient Voice Committee (TPVC) with the British Pain Society. The TPVC advocates for the needs and rights of pain patients and their families, tirelessly raising awareness about pressing issues such as long waiting times for access to pain clinics, inadequate treatment options, and limited access to mental health services.

This dedication to enhancing the lives of pain patients extends beyond our organisation and into the broader community. Our Founder is a passionate advocate for the rights for patients and their families, utilising her platform to highlight the challenges that many individuals and families face. By dedicating her expertise, time, and energy to the TPVC and other initiatives, she is genuinely making a difference in the lives of those living with chronic pain.

At the heart of our organisation lies a profound sense of compassion and empathy for individuals with Complex Regional Pain Syndrome (CRPS) and their families. Our volunteers and trustees embody these values in all their efforts, serving as leaders and advocates for our mission. Through their ongoing work, we are optimistic about continuing to make strides in combating chronic pain and CRPS, ultimately hoping for a brighter, more hopeful future for all affected.

We engage in various campaigns and initiatives to advocate for CRPS awareness and address the challenges patients face, including:

CRPS Awareness Sessions

We have conducted a small number of informational sessions, providing 8.5 hours of insights to healthcare and legal students and professionals. Additionally, we have organised various talks, primarily in virtual formats. One of our regular engagements is at Derby University, where we speak to first-year Occupational Therapy students about the profound impact of CRPS on individuals' lives whether that's a social/societal, financial or emotional. By sharing personal stories, we aim to encourage a deeper understanding of the condition and its effects. We firmly believe that education and awareness are vital for improving outcomes, facilitating quicker diagnoses, and ensuring better treatments for CRPS. Moving forward, we aim to develop online CRPS awareness sessions to enhance accessibility and encourage broader participation in learning about this condition.

"The CRPS awareness session was well presented, good materials shown. Personal experience added appropriate extra emphasis." - Physio, CRPS Awareness Session, MSK Physio team

Exhibiting at Exhibitions

In the past year, we have participated in two significant exhibitions aimed at professionals in Primary Care, Public Health, and the disabled community, including Naidex. These events have provided valuable opportunities to raise awareness about our charity and CRPS. By educating the public and healthcare professionals about the condition, we aim to facilitate timely diagnoses and effective treatments for patients. We plan to continue our involvement in select health and disability exhibitions to highlight our work and the challenges faced by those living with CRPS.

Parliament and Campaigning

Our commitment to raising awareness about CRPS, particularly regarding available mental health support, remains unwavering. We continue to collaborate with our local MP and have also worked with MSP Clare Adamson to ensure that essential questions are raised in the House of Commons.

Our objective is to advocate for answers that not only support those currently battling CRPS but also provide assistance to their families and loved ones, who often feel overwhelmed and helpless. By maintaining our engagement with politicians across the UK, we aim to make a meaningful difference in the lives of those affected by CRPS.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

ACHIEVEMENTS AND PERFORMANCE

We have also become more involved in the Scottish Cross Party Group for Chronic Pain which supports pain patients in Scotland, and have indeed become a charity organisation within the Cross Party Group which has led onto some interesting conversations and groups. In December 2023, we were extremely honoured to have been included in the speech during the Debate in the Scottish Parliament by Clare Adamson MSP (Wishaw and Motherwell) who gave a great speech and debate on CRPS in December 2023 where she spoke about her son and their experiences of the health service and his condition, as he also lives with CRPS.

Information and education

One of our primary objectives is to provide comprehensive guidance and education to individuals living with Complex Regional Pain Syndrome (CRPS), as well as their families and loved ones. We also aim to raise awareness among the general public, healthcare professionals, and students regarding this condition. To facilitate the dissemination of information, we use various platforms, including our annual national conference (newly termed the CRPS Patients and Carers Information Day), educational webinars, our website, literature, and resource materials.

CRPS patients and carers Information day 2023

For 2023, we decided to redesign the annual conference to an event where more networking and talking could be the centre. We titled the conference, the CRPS Patients and Carers Information Day.

It is still designed to offer an in-depth understanding of CRPS, treatment options, and self-management strategies but we chose to split the day in 2 distinct parts. The morning session was where we invited leading experts in the field of CRPS, chronic pain and disability to discuss the latest research and advancements in CRPS management, allowing patients, their families, and loved ones to engage with medical professionals and connect with others who share similar experiences. The second part of the day was the networking part where we had not only the speakers but invited guests who could then visit each table of attendees and speak to them more on a one-to-one basis. This event creates a supportive environment for learning, sharing, and networking.

On 5th November 2023, we had the honour of hosting the conference at Double Tree Hilton Nottingham. The event still aimed to provide vital information and support to those affected by CRPS and their families.

The event attracted 67 attendees. We were fortunate to have four expert speakers from diverse health professions, each with a strong interest in CRPS, chronic pain, or disability. They shared invaluable insights on various topics, including the latest research and management strategies for CRPS, such as neuromodulation which sparked significant interest. The event was definitely a success, and attendees found it both helpful and informative.

"Many thanks for an excellent conference yesterday and your outstanding commitment to support everyone with CRPS and promote greater awareness of the ongoing everyday challenges of living with this condition. Thankyou!" - CI, CRPS Patient

Educational webinars

Building on the success of our previous years of webinars, we continued to offer online talks in the 2023-2024. We held three webinars, each focusing on a different topic. One webinar, co-organised with Brian Barr, addressed 'Understanding your Legal Rights: Navigating the Personal Injury Claims Process for CRPS Patients,' offering information to support people who are or who are thinking of making a legal claim due to their CRPS. The second webinar, "Discover a New Way: Everything You Need To Know About Medical Cannabis and Pain Management," explored the latest advancements in medical cannabis, including its uses and how to access it as a pain management option. This webinar was held in conjunction with the Leva Clinic. Our final webinar, presented by one of our psychotherapist volunteers, focused on "Managing Relationships with Chronic Pain", detailing how patients living with chronic pain and CRPS can manage a healthier relationship despite of their condition.

ACHIEVEMENTS AND PERFORMANCE

We extend our heartfelt gratitude to Brian Barr Solicitors, The Leva Clinic and Daniel Leech for their unwavering support in making our webinars successful. Their extensive knowledge and valuable insights have been crucial in helping us create engaging and informative online sessions that our audience has greatly appreciated. We are proud to have supported 116 individuals providing 4.5 hours of expertise through our webinars and we remain committed to keep offering and providing quality educational resources in the future.

Our webinars offer a unique opportunity for anyone interested in expanding their knowledge or improving their health by learning from leading experts in their fields. Our dedicated speakers aim to provide participants with the latest research and practical strategies to help them achieve their goals, whether that involves discovering breakthroughs in medical research or exploring new methods to enhance physical and mental well-being.

We believe everyone deserves access to quality educational resources, and our webinars are designed to be inclusive and accessible to all. We welcome individuals from diverse backgrounds to join us in promoting lifelong learning and personal growth. If you're looking for an opportunity to learn from the best and broaden your knowledge, we invite you to participate in our upcoming webinars and become part of our community of lifelong learners!

Website

The new website continued to be updated and expanded to ensure we had fresh content added to it every month.

We feel we've achieved some key objectives with our newly designed website including:

- Enhancing content clarity and accessibility
- Creating dedicated sections for caregivers, patients and healthcare professionals and students
- Providing up-to-date, evidence-based information for everyone in the CRPS community, including patients, families, friends, and caregivers
- Offering a resource where healthcare professionals and students can better understand CRPS and improve their patient services
- Raising awareness among CRPS patients and families about our charity and available services, reassuring them that they are not alone on their challenging journey
- Improving loading speed
- Reducing our bounce rate from 75% to 40% or lower

Our website serves as a comprehensive resource for individuals seeking information about Complex Regional Pain Syndrome (CRPS). Our mission is to deliver detailed and reliable insights into this condition, which can be complex to understand and manage. Designed as a one-stop shop, our site covers everything from symptoms and diagnosis to treatment options.

In the past year, we recorded nearly 92,000 unique visitors and a total of 95,500 visits (including both unique and returning users), along with 121,000 sessions. These have a slight increase on last year, however we are hoping that our improved SEO and fresh and important content will see a bigger rise next year.

Understanding the debilitating nature of CRPS and the difficulty of finding accurate information, we are committed to providing thorough, evidence-based content. Our website addresses various aspects of the condition, including causes, risk factors, and available treatment options. Our team continually compiles the latest research and medical guidelines to ensure access to the most current information.

Additionally, we showcase personal stories from individuals who have experienced CRPS first-hand. We believe these narratives provide valuable insights into the challenges faced by those affected, fostering a supportive and informative community.

ACHIEVEMENTS AND PERFORMANCE

Why not take a look and discover the wealth of information we have available? Whether you're a patient, caregiver, or healthcare professional, our site is a valuable resource for anyone seeking to learn more about CRPS.

"I'm delighted to be writing to let you know that as a result of conversations that partly were already in the works and partly as a result of the [blog] article I worked on with you, I am beginning to work with the independent living movement of Ireland to get Paralympics Ireland to consider eligibility for athletes with CRPS and other impairments as well as a beginning to move from the medical model to social model approach... Ireland would be the first country to adopt this. Thank you for sharing my story!"

Literature and awareness products

We recognise and empathise with the daily struggles faced by individuals affected by CRPS. To assist in managing their condition and improving their quality of life, we offer a range of tangible resources. Our literature and products aim to provide practical advice, guidance, and support to individuals with CRPS, their families, and healthcare providers.

Our literature resources include books, booklets, leaflets, and other materials such as bookmarks and folded cards tailored to the unique needs of those with CRPS and their families. Carefully crafted, our literature offers practical tips and strategies for managing pain, enhancing mobility, and improving overall well-being. Whether you're looking for information on the latest treatment options or tips for managing symptoms at home, we have the resources to help you take control of your condition.

We continue to distribute our CRPS information leaflets for both adults and young people to various NHS hospitals and private clinics across the UK.

In addition to our literature resources, we provide products specifically designed to help manage the pain and discomfort associated with CRPS. Our self-care packs offer effective strategies for symptom management and mental health support when it's most needed. With our products, individuals can take a proactive approach to managing their condition and improving their quality of life.

In summary, we are committed to ensuring that people whose lives have been touched by CRPS, healthcare professionals, and the general public have the necessary information and resources they need to navigate this challenging condition. Whether you seek practical advice, guidance, or support, we have the resources to help you take control of your condition and enhance your overall well-being.

Research and studies

Burning Nights CRPS Support have been actively collaborating with Professor Holly Blake from Nottingham University on the **Pain at Work (PAW) Toolkit** which has now been formally funded as a research trial. The charity has been involved as a part of the trial's Public and Patient Involvement (PPI). This innovative resource is designed to tackle the unique challenges faced by individuals with chronic pain in the workplace.

The PAW trial is looking to see if the Toolkit is a suitable and useful resource for employees with chronic pain to help them improve their overall support together with their mental health and physical health. It seeks to provide extensive information, including tips on how to effectively communicate with colleagues and employers about one's condition, strategies for managing pain while on the job, and guidance on accessing workplace accommodations and support. By utilising this toolkit, individuals with chronic pain will hopefully better understand their rights and responsibilities in the workplace, enabling them to manage their condition more effectively.

This collaborative effort involves Burning Nights CRPS Support, our Founder & Chair Victoria Abbott-Fleming MBE, and Professor Holly Blake. The PAW Toolkit marks a significant advancement in pain management, and we are proud to have contributed to its development. We hope it will enhance the lives of individuals with chronic pain and foster a more accommodating and inclusive workplace environment.

The trial is due to conclude in November 2025. We participate in regular meetings as members of the Management Committee, focusing on Public and Patient Involvement and Engagement.

As part of our commitment to PPIE we were also honoured to be involved in the OptiMeth Trial for CRPS which involved a prestigious team of researchers, clinicians and lived experience of CRPS from across the world. This was a year long trial which is due to complete towards the end of 2024.

ACHIEVEMENTS AND PERFORMANCE

Our dedication to finding a cure for CRPS and chronic pain has also led us to engage in 21 research studies conducted by universities across the UK and Canada. Our involvement has been crucial in advancing the understanding of the causes, treatments, and potential cures for these debilitating conditions.

As part of our support, we have assisted researchers in recruiting potential participants by promoting their studies across our various platforms. Our robust social media presence, e-newsletters, and website have played a vital role in raising awareness of these studies. Additionally, we have occasionally highlighted these research efforts on our blog to reach an even broader audience. Our new website features a research tracker that allows us to open, pause, and close various studies as needed.

We are proud to share that our initiatives extend beyond recruitment. We continue to disseminate the results of the studies and clinical trials we have supported through our various channels. Our online community forum has also been instrumental in connecting participants with researchers, providing a space for sharing information and experiences.

Through our collaborative efforts, we strive to bring hope and relief to those affected by CRPS and chronic pain.

VALUING OUR VOLUNTEERS

We are incredibly grateful for our 51 dedicated volunteers who have generously contributed their time and energy to help us deliver 12 essential services and projects to the CRPS community. Thanks to their selflessness and unwavering commitment, we provided an impressive 8,769 hours of support to our charity, significantly impacting the lives of those in need. If we had to pay for the hours volunteered, it would have saved the charity over £91,370.

At Burning Nights CRPS Support, we firmly believe that our volunteers are the heart and soul of our charity. We are committed to ensuring they have a positive and fulfilling experience while contributing to our mission. To support them, we offer ongoing resources, including regular wellbeing support sessions and bi-monthly meetings where they can share best practices and uplift one another.

For our volunteer Befrienders and Counsellors/Therapists, we provide additional support through monthly peer and clinical supervision and peer sessions, ensuring they have access to the necessary resources and training to offer the best possible service to our community. For new Therapists/Counsellors we also provide a monthly wellbeing check-in with two of the trustees who are also volunteers. This wellbeing hour is set up to ensure therapists are settling in okay and are happy with all our processes and procedures. We're also there to support their knowledge of CRPS.

Our volunteers are the backbone of our charity, and we cannot express enough gratitude for their tireless efforts and steadfast dedication. Thank you to each and every one of them for helping to shape our charity into what it is today.

Volunteer induction and training

At our charity, we take the induction and training of our volunteers very seriously. We believe that a comprehensive induction is essential for equipping our volunteers to support our community effectively. Each new volunteer undergoes a thorough induction process that covers not only our charity's aims, mission, and values but also vital safeguarding training for those in client-facing roles. We want to ensure that our volunteers are prepared to recognise, respond to, and report any safeguarding concerns that may arise.

Everyone also goes through GDPR, confidentiality and Equality, Diversity and Inclusion (EDI) training as well as part of the induction.

ACHIEVEMENTS AND PERFORMANCE

In addition to safeguarding training, all volunteers are required to complete CRPS awareness training. This consists of a video followed by a set of questions to reinforce their understanding. We believe this training is crucial for helping our volunteers empathise with and understand the challenges they may encounter in their roles.

For our volunteer Befrienders and Counsellors & Psychotherapists, we provide four mandatory e-learning courses tailored specifically to their responsibilities. These courses cover suicide awareness, suicide prevention, mental health awareness, and self-harm awareness. We have expanded this mandatory training to include additional roles as well. We believe that equipping our volunteers with this knowledge and skills is essential for providing effective support to our community.

We are committed to offering regular training courses for all our volunteers, ensuring that essential courses, such as safeguarding, are renewed annually, while mental health and suicide awareness training are updated every two years. Investing in our volunteers' training is vital to guarantee that our community receives the highest quality of support from our dedicated volunteers.

ENGAGING OUR SUPPORTERS

Principle sources of funding

To support our essential work, we draw from multiple funding streams, including fundraising activities, grants, and donations. Additionally, we sell a range of branded merchandise through our online shop, with all proceeds going directly to our organisation.

We introduced a new income stream in November 2022, through a paid membership scheme for UK and International, which we will continue to expand over the coming years.

We currently have 98 members from UK, Australia, Germany and USA. As part of our membership scheme, we provide a twice-yearly magazine which has exclusive content featuring latest research, fundraising stories, beneficiary/impact stories of people accessing our services plus informative and interesting content to support people impacted by CRPS.

Our fundraising efforts include events such as sponsored walks, runs, bike rides, and charity raffles. We also seek grants from various trusts and foundations that support health and wellbeing initiatives. Donations are a crucial source of funding for Burning Nights CRPS Support. We depend on the generosity of individuals and businesses who are passionate about our cause to help us continue our mission.

Fundraising and donations

Without the support of generous donors and fundraisers, we would be unable to provide essential services to those in need.

We are always open about how we raise our funds and are committed to training our staff to identify and protect individuals in vulnerable circumstances, in line with our Safeguarding and Fundraising Policies. We also make it easy for supporters to opt-out of receiving further communications from us.

We receive donations through various channels, including regular appeals and gifts left in Wills. Our community also hosts fundraisers for us, such as running, cycling, and walking events like The Three Peaks Challenge, the Great North Run and the Great Manchester Run.

We are grateful for all the support we receive, including donations from Facebook and Instagram fundraisers set up for birthdays, anniversaries, and holidays in support of our cause.

Every contribution, big or small, helps us continue our mission of supporting those affected by CRPS and improving care for all. Thank you for your ongoing support.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

ACHIEVEMENTS AND PERFORMANCE

Trusts and foundations

We extend our heartfelt gratitude to the following Trusts and Foundations:

- EC Graham (Cumbria)
- Nationwide Colleague Grant

Their unwavering support during challenging times has enabled us to continue our services and fulfil our commitments to our community.

Organisational health

During 2023-2024, we experienced a reduction in donations due to the aftermath of the pandemic and the high Cost of Living crisis, plus a significant rise in our outgoings due to the rising cost of resources and services in addition to the unprecedented increase in demand for support from the charity which has placed a significant strain on the existing service offering.

We have also seen high outgoings for IT and Digital Support including SEO. This has translated to improved online rankings and impressions meaning more visitors to the website, helping to raise awareness of CRPS.

Despite this, we have actively pursued grants from trusts and foundations and strengthened our relationships with corporate firms. As we move forward, we are committed to further diversifying our funding sources in the upcoming financial year. We remain steadfast in our mission to help our community and look forward to the opportunities and challenges ahead.

Corporate Donors

Our charity has been fortunate to receive continuous support from companies through their generous donations. From Dress Down Days to company walking days, Christmas quizzes, and being selected as the Charity of the Year, we are amazed by the ongoing financial contributions.

Many of our corporate donations come from our CRPS Legal Panel. All our specialist legal firms make an annual donation to join and be on the Panel. Additionally, we received an annual donation from a law firm from unclaimed client compensation.

We had the privilege of attending several corporate donor meetings, which were highly productive and successful, securing funding and grants for various projects and the charity itself. As the financial year came to a close, we began discussions with other companies, exploring potential partnerships and collaborations. We are excited about the possibilities these talks may bring and look forward to continued growth and support for our charity in the future.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

ACHIEVEMENTS AND PERFORMANCE

The charity's principal sources of funds

Burning Nights CRPS Support relies on multiple income sources to fund its services and projects, including fundraising events, grants from trusts and foundations, and generous donations from individuals and corporate partners. The charity also generates revenue through the sale of branded merchandise via its online shop.

However, the ongoing cost of living crisis, have negatively impacted donations and fundraising efforts. In response, Burning Nights CRPS Support has been exploring additional income streams, such as applying to more trusts and foundations and promoting legacy giving and payroll giving.

One of the charity's initiatives we began last year was the introduction of a Membership Scheme, allowing supporters to become paid members. In return, members receive exclusive benefits, such as access to the charity's magazine, 'The Warriors Lifeline', and other perks. It's important to note that paid members do not have voting rights.

Despite these financial challenges, Burning Nights CRPS Support continues to receive corporate donations, particularly from law firms that participate in their small legal panel. The charity also secures general corporate donations and grants, including support from medical device companies.

Overall, Burning Nights CRPS Support remains committed to its mission of assisting those affected by Complex Regional Pain Syndrome and is deeply grateful for the ongoing support it receives from its diverse income streams.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its Constitution adopted 20th October 2015, and constitutes a Charitable Incorporated Organisation.

Recruitment and appointment of new trustees

The process for appointing trustees is clearly defined in our Constitution to ensure transparency and accountability. Trustees are selected according to these guidelines and must retire or be re-appointed every three years at the Annual General Meeting (AGM).

For any new trustee appointment, approval from at least three (3) current trustees is required. Each new trustee is chosen with great care and consideration to ensure they align with the charity's mission and values.

Except for the founding trustees, all trustees serve a three-year term. This approach promotes continuity and stability within the board while also allowing for fresh perspectives and new voices.

The appointment of trustees is a vital part of the charity's governance. By adhering to the Constitution and maintaining a thoughtful selection process, the board ensures it comprises individuals who are dedicated to the charity's goals and bring diverse experiences and backgrounds to the table.

As of March 2024, 60% of the trustees had chronic pain and/or a disability.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

Burning Nights CRPS Support is a national charity operating across the UK. It is overseen by a Board of Trustees, which includes a Chair who leads the Board, a Treasurer, and other dedicated trustees. The charity employs one paid staff member, the Charity Administrator, and relies on a team of volunteers.

The day-to-day operations are managed by the volunteer team, the staff member, the Chair, and an additional Trustee. Although the other trustees do not hold specific titles, they work tirelessly to ensure the charity runs smoothly and effectively, and their contributions are invaluable.

Burning Nights CRPS Support recognises the importance of collaboration in achieving its goals. To this end, the charity fosters strong working relationships with other charities and umbrella organisations that share its mission. These relationships, while essential, are not classified as related parties under the Statement of Recommended Practice (SORP).

By partnering with these organisations, Burning Nights CRPS Support is able to expand its reach and provide support to more individuals across the UK affected by Complex Regional Pain Syndrome (CRPS).

Induction and training of new trustees

To ensure that all trustees are fully prepared to carry out their responsibilities, we provide a comprehensive induction into the charity. This is a vital step to ensure they understand the charity's values, mission, and objectives. The induction also includes briefings on the core responsibilities of the trustees and the Board, as well as an overview of CRPS and the specific needs of the CRPS community that we serve.

In addition, we offer annual training sessions covering key areas such as safeguarding vulnerable adults and children, confidentiality, and GDPR compliance-critical aspects of our work. Trustees are also provided with access to the Charity Commission's resources on trustee rights and responsibilities.

We have robust policies and procedures in place to guide our trustees in their duties, including those related to financial management, confidentiality, GDPR, social media, safeguarding, and conflicts of interest. The Board of Trustees regularly reviews these policies to ensure they remain current and in line with the latest legal and regulatory standards.

We are proud to have a team of dedicated trustees who volunteer their time to support our mission. None of our trustees receive remuneration or benefits, apart from expenses, which are reimbursed according to our expenses policy. This commitment helps maintain the integrity of our charity, ensuring that all resources are directed towards benefiting the people we serve.

By providing our trustees with the necessary policies, training, and ongoing support, we ensure they are well-equipped to perform their roles effectively and responsibly.

Burning Nights CRPS Support

Report of the Trustees
for the Year Ended 31 March 2024

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number
1166522

Registered office
1 Alder Brook
Chinley
High Peak
Derbyshire
SK23 6DN

Trustees
Mrs V Abbott - Fleming MBE
Mr R A Ingham
Miss L Davis
Mr A Patel
Mr T Craig Lowe Treasurer

Independent Examiner
Evelyn Partners (Leeds) Limited
Accountants
3rd Floor
56 Wellington Street
Leeds
West Yorkshire
LS1 2EE

Approved by order of the board of trustees on the 23rd of October 2024 and signed on its behalf by:



.....
Trustee

Burning Nights CRPS Support

Statement of Trustees' Responsibilities for the Year Ended 31 March 2024

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Charity law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently;
- Observe the methods and principles in the Charity SORP;
- Make judgements and estimates that are reasonable and prudent;
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the constitution. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Independent Examiner's Report to the Trustees of
Burning Nights CRPS

Independent examiner's report to the trustees of Burning Nights CRPS ('the Charity')

I report to the charity trustees on my examination of the accounts of the Charity for the year ended 31 March 2024.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011.

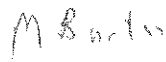
Having satisfied myself that the accounts of the Charity are not required to be audited under Section 144(2) of the Charities Act 2011 and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Charity as required by Section 130 of the 2011 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of the 2011 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Matthew Barton BA (Hons) FCA CTA

Evelyn Partners (Leeds) Limited
Accountants
3rd Floor
56 Wellington Street
Leeds
West Yorkshire
LS1 2EE

6 November 2024

Burning Nights CRPS Support

Statement of Financial Activities
(Incorporating an Income and Expenditure Account)
for the Year Ended 31 March 2024

		Unrestricted fund	Restricted funds	2024 Total funds	2023 Total funds as restated
	Notes	£	£	£	£
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	44,847	11,894	56,741	59,090
Other trading activities	3	5,174	-	5,174	3,753
Other income	4	<u>758</u>	<u>-</u>	<u>758</u>	<u>1,993</u>
Total		<u>50,779</u>	<u>11,894</u>	<u>62,673</u>	<u>64,836</u>
EXPENDITURE ON					
Raising funds	5	16,366	-	16,366	9,903
Charitable activities					
Charitable activities	6	<u>73,900</u>	<u>1,267</u>	<u>75,167</u>	<u>70,148</u>
Total		<u>90,266</u>	<u>1,267</u>	<u>91,533</u>	<u>80,051</u>
NET INCOME/(EXPENDITURE)		(39,487)	10,627	(28,860)	(15,215)
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>89,983</u>	<u>-</u>	<u>89,983</u>	<u>105,198</u>
TOTAL FUNDS CARRIED FORWARD		<u>50,496</u>	<u>10,627</u>	<u>61,123</u>	<u>89,983</u>

CONTINUING OPERATIONS

All income and expenditure has arisen from continuing activities.

The notes form part of these financial statements

Burning Nights CRPS Support

Balance Sheet
31 March 2024

	Notes	Unrestricted fund £	Restricted funds £	2024 Total funds £	2023 Total funds as restated £
FIXED ASSETS					
Intangible assets	13	8,022	-	8,022	12,829
Tangible assets	14	-	-	-	176
		8,022	-	8,022	13,005
CURRENT ASSETS					
Stocks	15	2,411	-	2,411	3,529
Debtors	16	-	-	-	3,208
Cash at bank		43,813	10,627	54,440	73,030
		46,224	10,627	56,851	79,767
CREDITORS					
Amounts falling due within one year	17	(3,750)	-	(3,750)	(2,789)
NET CURRENT ASSETS		42,474	10,627	53,101	76,978
TOTAL ASSETS LESS CURRENT LIABILITIES		50,496	10,627	61,123	89,983
NET ASSETS		50,496	10,627	61,123	89,983
FUNDS	18				
Unrestricted funds				50,496	89,983
Restricted funds				10,627	-
TOTAL FUNDS				61,123	89,983

The Charity is entitled to exemption from audit under Section 144(2) of the Charities Act 2011 for the year ended 31 March 2024.

The trustees acknowledge their responsibilities for

- ensuring that the Charity keeps accounting records that comply with the Charities Act 2011.
- preparing financial statements which give a true and fair view of the state of affairs of the Charity as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of the Charity Act 2011.

The notes form part of these financial statements

Burning Nights CRPS Support

Balance Sheet - continued
31 March 2024

The financial statements were approved by the Board of Trustees and authorised for issue on the 23rd of October 2024 and were signed on its behalf by:



.....
Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the Charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

The Charity has taken advantage of the following disclosure exemption in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Intangible fixed assets

Amortisation is charged at the following annual rates in order to write off each asset over its estimated useful life.

Website - 25% Straight line

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Furniture and equipment - 25% Straight line

Stocks

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Pension costs and other post-retirement benefits

The Charity operates a defined contribution pension scheme. Contributions payable to the Charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

Burning Nights CRPS Support

Notes to the Financial Statements - continued
for the Year Ended 31 March 2024

2. DONATIONS AND LEGACIES

	2024	2023 as restated
	£	£
Donations	42,417	57,673
Gift aid	993	662
Grants	11,894	-
Income from membership	<u>1,437</u>	<u>755</u>
	<u>56,741</u>	<u>59,090</u>

Grants received, included in the above, are as follows:

	2024	2023 as restated
	£	£
Other grants	<u>11,894</u>	<u>-</u>

3. OTHER TRADING ACTIVITIES

	2024	2023 as restated
	£	£
Sales of goods and services	<u>5,174</u>	<u>3,753</u>

4. OTHER INCOME

	2024	2023 as restated
	£	£
Other income	<u>758</u>	<u>1,993</u>

5. RAISING FUNDS

Other trading activities

	2024	2023 as restated
	£	£
Purchases	1,419	5,707
Marketing and publicity	13,957	4,196
Events	<u>990</u>	<u>-</u>
	<u>16,366</u>	<u>9,903</u>

Burning Nights CRPS Support

Notes to the Financial Statements - continued
for the Year Ended 31 March 2024

6. EXPENDITURE ON CHARITABLE ACTIVITIES

	Direct Costs (see note 7) £	Support costs £	Totals £
Charitable activities	<u>17,654</u>	<u>57,513</u>	<u>75,167</u>

7. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2024 £	2023 as restated £
Trustees' expenses	4,024	3,386
Travel expenses	835	2,640
Conference expenses	8,714	15,014
Staff training	<u>4,081</u>	<u>1,771</u>
	<u>17,654</u>	<u>22,811</u>

8. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2024 £	2023 as restated £
Depreciation - owned assets	176	3,386
Website amortisation	<u>4,807</u>	<u>-</u>

9. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2024 nor for the year ended 31 March 2023.

Trustees' expenses

	2024 £	2023 as restated £
Trustees' expenses	<u>4,024</u>	<u>3,386</u>

The trustee expenses were paid to 3 trustees for training and travel costs during the year.

Burning Nights CRPS Support

Notes to the Financial Statements - continued
for the Year Ended 31 March 2024

10. STAFF COSTS

	2024	2023 as restated
	£	£
Wages and salaries	26,625	23,553
Other pension costs	<u>580</u>	<u>518</u>
	<u>27,205</u>	<u>24,071</u>

The average monthly number of employees during the year was as follows:

	2024	2023 as restated
Staff	<u>1</u>	<u>1</u>

No employees received emoluments in excess of £60,000.

11. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund as restated £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	59,090
Other trading activities	3,753
Other income	<u>1,993</u>
Total	<u>64,836</u>
EXPENDITURE ON	
Raising funds	9,903
Charitable activities	
Charitable activities	<u>70,148</u>
Total	<u>80,051</u>
NET INCOME/(EXPENDITURE)	(15,215)
RECONCILIATION OF FUNDS	
Total funds brought forward	<u>105,198</u>
TOTAL FUNDS CARRIED FORWARD	<u>89,983</u>

Notes to the Financial Statements - continued
for the Year Ended 31 March 2024

12. PRIOR YEAR ADJUSTMENT

Website costs were incorrectly classified as tangible fixed assets rather than intangible fixed assets in the accounts for year ending 31 March 2022. A Prior Year Adjustment has been made to amend this.

13. INTANGIBLE FIXED ASSETS

	Website £
COST	
At 1 April 2023 and 31 March 2024	<u>19,229</u>
AMORTISATION	
At 1 April 2023	6,400
Charge for year	<u>4,807</u>
At 31 March 2024	<u>11,207</u>
NET BOOK VALUE	
At 31 March 2024	<u>8,022</u>
At 31 March 2023	<u>12,829</u>

14. TANGIBLE FIXED ASSETS

	Furniture and equipment £
COST	
At 1 April 2023 and 31 March 2024	<u>744</u>
DEPRECIATION	
At 1 April 2023	568
Charge for year	<u>176</u>
At 31 March 2024	<u>744</u>
NET BOOK VALUE	
At 31 March 2024	<u>-</u>
At 31 March 2023	<u>176</u>

15. STOCKS

	2024	2023 as restated
	£	£
Stocks	<u>2,411</u>	<u>3,529</u>

Notes to the Financial Statements - continued
for the Year Ended 31 March 2024

16. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023 as restated
	£	£
Prepayments and accrued income	<u>-</u>	<u>3,208</u>

17. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023 as restated
	£	£
Trade creditors	336	57
Social security and other taxes	704	291
Other creditors	114	101
Accruals and deferred income	<u>2,596</u>	<u>2,340</u>
	<u>3,750</u>	<u>2,789</u>

18. MOVEMENT IN FUNDS

	At 1/4/23 £	Net movement in funds £	At 31/3/24 £
Unrestricted funds			
General fund	89,983	(39,487)	50,496
Restricted funds			
Nationwide colleagues	-	9,894	9,894
E C Graham's Charitable Settlement	<u>-</u>	<u>733</u>	<u>733</u>
	<u>-</u>	<u>10,627</u>	<u>10,627</u>
TOTAL FUNDS	<u>89,983</u>	<u>(28,860)</u>	<u>61,123</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	50,779	(90,266)	(39,487)
Restricted funds			
Nationwide colleagues	9,894	-	9,894
E C Graham's Charitable Settlement	<u>2,000</u>	<u>(1,267)</u>	<u>733</u>
	<u>11,894</u>	<u>(1,267)</u>	<u>10,627</u>
TOTAL FUNDS	<u>62,673</u>	<u>(91,533)</u>	<u>(28,860)</u>

Notes to the Financial Statements - continued
for the Year Ended 31 March 2024

18. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/22 £	Net movement in funds £	At 31/3/23 £
Unrestricted funds			
General fund	105,198	(15,215)	89,983
TOTAL FUNDS	<u>105,198</u>	<u>(15,215)</u>	<u>89,983</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	64,836	(80,051)	(15,215)
TOTAL FUNDS	<u>64,836</u>	<u>(80,051)</u>	<u>(15,215)</u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1/4/22 £	Net movement in funds £	At 31/3/24 £
Unrestricted funds			
General fund	105,198	(54,702)	50,496
Restricted funds			
Nationwide colleagues	-	9,894	9,894
E C Graham's Charitable Settlement	-	733	733
	-	10,627	10,627
TOTAL FUNDS	<u>105,198</u>	<u>(44,075)</u>	<u>61,123</u>

18. MOVEMENT IN FUNDS - continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	115,615	(170,317)	(54,702)
Restricted funds			
Nationwide colleagues	9,894	-	9,894
E C Graham's Charitable Settlement	<u>2,000</u>	<u>(1,267)</u>	<u>733</u>
	<u>11,894</u>	<u>(1,267)</u>	<u>10,627</u>
TOTAL FUNDS	<u>127,509</u>	<u>(171,584)</u>	<u>(44,075)</u>

19. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2024.

Burning Nights CRPS Support

Detailed Statement of Financial Activities
for the Year Ended 31 March 2024

	2024 £	2023 as restated £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	42,417	57,673
Gift aid	993	662
Grants	11,894	-
Income from membership	<u>1,437</u>	<u>755</u>
	56,741	59,090
Other trading activities		
Sales of goods and services	5,174	3,753
Other income		
Other income	<u>758</u>	<u>1,993</u>
Total incoming resources	62,673	64,836
EXPENDITURE		
Other trading activities		
Costs of good sold	1,419	5,707
Marketing and publicity	13,957	4,196
Events	<u>990</u>	<u>-</u>
	16,366	9,903
Charitable activities		
Trustees' expenses	4,024	3,386
Travel expenses	835	2,640
Conference expenses	8,714	15,014
Staff training	<u>4,081</u>	<u>1,771</u>
	17,654	22,811
Support costs		
Management		
Insurance	604	433
Telephone	490	517
Postage and stationery	2,193	2,091
subscriptions	<u>3,651</u>	<u>3,247</u>
	6,938	6,288
Finance		
Bank charges	316	662
Information technology		
IT software and consumables	13,768	7,875

This page does not form part of the statutory financial statements

Burning Nights CRPS Support

Detailed Statement of Financial Activities
for the Year Ended 31 March 2024

	2024	2023
	£	as restated £
Information technology		
Human resources		
Wages	26,625	23,553
Pensions	580	518
Supervision	<u>1,113</u>	<u>1,982</u>
	28,318	26,053
Other		
General expenses	427	-
Entertainment - 100% business	352	653
Amortisation of intangible fixed assets	4,807	-
Depreciation of tangible fixed assets	<u>176</u>	<u>3,386</u>
	5,762	4,039
Governance costs		
Accountancy and legal fees	<u>2,411</u>	<u>2,420</u>
Total resources expended	<u>91,533</u>	<u>80,051</u>
Net expenditure	<u>(28,860)</u>	<u>(15,215)</u>

Accounts

Charity registration number: 1166522

Burning Nights CRPS Support

Annual Report and Financial Statements

for the Year Ended 31 March 2023

Burning Nights CRPS Support

Contents

Reference and Administrative Details	1
Trustees' Report	2 to 31
Statement of Trustees' Responsibilities	32
Independent Examiner's Report	33
Statement of Financial Activities	34
Balance Sheet	35
Notes to the Financial Statements	36 to 44

Burning Nights CRPS Support

Reference and Administrative Details

Trustees	Mrs Victoria Abbott-Fleming MBE Miss Lisa Davies Mr Thomas Craig Lowe Mr Altaf Patel Mr Richard Anthony Ingham (appointed 22 November 2022)
Principal Office	1 Alder Brook Chinley High Peak Derbyshire SK23 6DN
Charity Registration Number	1166522
Bankers	National Westminster Bank plc Western Avenue Waterside Court Chatham Maritime Chatham Kent ME4 4RT
Independent Examiner	Andrew J McLaren FCA Beever and Struthers Chartered Accountants One Express 1 George Leigh Street Manchester M4 5DL

Burning Nights CRPS Support

Trustees' Report

The trustees present the annual report together with the financial statements of the charity for the year ended 31 March 2023.

Objectives and activities

Objects and aims

Summary of objects

The purposes and objectives of the charity, as set out in its governing document, are as follows:

1) to promote and protect the health of sufferers (patients) of Complex Regional Pain Syndrome (CRPS), their families and carers by the provision of information, advice and support including raising awareness of all aspects of CRPS amongst the public in general but in particular those involved in the diagnosis, treatment and care of those suffering from CRPS; and

2) to assist and support research into CRPS, its causes, treatment and cure and to ensure the useful results of such research are published.

Within our aims and objectives we offer a range of support services including mental health support such as a Befriending Service, Counselling & Psychotherapy Service for anyone affected by CRPS aged 5 and over, telephone helpline, live web chat, online community forum, support groups and more.

We provide services to both adults and children due to the fact that Complex Regional Pain Syndrome can affect anyone at any age.

Aims of the Charity

A diagnosis of complex regional pain syndrome (CRPS) can bring profound emotional and economic impacts upon individuals and families living with CRPS.

Over 15,000 people are diagnosed every year with CRPS. Sadly, being diagnosed with CRPS doesn't just affect those living with it. But it can have a devastating effect on all those around them.

60% of the current Trustee board live with CRPS or chronic pain, and having lived experience is beneficial to the work of the charity. Over half of our volunteers also have lived experience of CRPS or chronic pain.

In planning our activities for the year, we kept in mind the Charities Commission's guidance on public benefit at our trustees' meetings.

Every year, the trustees evaluate the charity's aims, objectives, and activities. This report looks at the accomplishments made by the charity and the impact of its work during the year. The trustees provide an account of the success of each activity and the impact that the charity has delivered to those it has been created to support.

Moreover, the review process serves as a means for the trustees to ensure that the charity's aims, objectives, and activities remain aligned with its stated purposes. By doing so, the charity can stay committed and focused on its mission to help those in need, and continue making a positive impact in the community.

Burning Nights CRPS Support

Trustees' Report

Objectives, strategies and activities

The charity's main activities and who it aims to support are described below. All its charitable activities are undertaken to further Burning Nights CRPS Support's charitable purposes for the public benefit, and focus on:

- Providing information and support through various means for everyone affected by Complex Regional Pain Syndrome (CRPS) including patients, families, close relatives and caregivers
- Raising awareness, education and campaigning
- Information and supporting research

In the aftermath of the Covid-19 pandemic and subsequent problems such as the high cost of living and mortgage rates it continued to have a significant impact on the CRPS community. Many patients have found themselves with long waiting for appointments or little access to pain management programmes or mental health support, and with little support from the NHS due to overloading and continued pressures.

With the difficulty in accessing GP appointments and pain clinic appointments, some were not able to get a diagnosis nor access the treatments they so desperately needed.

We have continued to try to ensure that CRPS is discussed at all levels within the necessary decision makers but also in the general public, trying to show how a diagnosis of CRPS can have a major impact on all aspects of life including for those around them.

We have worked hard to fill in the gaps where we could so we could continue to deliver a number of virtual support services such as our regular online support groups, as well as offer information and guidance. Our online / virtual Support Groups have continued offering a lifeline to many people needing a community who listens and hears their cries for help and support. We delivered some webinars, expanded our CRPS Counselling and Psychotherapy Service and continued with our web chat service and helpline.

We have been very proud of the amazing support given by volunteers, working hard to increase our Befriending Service and other virtual services such as social media and support. Our volunteer network has continued and thanks to our team of 44 trained volunteers, Burning Nights CRPS Support continues to be there for those whose lives have been touched by CRPS when they need it most.

The main activities of the charity pursuant to its purposes this year have included:

- (1) **Providing information and support through various means to people with, affected by, or involved with the diagnosis and treatment of CRPS;**

As usual our main focus for all our activities and services lay with promoting and protecting the health of all those whose lives have been affected by Complex Regional Pain Syndrome (CRPS) which includes those who live with CRPS (patients), their families, close relatives and caregivers, as well as reducing the isolation and loneliness that comes with living with a pain condition like Complex Regional Pain Syndrome (CRPS). As a charity we support both adults as well as children and young people.

Partners, family members, and close relatives, relationships can also be affected by CRPS, therefore it is crucial that they also receive support. This is evident from the high number of partners and family members who reach out to our charity across our services.

Burning Nights CRPS Support

Trustees' Report

The impact of CRPS can lead to poor mental health, low self-esteem, low confidence levels, feelings of loneliness, isolation, and confusion. These effects were exacerbated in the past during the years of the Covid-19 pandemic but have continued to be evident throughout this year in the high cost of living crisis that we have all faced. These have been noticed in the assessment scores and responses to our surveys. However the need for support services like the Counselling and Psychotherapy service and Befriending Service has become more pressing than ever before. As a result, the demand for all of our support services within our community is continually growing.

We are incredibly thankful for all the amazing supporters who have come up with new ways of raising money and supporting Burning Nights CRPS Support. Their contributions are invaluable to us.

Our efforts persist in providing education, increasing awareness, offering valuable information, emotional and psychological support, and general advice not only to individuals whose lives have been affected by Complex Regional Pain Syndrome (CRPS) such as patients, caregivers, and family members, but also to the general public, healthcare professionals, students, as well as legal and financial professionals.

Our Befriending Service and Counselling & Psychotherapy Service continued to grow both in numbers of people wanting support but also in the number of volunteers for each of the services.

Our CRPS Counselling & Psychotherapy Service continued to offer one-to-one person centred and specialist CBT / EMDR / ACT counselling and psychotherapy either online through Zoom or via the telephone to people affected by CRPS. The sessions are offered to anyone aged 5 and above. We continued to offer up to 20 hours of counselling or psychotherapy including 4 assessments with one of our volunteer counsellors or psychotherapists. We ask all clients accessing our Counselling & Psychotherapy Service to complete a before & after survey so we can monitor the impact of the therapy. We also ask clients to complete a monitoring form which monitors EDI information and we also monitor the number of sessions completed, assessment scores and other basic information.

We eventually took on a child & young person therapist for our younger clients as the waiting list had grown substantially and far too long. We continue to expand and grow this service especially for children and young people.

Our other highly sought after service is the Befriending Service. This has continued to see regular registrations from CRPS patients and families. Clients wanting to use this service will receive 12 weekly phone calls or video calls via Zoom. Each call will last up to 40 minutes with one of our lived experience volunteers.

Burning Nights CRPS Support

Trustees' Report

(2) Updating & publishing literature;

We have continued our programme of updating all our information leaflets and booklets helping to support people affected by Complex Regional Pain Syndrome. We updated the adult leaflet to account for the IASP Valencia Consensus on CRPS which changed the types of CRPS.

The 3 self care packs have been very well received by patients and families. The self-care packs aim to enhance the mental health and emotional wellbeing of CRPS and chronic pain patients and their families by equipping them with valuable information and activities such as breathing, mindfulness meditation, sleep diary and physiotherapy exercises that were designed by a pain physiotherapist. The packs serve as a toolkit, offering resources and techniques to help cope with the challenges of CRPS. They focus on promoting self-esteem and resilience, while instilling a sense of belief that they can overcome each day's hurdles, and emphasising the importance of prioritising their needs.

Our information literature serves a variety of audiences, including the general public, but most importantly, individuals living with CRPS, their families, and caregivers. Additionally, our literature also benefits healthcare, legal, and financial professionals by providing valuable information, advice, and support. We strive to raise awareness of all aspects of the condition, ensuring that everyone impacted by CRPS is well-informed and supported.

(3) Developing a membership scheme for mutual support;

As our website underwent redevelopment, we decided to introduce a membership scheme in November 2022, that offers a range of exclusive benefits. By becoming a member, you gain access to a wealth of exclusive content, as well as the opportunity to participate in research studies and connect with a community of like-minded individuals for support.

Our exclusive content is carefully curated by our team of experts to provide you with the latest insights and trends in your field of interest. From informative articles and whitepapers to webinars and podcasts, our members are always the first to know about the latest developments.

In addition to exclusive content, members also have the opportunity to participate in research studies, providing valuable insights and feedback on relevant topics. By getting involved in research, you can have a real impact on the industry and help shape its future.

Finally, our membership scheme provides a supportive community of individuals who share your interests and goals. Whether you're looking for advice, inspiration, or simply a sounding board, our community is there to help patients and their families as well as health care every step of the way.

(4) Producing a magazine (The Warriors Lifeline) which is available on payment of a small subscription, online and in hard copy (new addition to the charity, a membership scheme started November 2022;

As part of the relaunch of our website in November 2022, we introduced the membership scheme with a range of benefits, including a bi-annual magazine called The Warriors Lifeline. While we faced some initial challenges in getting articles written and the magazine created, we were able to successfully publish our first edition at the start of November 2023 (please see our next financial year's report). The aim of the magazine is to provide exclusive content for our membership community, increasing knowledge of CRPS, sharing personal CRPS stories and recent fundraisers and a regular feature named 'Lisa's Gadget Corner'. This is where one of the Trustees, Lisa Davis, shares her experience of using a disability or accessibility gadget or piece of equipment and where to purchase it. Despite the teething issues, we are committed to continuing to produce high-quality content for our members through The Warriors Lifeline on a bi-annual basis. Stay tuned for more updates in our next year's Annual Report.

Burning Nights CRPS Support

Trustees' Report

(5) Organising annual conferences and educational webinars;

During the year, three webinars were conducted on the topics of mobility and accessibility aids, demystifying medical cannabis for chronic pain and Cognitive Behavioural Therapy (CBT) for CRPS and chronic pain. The webinar on mobility and accessibility aids was presented by a colleague of one of our legal panel - Express Solicitors, the one on demystifying medical cannabis for chronic pain was supported by a the Lyphe Group, and the CBT for CRPS and chronic pain was facilitated by one of our volunteers and cognitive behavioural psychotherapist. The webinars were attended by many people who found them informative and well worth attending.

The annual national CRPS conference was held in Edinburgh this year, owing to an in memory donation. The donation had stipulated that we spend the money supporting the people in Scotland. As usual we held the conference during CRPS awareness month in November, and it was free of charge for everyone attending live or virtually. The attendees were mainly people affected by CRPS, including patients, their families, and caregivers. We did however have the honour of having a local MSP who kindly gave a short speech about CRPS and the cross party events that Scotland hold. We had some great health professionals, legal and disability speakers who were invited to speak at the conference.

We hold the conference annually as it's a great way to raise awareness about CRPS and help people manage and live with the condition. Attendees found it useful and insightful, and they gained support from others who shared their stories and journeys of living with and managing their condition. Trained health professionals offer help, advice, support, and information, giving hope to patients and families and showing them that there is life after diagnosis.

(6) Maintaining a website and social media presence to promote public awareness and provide support;

The website was finally updated thanks to several trusts and foundations as well as fundraisers and donors, and was eventually launched in November 2022.

Redeveloping and relaunching our website has been vital for us to continue promoting public awareness and providing support to those affected by CRPS, their relatives, carers and friends as well as health and legal professionals. By maintaining a website and social media presence, we have effectively communicated not only the condition but also the charity. It keeps everyone informed about our charity's activities as well as its mission, vision, aims and objectives. Through the website we have been able to offer resources and support to those in need, and build a community where people can share their experiences and find comfort in knowing they are not alone. Overall, we believe that investing time and resources into maintaining a strong online presence can and does make a significant impact on the success of our charity.

Our website has been thoughtfully designed with support from our CRPS community through polls and surveys, to provide a wide range of resources and support to those who live with CRPS, as well as their families and caregivers. We offer an online community forum, an awareness product store, live chat, and other resources that detail our services, impact, and a new membership scheme. Our online community activities, such as social media support and our online community forum, have been particularly helpful for Millennials, Gen Z, and teens who are looking for a different format of interaction.

Burning Nights CRPS Support

Trustees' Report

Our blog articles are highly regarded, with patients frequently taking printed pages to their doctors and other healthcare professionals.

The charity offers support to anyone affected by Complex Regional Pain Syndrome (CRPS), including patients, families, and caregivers, and one of the many ways we offer support is through one of six different social media channels, such as Facebook, Twitter, Instagram, Pinterest, YouTube, and LinkedIn, where our volunteers are available to provide signposting, information, and a listening ear. We also started a new channel - TikTok at the request of not only volunteers but members of our community and we launched our profile on the channel in August 2022.

We have continued to have a steady increase in our supporters across our social media channels where we have profiles which during 2022-2023 include Facebook, Twitter, Instagram, Pinterest, YouTube, LinkedIn and TikTok.

Our social media support volunteer team has been busy once again, with a large increase in private messages, and an increase in engagement with comments and questions in response to our posts. As usual, we regularly received direct private messages and questions from patients, their families and friends which we continued to respond to. These direct private messages ranged from requests for support and help to signposting and mental health support. Providing the latest research, articles, and information about all aspects of CRPS, living with the condition, and caring for someone with CRPS continued to be a priority for our social media.

To respond to these queries, we have a team of dedicated and trained volunteers who provide signposting, information, and a listening ear to anyone affected by CRPS, including patients, families, caregivers, and even health professionals and law firms. We aim to reduce the isolation of people with CRPS and their loved ones by being available on the different social media channels. We also offer understanding and empathy to patients and their families.

In addition, our Closed Facebook group for Parents & Caregivers of Young People with CRPS has been a valuable resource for those seeking advice, information, and support from others in similar situations. The group has gradually increased in numbers and continues to be a supportive community for parents, caregivers, and guardians of young people with CRPS.

(7) Running well-being events to bring our community together for both adults and children;

One of the common requests we received post-Covid was to get some regular exercise that was low impact so that people with CRPS especially those with mobility problems can access and attend. We chose to try different options so our community could try. We started with a couple of taster sessions in chair yoga with dance and tai chi.

Engaging in low-impact physical activities can have numerous benefits for a person's physical well-being. It can help reduce inflammation, promote better mobility, and alleviate pain. This is because physical activity prompts the release of natural endorphins, which are mood-enhancing chemicals in the brain that also help to ease pain signals. Moreover, incorporating a regular exercise routine into a person's lifestyle can enhance the quality of your sleep and potentially decrease reliance on pain medications.

People who attended found the sessions helpful for both their mental and physical health, and it gave them a focal point in the week.

Burning Nights CRPS Support

Trustees' Report

(8) Facilitating online support groups;

Our online support groups for Complex Regional Pain Syndrome (CRPS) have continued to be a great help to all those who attend, including patients, family members, young people, and friends of those living with the condition. These monthly peer support groups offer a private, safe, and confidential space for our CRPS community to connect with others who are facing similar challenges. Our volunteer-led groups are facilitated by CRPS patients themselves, which means that attendees can learn new skills, meet new people, and share their experiences with others who understand what they are going through.

Our last report highlighted the need for online support groups specifically for those aged 18 years and under, as well as for loved ones and caregivers. We had hoped to continue offering these groups to those sections of our community, however we only held one group for young people aged 18 and under. This is because of lower attendance numbers than our main peer support group. We are looking into what else we can offer these groups in the next year. Nonetheless, we know that these groups have been useful to those who have attended, providing a sense of security and reducing isolation and loneliness for everyone involved.

(9) Running a telephone information and helpline and online web/live chat for all our CRPS community whether they're a patient, family member, carer, close relative or friend;

Our telephone Helpline has been a constant source of support throughout 2022-2023. We have maintained our usual opening times during the working week from Monday to Friday. For those who need assistance outside of these hours, we have a voicemail service available and we always return any voicemails. In addition, we have included the phone number of the Samaritans on our contact page on our website as well as on our voicemail to provide further support.

The majority of people who reach out to our Helpline are CRPS patients, along with their loved ones and caregivers. We receive a range of questions and issues that we are able to address or signpost. Our Helpline is a confidential space for people to speak with someone who understands what they are going through. We joined the Helplines Partnership organisation as a way to raise awareness of our Helpline.

Our Helpline calls are answered by CRPS patients who volunteer their time to help others as well as our Charity Administrator who has received awareness training in CRPS. It is a lifeline for many individuals who are housebound, vulnerable, and isolated. We are here to help people cope with the challenges of each day and find strategies that work for them. We also provide a listening ear to the CRPS community when they are finding things difficult or as they begin their journey of acceptance of this condition.

Our Helpline really does benefit those living with CRPS, but also their family members, friends, and loved ones. It is a valuable resource used by many healthcare professionals and health students, including school nurses who work with patients, school children, and teenagers with this condition.

Burning Nights CRPS Support

Trustees' Report

We understand that living with and being affected by Complex Regional Pain Syndrome (CRPS) can be a challenging and isolating experience. That's why we're here to provide callers with crucial information, empathy, and understanding. Our compassionate team is dedicated to not only offering helpful advice and support, but also connecting individuals with other organisations and resources that can further assist them on their journey. One of the most important aspects of our Helpline is the sense of community that we provide. We know that it can be difficult to feel understood and supported when dealing with CRPS, which is why we're committed to fostering a safe and welcoming environment for all of our callers. By offering a listening ear, a reassuring voice, and a wealth of knowledge and resources, we aim to help individuals with CRPS feel more confident and empowered in their daily lives.

Whether people were looking for practical advice on managing symptoms, emotional support during a difficult time, or simply a friendly conversation with someone who understands what they were going through, our Helpline was here to help. We believe that with the right support and guidance, people affected by CRPS can not only survive, but thrive in their lives.

Once again, our online live web chat has proven to be an invaluable resource for the CRPS community, with hundreds of patients, their families, and friends reaching out to us for support. In addition to this, we were thrilled to see a growing number of health professionals engaging with our platform, seeking to learn more about this debilitating condition in real-time.

One of the unique aspects of our web chat is that our team of dedicated volunteers are all patients themselves, which allows them to truly understand and empathise with the struggles of those who reach out to us. This personal connection is something we believe makes a real difference in the support and guidance we are able to provide to our users.

We are proud to offer a safe and welcoming space for anyone who may be affected by CRPS, whether they are seeking to connect with others who understand their experiences, or they are looking for reliable information and resources. We remain committed to continuing our work to raise awareness about this condition and provide meaningful support to those who need it most.

(10) Supporting research projects that will benefit those affected by CRPS.

As a charity, one of our aims is that we support research into Complex Regional Pain Syndrome (CRPS) and chronic pain. Our efforts have taken various forms, such as assisting researchers in finding prospective participants and providing them with the necessary resources to carry out their studies.

One of our most notable contributions to this cause has been through our collaboration with Professor Holly Blake at Nottingham University, regarding the Pain At Work (PAW) Toolkit. This initiative has led to further research, and we are proud to have been part of its growth. In fact, a research proposal was accepted and the charity is now heavily involved in this piece of research as the Public and Patient Engagement.

We were also approached by another researcher who wanted us to take part in another research study as the Public and Patient Engagement but that isn't due to start until 2023-2024.

We take pride in the fact that our involvement in research projects has provided our community with the opportunity to support the fight against CRPS and chronic pain. We strongly believe that the results of such research must be shared with the world, and we make sure to publish them across our social media, website, and newsletters. This way, we can raise awareness about the importance of this cause and encourage others to join us in our efforts.

Burning Nights CRPS Support

Trustees' Report

(11) Running an online community forum for mutual support, help, information and an exchange of ideas;

Our online community forum has been a beacon of hope for many individuals seeking support for various issues. The community forum is an ideal alternative for anyone who is not active on social media or for others who simply prefer a more dependable platform, our forum is here to cater to their needs. At its core, the community forum is designed to provide peer-to-peer support, advice, and information on a wide range of topics.

As a charity, we have also utilised this forum to guide patients and their families towards our own support services. We offer valuable insight into treatment options available on the NHS, as well as private healthcare systems. Furthermore, we strive to provide comprehensive information on the condition itself, from managing it to living with it.

For those who are specifically dealing with Complex Regional Pain Syndrome (CRPS), our online community forum provides a safe space for patients, their families, and their carers to communicate with one another. It is a platform for individuals to share their stories, seek guidance, and find comfort in the knowledge that they are not alone. Together, our community fosters a sense of camaraderie and social networking that can be invaluable in navigating the challenges of living with CRPS.

(12) Provision of information and education talks to promote understanding and awareness of CRPS;

One of our main aims has been dedicated to spreading awareness and knowledge about Complex Regional Pain Syndrome (CRPS). We've held numerous educational online and in person sessions that were designed to inform attendees about the condition, including its diagnosis, prognosis, and various treatment options. In addition, we've also provided guidance on how to manage the condition effectively, which has been particularly beneficial for individuals who are dealing with CRPS on a daily basis.

One of our primary goals has been to further the education of healthcare students and professionals who are involved in treating, diagnosing, and caring for those living with CRPS. Through our awareness and information sessions, we've been able to reach out to these trainees and equip them with the knowledge they need to provide optimal care for their patients. We also extend these educational opportunities to healthcare professionals, as we believe that anyone who may come into contact with a CRPS patient should be well-informed about the condition and its management.

Furthermore, we've been collaborating with various companies, including medical device companies, health/medicine companies, and law firms, in an effort to raise awareness about CRPS and its impact on patients, families, and carers. These meetings have been successful in many instances. Our hope is that by working with these organisations, we can continue to spread awareness about CRPS and provide support for those who are affected by this condition.

Burning Nights CRPS Support

Trustees' Report

(13) Attendance at exhibitions to promote public awareness;

Participating in exhibitions is an integral part of our outreach efforts, and we were thrilled to have taken part in two major events during 2022-2023. These events, Primary Care and Public Health Show and Naidex Disability Show, offered us an excellent opportunity to raise awareness about Complex Regional Pain Syndrome (CRPS) and our charity's mission to support and empower patients, their families, and healthcare professionals.

Our goal is to shed light on the debilitating impact of CRPS and encourage people to learn more about this condition. We believe that educating the public and healthcare professionals is essential to improve the diagnosis and treatment of CRPS. With this in mind, we used these exhibitions as a platform to share the latest research, information, and resources related to CRPS.

Our presence at these exhibitions such as Naidex also allowed us to connect with patients and their families, providing a space for them to share their experiences and seek support. We were able to inform them about our key services, including our helpline, support groups, and online resources, which are designed to help them manage the challenges of living with CRPS.

Additionally, we provided information to healthcare and legal professionals, enabling them to better understand the needs of their patients with CRPS and how to best support them.

Overall, our participation in these exhibitions was highly successful, and we look forward to continuing to raise awareness and support those affected by CRPS in any way we can.

(14) Campaigning to benefit those affected by CRPS especially patients.

Our commitment to helping those affected by Complex Regional Pain Syndrome (CRPS) knows no bounds. We are proud to maintain our active involvement with the charity's local Member of Parliament, who has tirelessly raised questions about this debilitating condition in Parliament. By keeping the issue at the forefront of political discourse, we are confident that we will be able to bring about meaningful change for those who are affected by CRPS.

Furthermore, we strongly encourage patients and their families to get involved with their own local MP. This type of grassroots activism is a powerful way to raise awareness and advocate for the needs of CRPS patients. By coming together and making our voices heard, we can help ensure that the necessary resources and support are available to those who need them most.

Our efforts are ongoing, and we remain fully committed to securing the best possible outcomes for CRPS patients. If we are successful in obtaining everything that we are asking for from Parliament, it will be a huge benefit to those struggling with this condition. We believe that by working together, we can make a real difference in the lives of those affected by CRPS.

Burning Nights CRPS Support

Trustees' Report

OUR SUPPORTERS

Principal Sources of Funding

In order to fund our important work, we utilise various streams of funding, including fundraising activities, grants, and donations. Additionally, we offer a variety of branded goods for sale through our online shop, with proceeds going directly back to us.

Since November 2022, we also now have a new income stream of the membership. This we hope to grow over the next few years.

Our fundraising includes events such as sponsored walks, runs, or bike rides, as well as hosting a charity raffle. We also apply for grants from various trusts and foundations that support health and wellbeing causes.

Donations are another important source of funding for Burning Nights CRPS Support. We rely on the generosity of individuals and businesses who are passionate about our cause to help us continue their mission.

Fundraising and donations

Without the support of generous donors and people fundraising, we would be unable to continue providing vital services to those in need.

In order to ensure that our fundraising practices are transparent and ethical, we are looking to register with the Fundraising Regulator in the upcoming financial year. However, we are always open about how we raise our funds and are committed to training and supporting our staff to identify and protect individuals in vulnerable circumstances in accordance with our Safeguarding Policy and Fundraising Policy. We also make it easy for supporters to opt-out of receiving further communication from us.

We receive donations in a variety of ways, including regular appeals and gifts left in Wills. Our community also hosts fundraisers for us, such as running, cycling, and walking events like The Three Peaks Challenge or Great Manchester Run. We had a supporter who took on two marathons, one of which being the New York Marathon to raise funds for us. Another supporter took on the challenge of walking up and down the Wrekin in Telford 10 times with a 30kg vest on in honour of his daughter who has CRPS. We are grateful for all the support we receive, including donations from Facebook and Instagram fundraisers, where people have set up fundraisers for their birthdays, anniversaries, and holidays in support of our cause.

We also still receive donations by text message, both as one-off contributions and regular donations. However this opportunity did finally stop in February 2023. Every donation, big or small, helps us to continue our mission of supporting those affected by CRPS and improving care for all. Thank you for your continued support.

Burning Nights CRPS Support

Trustees' Report

Trusts and Foundations

We would like to express our heartfelt gratitude to the following Trusts and Foundations:

- Arnold Clark Community Fund
- Persimmon Homes
- Magic Little Grants
- The Albert Hunt Trust
- St. James Place

for their unwavering support during these difficult times. Their contributions have enabled us to continue with our services and fulfil our commitments towards our community.

Organisational Health

During 2022-2023 we began to see a reduction in donations mainly due to the aftermath of the Pandemic and the start of the high Cost of Living crisis which continued into the next financial year.

However we have continued to actively pursue grants from trusts and foundations and fortify our relations with corporate firms.

As we move forward, we are committed to diversifying our funding sources even further in the upcoming financial year. Our new website, which launched in November 2022, will continue to play a pivotal role in this regard by providing us with greater visibility and outreach to potential donors and supporters. We remain steadfast in our mission to serve our community and look forward to the opportunities and challenges that lie ahead.

Corporate Donors

Our charity has been fortunate enough to receive continuous support from companies through their generous donations. From Dress Down Days to company walking days, Christmas quizzes, and even being selected as the Charity of the Year, we have been amazed with ongoing financial contributions.

Much of our Corporate donations have emanated from our CRPS Legal Panel. All our specialist legal firms make an annual donation to join and be on the Panel. However we also received an annual donation from a law firm from client compensation that had been unclaimed.

Furthermore, we had the privilege of attending several corporate donor meetings, which proved to be highly productive and successful. During these meetings, we were able to secure funding and grants for various projects and for the charity itself.

As the end of the financial year approached, we began holding discussions with other companies, exploring potential partnerships and collaborations. We are excited about the possibilities that these talks may bring and look forward to continued growth and support for our charity in the future.

Burning Nights CRPS Support

Trustees' Report

Public benefit

The trustees confirm that they have complied with the requirements of section 4 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Use of volunteers

During 2022-2023, the dedication and compassion of our volunteers have been instrumental in providing support and comfort to CRPS patients and their loved ones. Through various channels such as email, phone and social media, our volunteers have spent a total of 7,954 hours listening attentively, engaging in conversations, answering questions and offering counselling to those in need.

The impact of our volunteers cannot be overstated.

As a small charity, their contribution has been nothing short of invaluable. Their tireless efforts have enabled the charity to flourish and accomplish remarkable feats. It is through their selflessness, dedication and expertise that we have been able to offer meaningful assistance to those who need it most.

We express our heartfelt gratitude to our remarkable volunteers. Their unwavering commitment to our cause is truly inspiring and their generosity of time and skill is deeply appreciated. Without their support, we would not be where we are today. Thank you for all that you do volunteers!

Burning Nights CRPS Support

Trustees' Report

Achievements and performance

Our mission is to ensure that individuals living with Complex Regional Pain Syndrome (CRPS) and their families and close relatives have the best possible quality of life. We strive to provide support and resources not only for those with CRPS but also for their caregivers, families, and friends.

Our goal is to continually expand our range of services and literature to help people understand their rights, manage their condition, and pursue their passions. We understand that CRPS can be challenging for caregivers, families, and friends, and we aim to provide them with the highest quality of information to help them understand CRPS and their rights as caregivers.

We are dedicated to continuously improving the support we offer, with the ultimate intention of enhancing the overall health and wellbeing of everyone involved.

Our ultimate vision for the future is a world free of Complex Regional Pain Syndrome and pain free lives.

Our mission is: **Awareness. Education. Support.**

Our mission is to bring together the CRPS community to ensure people whose lives have been touched by this condition are not alone.

We aim to raise awareness of Complex Regional Pain Syndrome (CRPS) and provide education so that more people across healthcare and in the public understand the condition and its debilitating effects. From education, training and campaigning to advice and support, as the UK's leading CRPS charity we are on a mission to change the way that CRPS is looked at, managed and treated.

Finally our values are:

We're Stronger Together

We are a community. We work together to help people support themselves and we learn from everyone we work with.

We're Empowering

We empower one another not only so we can do our own roles, but we empower our patients/clients and supporters so they can continue on the fight for change.

We're Respectful

Everyone has their own story and journey they are going through. We are respectful to our supporters, patients/clients, stakeholders and each other.

We're Compassionate

We're there for everyone living with CRPS and their family and loved ones. When people turn to us for information and support, we listen and we care. You're not alone.

We're Empathetic

As we are mainly a patient and caregiver led organisation, our volunteers understand what you are going through.

Here is a roundup of our main areas of focus for 2022-2023

Burning Nights CRPS Support

Trustees' Report

SUPPORT FOR ALL THOSE WHO HAVE BEEN AFFECTED BY CRPS (SUFFERERS, PATIENTS, THEIR FAMILIES, FRIENDS AND CARERS)

We continue to be there to support, help and inform anyone who has been affected by Complex Regional Pain Syndrome (CRPS), whether they are patients, loved ones, families or caregivers.

We provide direct support through the following services:

- Online Support Groups
- Telephone Helpline
- Live Web Chat
- Social Media Support
- Email support
- Online Community Forum
- Befriending Service
- Counselling & Psychotherapy Service
- Wellbeing Sessions

Here is more detail about what we have achieved in each of our services and activities:

Online CRPS Support Groups

We have continued to provide our online peer support group meetings, run by lived experience volunteers which have continued to be highly successful.

Holding our support groups online has provided a more accessible service for most people within our community, and we have received positive feedback from our members about the convenience and effectiveness of this format.

However, we are still considering whether our community wants us to return our face-to-face support groups, and we will be consulting with our members and the CRPS community to gauge their interest in this option.

Our main adult online support group has been consistently meeting on a monthly basis, and we have been pleased to see a regular number of approximately 15-20 attendees every month. However, we did hold just one young person group that was run by one of our trustees who used to be a Youth Worker. However, in 2023-2024 we are looking at all options to support young people with CRPS and young carers.

Topics covered included pain management, fatigue, internal organs and CRPS, menopause, alternative and complementary management options, friends and family issues, dental problems, surgery and CRPS and dealing with loss through the lens of compassion.

Throughout the year, we have held a total of 12 online support groups which were run by our amazing volunteers, who all have CRPS themselves. These groups have been a fantastic outlet for people who want to network, find support, and ask for information. We have provided support to 117 individuals through these groups, and we are proud to have been able to offer this important service to those who need it. This was a lower number of attendees than in previous years however, those who attended found this service invaluable.

Burning Nights CRPS Support

Trustees' Report

Telephone Helpline

Both the Telephone Helpline and Email Support services offered by our charity are a cornerstone of our mission to provide exceptional support to those who are affected by Complex Regional Pain Syndrome (CRPS). These services provide vital assistance to not only CRPS patients, but also their families and friends, health professionals, and social prescribers.

Our Telephone Helpline receives numerous calls from individuals seeking help, information, and signposting for various issues. Some of these issues include difficulties accessing NHS services, particularly mental health services and benefits, accessing treatments and management options, and navigating the education system for children and young people with disabilities. Our trained volunteers are well-equipped to handle these situations and provide the necessary support and guidance. We are also extremely grateful to all our volunteers and staff who respond to the calls on our helpline. However, we are receiving a higher number of harrowing calls that consist of suicidal and self-harm related calls.

The Telephone Helpline is open for support five days a week and is manned by our dedicated volunteers who are themselves CRPS patients. They are passionate about helping others and have firsthand experience with the challenges and obstacles faced by those affected by CRPS. During 2022-2023, we responded to 353 calls to our Helpline, which accounted for over 50 hours of call time.

We are committed to continually improving and expanding our Telephone Helpline services. To that end, we are exploring options to recruit more volunteers and develop a comprehensive training program. Our goal is to ensure that anyone who reaches out to us for support receives the highest level of care and guidance possible.

Email Support

Burning Nights CRPS Support is dedicated to providing support to individuals affected by CRPS, including patients, their families, partners, and carers. We understand that those who live with CRPS may have questions or requests for support, help, or information, and we are committed to providing assistance via email.

Throughout the year 2022-2023, we were able to support a total of 935 individuals through our email support system. We received a wide variety of emails, ranging from requests to access our services to enquiries about CRPS specialist information and lawyers. We were also able to provide signposting to other services and organisations that may be helpful to those who are affected by CRPS.

Our email support system is an essential part of our efforts to reduce the loneliness and isolation that can often accompany living with CRPS or their families and friends. By providing education, support, advice, and knowledge through email, we aim to empower patients, their relatives, families, and carers with the tools they need to manage their condition and improve their quality of life.

We believe that everyone affected by CRPS deserves access to the support and resources they need to live their best life, and we are committed to providing that support through our email system and other channels of communication.

Burning Nights CRPS Support

Trustees' Report

Live Web Chat

We launched a Live Web Chat support service in July 2020 as a digital alternative for our customers who were unable to use our other communication channels. Our aim was to provide a seamless and efficient solution that would enable our customers to get the support they needed quickly and conveniently, regardless of their location or situation.

Since its launch, our Live Web Chat support has been available six days a week (Monday to Friday 11am-6pm and Saturdays 12 noon-4pm), providing our clients with a reliable and accessible means of communication. Our team of trained and lived experience volunteers has been working tirelessly to provide prompt and effective assistance to every customer who reaches out to us.

In 2022-2023, we were able to respond to and support 258 individuals through our Live Chat support service, which totalled to almost 78 hours of chat support time. This demonstrates the level of attention and dedication we give to each and every client who contacts us. We are proud of the success of our Live Web Chat support service and remain committed to providing our community with the best possible experience every time they interact with us. Although the number of chats had decreased the chat support time had increased by 316% which was a very large increase.

Social Media Support

We are proud to not only maintain a strong presence on six major social media platforms, including Facebook, Twitter, Instagram, Pinterest, LinkedIn, and YouTube, but we also started on another platform - TikTok. Through these channels, we regularly share informative articles, events, videos and research opportunities related to CRPS, connecting with patients, their loved ones, family members, friends, and carers.

We understand that dealing with CRPS can be challenging, and we believe that individual support is crucial. That's why we make sure to respond to private messages and comments on our posts, providing personalised support to those who need it with our trained lived experience volunteers. In fact, in the past year, we responded to almost 1,281 individual private messages, ensuring that no-one in our community feels alone. This was an increase of approximately 116% to the previous year.

Our consistent growth across all our social media platforms is a testament to the impact that our organisation is having. By the end of March 2023, we saw an 4.6% increase in our social media community compared to the previous year, with 59,249 followers and subscribers across all seven channels. This means that more and more people are finding our content helpful and informative year on year, and we are committed to continuing to provide valuable resources for those with CRPS and their families.

Additionally, we are proud to offer a closed online support group on Facebook specifically for parents and guardians of children and teens with CRPS. This group has grown to over 805 members from 681 in the previous year. It is a safe and supportive space for those who are navigating the unique challenges of caring for a young person with CRPS.

Burning Nights CRPS Support

Trustees' Report

Online Community Forum

One of the ways we offer support to the CRPS community is through our Online Community Forum, which can be accessed through our website. This Community Forum serves as a digital alternative to social media and provides a safe space for individuals to connect with others who understand the challenges of living with CRPS.

The Online Community Forum is moderated by a team of dedicated volunteers who have lived experience of CRPS either as a patient or as a carer or family member. The team ensures that all posts are appropriate and relevant to the forum's guidelines. These volunteers are also available to offer their own personal experiences and knowledge to the community. With over 2,100 participants, the forum provides a wealth of information and support to those in need.

However in November 2022, our newly developed website was finally launched. This meant that all the original forum members were removed, the forum cleared of posts and everyone had to re-register. Getting new members signing up for the forum is a challenge and is something we are working on.

The forum is available 24/7, allowing individuals to connect with others from around the world at any time. It serves as a platform for members to ask questions, share advice, and exchange information. Additionally, the forum helps combat loneliness and isolation by providing a social outlet where members can interact with others who truly understand what they are going through.

We are proud to offer this invaluable resource to the CRPS community and are committed to ensuring that it continues to be a safe and supportive space for all members.

Befriending Service

We have been thrilled to see such a positive response to our Befriending Service and continued to expand it. During 2022-2023 we had 4 dedicated volunteer Befrienders who provide weekly calls or online video calls for 40 minutes to those who have requested to be befriended. This service has quickly become one of our most popular support services, and it's easy to see why. Each client receives a total of 12 calls or video chats, which are conducted by trained volunteers who are themselves CRPS patients or are carers or relatives. Having that lived experience is essential to being a Befriender.

As the demand for our Befriending Service continues to grow, we are committed to expanding our volunteer base even further. In the upcoming financial year, we will be launching a volunteer recruitment drive to bring on an additional 4 volunteers. This will allow us to provide even more support to those affected by CRPS.

We have found that our Befriending Service has had huge benefits especially for CRPS patients and their families. These benefits have included a reduction in symptoms, social isolation and improved patient reported outcomes, including well-being and quality of life. We ask befriendees to complete a pre-survey and post-survey where we have seen these improved patient reported outcomes.

We are proud of the progress we have made so far, having provided 126 sessions, started 8 new clients and 12 clients were discharged. Our goal is to continue to expand this invaluable service and offer support and friendship to as many people as possible.

Burning Nights CRPS Support

Trustees' Report

CRPS Counselling & Psychotherapy Service

We started our specialist CRPS Counselling & Psychotherapy Service back in March 2021 initially as a trial. However, we were inundated with requests for support, as members of our community were unable to access NHS and community mental health services. As a result, we not only continued this service but also expanded it to have six counsellors and psychotherapists, as we had no fall off in demand for this service. In fact the demand for the service has increased so much that are waiting list continually grows.

Our service now offers up to 20 hours of counselling or psychotherapy for anyone aged over 5, along with four assessments to keep assessing their anxiety and depression. This is significantly more than what the NHS is currently able to offer. We feel having 20 sessions should really give the client time to understand and trust their therapist. We are continually developing this service and working with the therapists to provide the best possible service for the CRPS community.

Although most of our clients are adults, we have received a number of registration forms for young people aged 18 and under. Therefore, we advertised for a specific volunteer for a young person counsellor.

In the year 2022-2023, we provided over 460 sessions (each of one hour in length) and started 25 new clients. This is compared to just 200 sessions in the previous year. Our waiting list has varied from over 18 months to 2 years, but we have new people wanting to access this service every day. We're proud of our team of volunteers, consisting of four qualified counsellors, one trainee counsellor and one trainee psychotherapist. Without them giving up their time, knowledge and skills to support the charity, we wouldn't be able to offer this vital service.

From our clients' assessment scores for anxiety & depression, we see a significant improvement across from severe anxiety to mild anxiety levels. For depression scores, 60% started at severe depression & of those who have completed the full programme, 59% are now at mild depression level. 82% felt more confident afterwards compared with a confidence level of just 3.7 out of 10 beforehand, 100% saw a reduction in suicidal thoughts & 87.5% felt more able to cope.

We've found over the last 12 months the initial anxiety scores have increased, and we believe this is due to environmental factors including the cost-of-living crisis, high mortgage payments & the fallout from the Pandemic.

"Living with CRPS has often felt like navigating through a storm. Today, I'm not just surviving, I'm thriving, leading a healthier, happier life than I ever imagined possible. The journey hasn't been easy, but Burning Nights CRPS has been my lifeline, my lighthouse in the storm." - JMB, CRPS Patient, Counselling & Psychotherapy Service

Burning Nights CRPS Support

Trustees' Report

Wellbeing Sessions

Our Wellbeing Wednesday project initially began as a trial towards the end of 2022. However we decided that in 2023 we would run a Well-being Wednesday project. This meant holding activity sessions every Wednesday. We offered these low impact physical exercise activities online namely Chair Yoga and Dance as well as Qigong and meditation. We held the sessions online via Zoom every Wednesday to provide accessibility to anyone living with chronic pain including CRPS. Holding the classes online will help us reach more people who may be housebound or bed bound due to their condition. This was a fantastic opportunity for people with CRPS and chronic pain to try new activities and keep active or start being active.

We started initially with taster sessions and then 10 sessions followed the taster. Each class was around 45-60 minutes so as not to tire out everyone in the early classes. The classes should have held up to 35 people per session and were run by specialist instructors with at least 2 volunteers to assist with questions or concerns about their long term pain condition. These online sessions were to target various symptoms of CRPS and can help with strength and coordination.

We worked with the instructors to ensure the activity, exercises and moves in all of the exercise groups (chair yoga, Qigong and meditation) were designed for people with CRPS and chronic pain. The sessions, although aimed at those with chronic pain, are applicable for their families and friends as well as anyone with mobility problems. Regular activity is proven to help people manage their chronic pain, their symptoms and live well.

The project had 3 main aims:

- to improve and develop physical activity to people living with Complex Regional Pain Syndrome or chronic pain or their families and close relatives,
- improve mental well-being leading to a reduction in feelings of isolation and reducing additional stress meaning it's okay to talk about their condition
- offer a sense of community

Through offering these physical and mental health activities we wanted to bring the positivity from exercise to those attending so they can continue doing the activities we offer outside of the classes, making it a lasting effect on their mental and physical well-being.

"I love that it's not sweaty high impact and we are all limited in our ability and it's so inclusive and it's not embarrassing if you can't do a movement" - Anon, CRPS Patient

We also offered an alternative activity that wasn't physical but helped with mental well-being. These were Zentangle sessions. Zentangle is an American method of drawing patterns ie it is a form of self-help art therapy. This built on creativity, increasing self-confidence, relieving stress and anxiety, improving eye-hand coordination and importantly creating a social community. These Zentangle sessions enhanced the main Wellbeing Wednesday project and did indeed work hand in hand with the physical exercise. It also reduced loneliness and isolation as we created a real social community as everyone was able to talk, laugh and relax amongst people who understood.

We provided 131 sessions and 17 hours of well-being classes which really did achieve their aims. Thank you to the instructors who were involved - Jackie from Strictly Chair Yoga, David who ran the Tai Chi & Meditation sessions and Dawn who ran the Zentangle sessions.

Burning Nights CRPS Support

Trustees' Report

CAMPAIGNING, ADVOCACY AND AWARENESS

Our Founder and Chair is not only the driving force behind our organisation, but also is the Chair of The Patient Voice Committee (TPVC) with the British Pain Society. In particular, The Patient Voice Committee (TPVC), advocates for the needs and rights of pain patients and their families. Through this role, they work tirelessly to raise awareness of the pressing issues affecting those living with chronic pain, including long waiting times for access to pain clinics, inadequate treatment options, and limited access to mental health services.

This commitment to improving the lives of pain patients extends beyond the walls of our organisation and into the wider community. Our Founder and Chair is a passionate advocate for the rights of patients, and they use their platform to shine a light on the struggles that so many individuals and families face. By lending her expertise, time, and energy to the TPVC and other related initiatives, she is making a real difference in the lives of those living with chronic pain.

At the heart of our organisation is a deep sense of compassion and empathy for those who are living with CRPS and their families. Our volunteers and trustees embody these values in everything that they do, and we are proud to have them to be leaders and advocates for our cause. Through their ongoing efforts, we are confident that we will continue to make progress in the fight against chronic pain and CRPS and towards a brighter, more hopeful future for all.

We also have other ways in which we can campaign, advocate and raise awareness of CRPS and issues that patients face. These include:

- CRPS Awareness Sessions
- Exhibiting at Exhibitions
- Working with our MP

CRPS Awareness Sessions

We have conducted several informational sessions that have provided over nine hours of valuable insights to healthcare and legal students and professionals. Additionally, we have organised various talks, mainly virtual.

One of our regular speaking engagements is at Derby University, where we address the first-year Occupational Therapy students and discuss the impact of CRPS on an individual's life. By sharing personal experiences, we aim to provide a deeper understanding of the condition and its effects.

We strongly believe that education and awareness are crucial steps towards improving outcomes, quicker diagnosis, and better treatments for CRPS. Our goal is to collaborate with the NHS, patient groups, and other organisations to address the topic of CRPS and its impact on people.

In the future, we are looking to develop online CRPS awareness sessions to make them more accessible to people. By doing so, we hope to encourage more people to learn about CRPS and its implications.

Burning Nights CRPS Support

Trustees' Report

Exhibiting at Exhibitions

Over the past year, we have participated in 2 exhibitions as exhibitors. We participated in an exhibition aimed at those involved in Primary Care and Public Health as well as another exhibition aimed at the disabled community - Naidex. These have continually proved to be excellent opportunities for us to raise awareness about our charity and the condition itself.

As an organisation dedicated to raising awareness about Complex Regional Pain Syndrome (CRPS), we attended exhibitions to provide valuable information about the condition and its impact. We believe that by educating the public and healthcare professionals about CRPS, we can help patients receive a timely diagnosis and effective treatment.

Moving forward, we plan to continue our participation in select health and disability exhibitions. By showcasing our work and the challenges faced by those with CRPS, we hope to make a positive impact and increase awareness about this complex condition.

Parliament and Campaigning

Our commitment to raising awareness about CRPS, especially in relation to the mental health support available, and supporting patients and families affected by this devastating condition, remains steadfast.

We have continued to work with our local MP to ensure that important questions are being asked in the House of Commons. We have also worked with an MSP Clare Adamson.

Our goal was to keep pushing for answers, not only for those who are currently battling CRPS, but also for their families and loved ones who often feel helpless and overwhelmed. We believe that by continuing to work with politicians in all parts of the UK, we can help make a real difference in the lives of those affected by CRPS.

INFORMATION AND EDUCATION

One of our biggest aims and objectives is dedicated to providing extensive guidance and knowledge to people living with Complex Regional Pain Syndrome (CRPS), their families, and loved ones. Additionally, we strive to educate the general public, health professionals, and students about the condition. We offer various platforms to disseminate information, including our annual national conference, educational webinars, our website, literature, and products.

Burning Nights CRPS Support

Trustees' Report

Annual Conference 2022

Our annual national conference is designed to offer a comprehensive understanding of CRPS, treatment options and self-managing the condition. We gather leading experts in the field to discuss the latest research and advancements in the management of CRPS. Patients, their families, and loved ones have the opportunity to interact with medical professionals and other individuals with similar experiences. This event provides a supportive environment for individuals to learn, share, and connect with others affected by CRPS.

On the 26 November 2022, we had the pleasure of hosting a conference at the Novotel, Edinburgh Park. Thanks to a gift from a supporter's Will, we were able to put on this event, and we are incredibly grateful for this gift. There was a caveat in that we had to use the gift to support people in Scotland, hence the reason why we held the conference in Edinburgh. The purpose of the conference was to provide information and support for people with Complex Regional Pain Syndrome (CRPS) and their families. We had 57 people attending the conference which did include Clare Adamson MSP.

We were fortunate to have four (4) expert speakers from various health professions, all of whom had a keen interest and extensive knowledge of CRPS, chronic pain, or disability. They provided invaluable insights and information on a range of topics, including the latest research and management options for CRPS, such as neuromodulation. We also heard about medicinal cannabis, which was a fascinating and informative topic. We also heard from 2 patients living with CRPS plus a parent of someone with CRPS. Overall the conference was a great success, and everyone who attended found it helpful and informative.

Educational Webinars

As a result of the tremendous success of our webinars over the last couple of years, we decided to continue offering online talks this year. Despite the challenges we faced, we persevered and held a total of three webinars in 2022-2023, each of which covered a different topic. Those included Disability and Accessibility Products that was arranged in conjunction with Express Solicitors. This focused on providing practical tips and equipment for improving daily life for those with CRPS and disabilities. The second webinar, "Demystifying Medical Cannabis for Chronic Pain," delved into the latest advancements in medical cannabis, what it was, how it is used and how to access this pain management treatment. The third and final webinar, "Cognitive Behavioural Therapy (CBT)" was presented by one of the charity's Psychotherapist volunteers. He discussed the use of this psychological approach for CRPS, what is involved and how it works to help manage the mental health aspects of complex regional pain syndrome.

We cannot express enough our gratitude towards Express Solicitors and Sue Tomkinson, the Lyphe Group and Daniel Leech for their unwavering commitment to making our webinars a resounding success. Their vast knowledge and insightful contributions have been invaluable in helping us create informative and engaging online talks that have been highly appreciated by our audience. We are proud to have supported 85 individuals through our webinars, and we are committed to continuing to offer high-quality educational resources in the future.

Our webinars are a unique opportunity for anyone who wants to expand their knowledge or improve their health to learn from leading experts in their respective fields. Our team of exceptional speakers is dedicated to providing participants with the latest research and strategies that can help them achieve their goals. Whether it's learning about the latest breakthroughs in medical research, exploring new ways to improve your physical or mental health, or simply discovering new ideas, our webinars are an excellent platform to enhance your learning experience.

We believe that everyone deserves access to high-quality educational resources, and our webinars are designed to be inclusive and accessible to all. We welcome individuals from all walks of life and backgrounds to join us in our mission to promote lifelong learning and personal growth. So, if you are looking for an opportunity to learn from the best and expand your knowledge, join us for our upcoming webinars and be part of a community of lifelong learners!

Burning Nights CRPS Support

Trustees' Report

Website

One of the biggest achievements of 2022-2023 was the launch of our newly developed website. Following the slow decline of our old website we managed to secure funding from various Trusts, foundations and general fundraising to have a new website developed. The launch took place on 22nd November 2022.

Our main aims that we achieved were to:

- Make content clearer and more accessible
- To have a section for healthcare professionals and students
- To continue to provide up to date and evidence-based information for everyone within the CRPS community whether they are patients, families, parents, loved ones, friends or carers,
- To provide a knowledgeable place where health professionals and students can understand the condition and use that information to improve their services for patients
- To have more CRPS patients and families become aware of our charity and our services so they can realise they are not going through this difficult and challenging journey alone
- Better loading speed
- Reduce our bounce rate from 75% to 40% or below

Our website is comprehensive resource for individuals seeking information about Complex Regional Pain Syndrome (CRPS). Our goal is to provide detailed and reliable information about this condition, which can be challenging to understand and manage. Our website is designed to be a one-stop-shop for all the information you need about CRPS, including its symptoms, diagnosis, and treatment options.

We saw just under 86,000 unique visitors to our website and 90,000 visitors - both unique and returning. We also saw 111,000 sessions on the website. We hope that next year we will see an increase.

We understand that CRPS can be a debilitating condition, and it can be challenging to find accurate information about it. That's why our website is dedicated to providing detailed and comprehensive information about CRPS. We cover everything from the causes and risk factors to the various treatment options available. Our team continually compiles the latest research and medical guidelines to ensure that people have access to the most up-to-date information.

Additionally, we offer a unique perspective on CRPS through personal stories from individuals who have experienced the condition first-hand. We believe that these stories offer valuable insights into the challenges faced by those affected by CRPS. By sharing their experiences, we hope to provide a supportive and informative community for those impacted by this condition.

We invite you to explore our newly launched website and discover the wealth of information available to you. Whether you're a patient, caregiver, or medical professional, our website is a valuable resource for anyone seeking to learn more about CRPS.

Burning Nights CRPS Support

Trustees' Report

Literature and Awareness Products

We understand the struggles that people affected by CRPS face on a daily basis. That's why we are dedicated to providing them with a range of tangible resources that can help them manage their condition and improve their quality of life. Our literature and products are designed to offer practical advice, guidance, and support to individuals with CRPS, as well as their families and healthcare providers.

We offer a wide range of literature resources, including books, booklets/leaflets, and other materials that are tailored to the unique needs of individuals with CRPS or their families. Our literature is carefully crafted to provide practical tips and strategies for managing pain, improving mobility, and enhancing overall well-being. Whether you're looking for information on the latest treatment options, or tips for managing symptoms at home, we have the resources you need to take control of your condition.

We continued to distribute our CRPS information leaflets for both adult and young people to various NHS hospitals and private clinics across the UK.

In addition to our literature resources, we also offer a range of products that are specifically designed to help manage the pain and discomfort associated with CRPS. Our self-care packs offer great ways to manage symptoms, and are designed to provide mental health support when it's needed most. With our products, individuals can take a proactive approach to managing their condition, and improve their overall quality of life.

In summary, we are deeply committed to providing individuals with CRPS, their families, healthcare professionals, and the general public with the information and resources they need to effectively manage this challenging condition. Whether you're looking for practical advice, guidance, or support, we have the resources you need to take control of your condition and improve your overall well-being.

Burning Nights CRPS Support

Trustees' Report

RESEARCH AND STUDIES

Research

Burning Nights CRPS Support and our Founder & Chair have continued to work closely with Professor Holly Blake at Nottingham University and the Pain at Work (PAW) Toolkit. The PAW Toolkit is an innovative resource that has been designed to address the unique challenges that people with chronic pain face in the workplace.

The toolkit offers a wealth of information, including tips on how to communicate with colleagues and employers about your condition, advice on managing pain while at work, and guidance on how to access workplace accommodations and support. By using this toolkit, individuals with chronic pain can gain a better understanding of their rights and responsibilities in the workplace, and can take steps to manage their condition more effectively.

Professor Blake has taken this one step further and is running a research trial with the PAW Toolkit and applied for funding to run the study for 2 years. The study behind the PAW Toolkit is a collaborative effort between Burning Nights CRPS Support, our Founder & Chair; Victoria Abbott-Fleming MBE, and Professor Holly Blake. The PAW Toolkit represents an important step forward in the field of pain management, and we are proud to have been a part of its creation. It is our hope that this toolkit will help to improve the lives of individuals with chronic pain, and make the workplace a more accommodating and inclusive environment for all.

The funding was granted and the trial began in September 2022. Regular meetings are held as we are also on the Management Committee as the Public and Patient Engagement.

Our commitment to finding a cure for CRPS and chronic pain has led us to actively participate in 13 research studies, conducted by esteemed universities in the UK, Ireland, and Switzerland. Our involvement has been instrumental in advancing the understanding of the causes, treatment, and cure of these debilitating conditions.

As a part of our support, we have assisted researchers in locating potential participants by promoting their studies on our various platforms. Our extensive social media presence, e-newsletters, and website have been key in spreading the word about these studies. Additionally, we have occasionally featured these studies on our blog section to reach a wider audience. The new website also contains a research tracker where we can open, pause and close various research studies as and when required.

We are proud to share that our efforts have not stopped there. We have continued to disseminate the results of the studies and clinical trials we have assisted in through our various channels. Our online community forum has also played a vital role in connecting participants and researchers, providing a platform for exchanging information and experiences.

Through our collaborative efforts, we aspire to bring hope and relief to those affected by CRPS and chronic pain.

Burning Nights CRPS Support

Trustees' Report

OUR VOLUNTEERS

We are immensely grateful for the 44 wonderful volunteers who dedicated their time and energy to help us deliver 11 crucial services and projects to our community. It is thanks to their selflessness and unwavering commitment that we were able to provide a staggering 7,954 hours of support to our charity, helping us achieve our mission of making a positive impact in the lives of those who need it most. If we were to pay for the hours that our volunteers gave, we would have saved the charity over £75,500.

At Burning Nights CRPS Support, we truly believe that our volunteers are the beating heart of our charity. We are dedicated to ensuring that they have a positive and enjoyable experience while contributing to our cause. We provide them with ongoing support and resources, including regular support sessions and bi-monthly meetings where they can share best practices and support one another. For our volunteer Befrienders and Counsellors/Therapists, we go the extra mile, offering monthly supervision and/or peer support to ensure that they have access to the resources and training they need to provide the best possible service to our community.

Our volunteers are the backbone of our charity and we cannot thank them enough for their tireless efforts and unwavering dedication. Thank you to each and every one of them for making our charity what it is today.

Induction and Training

At our charity, we take the induction and training of our volunteers very seriously. We believe that providing a comprehensive induction is essential to ensure that our volunteers are fully equipped to support our community. As such, all new volunteers are given a thorough induction, which includes not just information about our Charity, its aims, mission and values but also vital Safeguarding training for those in need of it ie who are client facing. We want to ensure that our volunteers are aware of how to recognise, respond and report any safeguarding concerns that may arise in their role.

In addition to the Safeguarding training, all volunteers are also required to complete CRPS awareness training. This training consists of a video, followed by a set of questions to answer. We believe that this training is essential to ensure that all of our volunteers are aware of the condition that we support, so they can empathise and understand any potential challenges that they may face in their role.

For our volunteer Befrienders and Counsellors & Psychotherapists, we also provide four mandatory e-learning courses that are specifically tailored to their roles. These courses cover suicide awareness, suicide prevention, mental health awareness, and self-harm awareness. We now also include other roles to receive this mandatory training. We believe that providing this training is crucial to ensure that our volunteers have the skills and knowledge they need to support our community in the best possible way.

We are committed to providing regular training courses for all of our volunteers, and we ensure that all basic courses, such as Safeguarding, are renewed on an annual basis plus mental health and suicide awareness are every 2 years. We believe that investing in our volunteers' training is essential to ensure that our community receives the best possible support from our volunteers.

Financial review

The Charity has received incoming resources during the year of £64,836 (2022: £84,469) and its outgoing resources for the year were £80,052 (2022: £59,669) resulting in net outgoing resources of £15,216 (2022: £24,800).

The balance sheet shows net assets of £89,982 (2022: £105,198) including restricted funds of £Nil (2022: £5,000).

Burning Nights CRPS Support

Trustees' Report

Policy on reserves

The aim of the reserves policy is to ensure that the charity's ongoing and future activities are reasonable protected from unexpected fluctuations in its income and expenditure. The board reviewed its reserves policy and agreed that a minimum level of unrestricted general funds, also known as free reserves, of £45,000. This is approximately six months of running costs.

The total reserves at 31 March 2023 was £89,982 (2022: £105,198) of which £Nil (2022: £5,000) are held in restricted funds. The balance held in unrestricted funds was £89,982 (2022: £100,198) of which £76,977 (2022: £90,236) are free reserves, after allowing for funds tied up in tangible fixed assets.

The trustees consider the excess reserves held are prudent in current economic climate.

Principal funding sources

Burning Nights CRPS Support is a charity that relies on various sources of income to fund its services and projects. These sources include fundraising events, grants from trusts and foundations, and generous donations from individuals and corporate entities. The charity also generates income by selling branded merchandise through its online shop.

However, the challenges posed by the aftermath of the Covid-19 pandemic and the increasing cost of living crisis have had a negative impact on the charity's donations and fundraising efforts. As a result, Burning Nights CRPS Support has had to explore alternative income streams, such as more trusts and foundations and legacy giving.

One of the charity's recent initiatives has been the introduction of a Membership Scheme. This scheme allows supporters to become paid members, receiving exclusive benefits such as access to the charity's magazine, The Warriors Lifeline, and other benefits. The paid members don't have any voting rights.

Despite these challenges, Burning Nights CRPS Support has continued to receive corporate donations from law firms who join their small legal panel. Additionally, the organisation receives general corporate donations and grants such as from medical device companies.

Overall, Burning Nights CRPS Support is dedicated to continuing its work in supporting those affected by Complex Regional Pain Syndrome, and is grateful for the support it receives from its various income streams.

Structure, governance and management

Nature of governing document

Burning Nights CRPS Support was established as a charity and is governed by a constitution adopted on 20 October 2015. It was registered as a Charitable Incorporated Organisation on 13 April 2016.

Burning Nights CRPS Support

Trustees' Report

Recruitment and appointment of trustees

The appointment process for trustees is carefully outlined in the Constitution to ensure transparency and accountability.

Trustees are appointed in accordance with these provisions and are subject to retirement or re-appointment every three years at the Annual General Meeting (AGM).

Three (3) of the current trustees must agree upon the appointment of any new trustees, ensuring that all new trustees are selected with the utmost care and consideration.

It is important to note that, with the exception of the first charity trustees, all trustees must be appointed for a term of three years. This helps to ensure that there is continuity and stability within the board, while also providing opportunities for new voices and perspectives to be brought to the table.

Overall, the appointment process for trustees is a critical component of the charity's governance structure. By adhering to the Constitution and following a careful selection process, the board can ensure that it is composed of individuals who are committed to the charity's mission and values, and who bring diverse backgrounds and experiences to the table.

At the end of March 2023, 60% of the Trustees had chronic pain and/or a disability.

Induction and training of trustees

To ensure that all our trustees are well-equipped to carry out their duties, we provide them with a comprehensive induction into the charity. We believe that this is an essential step in ensuring that they understand the values, mission, and objectives of the charity. The induction also provides briefings on the key responsibilities of Trustees and the Board, as well as an understanding of CRPS and the specific needs of the CRPS community we are seeking to address.

Additionally, we provide annual training sessions for Safeguarding of Vulnerable Adults and Children, as well as confidentiality and GDPR which is a crucial aspect of our work.

All trustees are given the link to the Charities Commission information on Trustees' rights and responsibilities.

We believe it is imperative to have policies and procedures in place that guide our trustees on their duties and responsibilities. These policies include financial, confidentiality, GDPR, social media, vulnerable adult and children safeguarding, and conflicts of interest plus more. The Board of Trustees ensures that these policies are reviewed periodically to ensure that they are up to date with the latest laws and regulations.

We are proud to have a team of dedicated trustees who give their time voluntarily to support our work. None of our trustees receive any form of remuneration or benefits, except for expenses, which are paid in line with our expenses policy. We believe that this is an essential part of maintaining the integrity of our charity and ensuring that all our resources are used for the benefit of those we serve.

We believe that by providing them with the necessary policies, training, and support, we can ensure that they are well-equipped to carry out their duties and responsibilities effectively.

Burning Nights CRPS Support

Trustees' Report

Organisational structure

Burning Nights CRPS Support is a charity that operates nationally across the UK.

It is run with a Board of Trustees which consists of a Chair who leads the Board, a Treasurer plus other board members as Trustees.

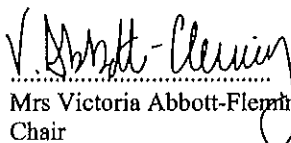
There is one paid member of staff who is the Charity Administrator and a volunteering team.

The day to day running is taken on by the volunteering team, staff member, the Chair and another Trustee. The other trustees also work tirelessly to ensure that the charity runs smoothly and effectively. These individuals do not hold any specific titles, but their contributions are invaluable.

Burning Nights CRPS Support understands that it cannot achieve its goals alone. That's why the charity maintains strong working relationships with other charities and umbrella organisations that share its common purpose. These relationships are not considered related parties under the Statement of Recommended Practice (SORP).

Through these relationships, Burning Nights CRPS Support is able to extend its reach and provide support to more individuals across the UK who are affected by Complex Regional Pain Syndrome (CRPS).

The annual report was approved by the trustees of the charity on 23 January 2024 and signed on its behalf by:


.....
Mrs Victoria Abbott-Fleming MBE
Chair

Burning Nights CRPS Support

Statement of Trustees' Responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Burning Nights CRPS Support

Independent Examiner's Report to the trustees of Burning Nights CRPS Support

I report on the accounts of the charity for the year ended 31 March 2023 which are set out on pages 34 to 44.

Respective responsibilities of trustees and examiner

The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

Independent examiner's statement

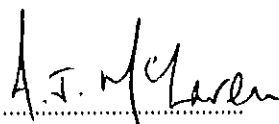
In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the Charities Act 2011; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Andrew J McLaren FCA
Beever and Struthers

Chartered Accountants
One Express
1 George Leigh Street
Manchester
M4 5DL

Date: 23/1/24

Burning Nights CRPS Support

Statement of Financial Activities for the Year Ended 31 March 2023

	Note	Unrestricted funds £	Restricted funds £	Total 2023 £	Total 2022 £
Income and Endowments from:					
Donations and legacies	2	52,590	6,500	59,090	80,821
Other trading activities		3,753	-	3,753	3,648
Other income	4	<u>1,993</u>	<u>-</u>	<u>1,993</u>	<u>-</u>
Total Income		<u>58,336</u>	<u>6,500</u>	<u>64,836</u>	<u>84,469</u>
Expenditure on:					
Raising funds		(9,903)	-	(9,903)	(16,178)
Charitable activities		<u>(58,649)</u>	<u>(11,500)</u>	<u>(70,149)</u>	<u>(43,491)</u>
Total Expenditure		<u>(68,552)</u>	<u>(11,500)</u>	<u>(80,052)</u>	<u>(59,669)</u>
Net movement in funds		(10,216)	(5,000)	(15,216)	24,800
Reconciliation of funds					
Total funds brought forward		<u>100,198</u>	<u>5,000</u>	<u>105,198</u>	<u>80,398</u>
Total funds carried forward	16	<u><u>89,982</u></u>	<u><u>-</u></u>	<u><u>89,982</u></u>	<u><u>105,198</u></u>

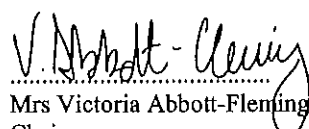
All of the charity's activities derive from continuing operations.

The funds breakdown for 2022 is shown in note 16.

Burning Nights CRPS Support
(Registration number: 1166522)
Balance Sheet as at 31 March 2023

	Note	2023 £	2022 £
Fixed assets			
Tangible assets	12	13,005	9,962
Current assets			
Stocks	13	3,529	4,688
Debtors	14	3,207	500
Cash at bank and in hand		73,030	92,873
		79,766	98,061
Creditors: Amounts falling due within one year	15	(2,789)	(2,825)
Net current assets		76,977	95,236
Net assets		89,982	105,198
Funds of the charity:			
Restricted funds		-	5,000
Unrestricted income funds			
Unrestricted funds		89,982	100,198
Total funds	16	89,982	105,198

The financial statements on pages 34 to 44 were approved by the trustees, and authorised for issue on 23 January 2024 and signed on their behalf by:


 Mrs Victoria Abbott-Fleming MBE
 Chair

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

1 Accounting policies

Statement of compliance

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

Basis of preparation

Burning Nights CRPS Support meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Exemption from preparing a cash flow statement

The charity opted to early adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees's meetings and reimbursed expenses.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Tangible fixed assets

Individual fixed assets costing £0.00 or more are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Stock

Stock is valued at the lower of cost and estimated selling price less costs to complete and sell, after due regard for obsolete and slow moving stocks. Cost is determined using the first-in, first-out (FIFO).

Trade debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that they will not be able to collect all amounts due according to the original terms of the receivables.

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees's discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Financial instruments

Classification

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

2 Income from donations and legacies

	Unrestricted funds	Restricted funds	Total 2023	Total 2022
	General £	£	£	£
Donations and legacies;				
Donations	51,173	6,500	57,673	64,371
Gift aid reclaimed	662	-	662	3,150
Grants, including capital grants;				
Grants received	-	-	-	13,300
Income from membership	755	-	755	-
	<u>52,590</u>	<u>6,500</u>	<u>59,090</u>	<u>80,821</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

3 Income from other trading activities

	Unrestricted funds	Total 2023	Total 2022
	General £	£	£
Trading income;			
Sales of goods and services	3,753	3,753	3,648
	<u>3,753</u>	<u>3,753</u>	<u>3,648</u>

4 Other income

Total
2023
£

5 Expenditure on raising funds

a) Costs of trading activities

	Unrestricted funds	Total 2023	Total 2022
	General £	£	£
Note			
Costs of goods sold	5,707	5,707	1,796
Events and conferences	444	444	301
Marketing and publicity	3,752	3,752	2,640
	<u>9,903</u>	<u>9,903</u>	<u>4,737</u>

6 Expenditure on charitable activities

	Unrestricted funds	Restricted funds	Total 2023
	General £	£	£
Note			
Charitable activities	11,313	11,500	22,813
Staff costs	24,071	-	24,071
Allocated support costs	20,925	-	20,925
Governance costs	2,340	-	2,340
	<u>58,649</u>	<u>11,500</u>	<u>70,149</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

7 Net incoming/outgoing resources

Net incoming/outgoing resources for the year include:

	2023 £	2022 £
Depreciation of fixed assets	<u>3,386</u>	<u>3,386</u>

8 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

During the year 3 trustees were paid expenses for travel and training costs totalling £3,952 (2022: £2,532).

9 Staff costs

The aggregate payroll costs were as follows:

	2023 £	2022 £
Staff costs during the year were:		
Wages and salaries	23,553	11,441
Pension costs	<u>518</u>	<u>-</u>
	<u>24,071</u>	<u>11,441</u>

No employee received emoluments of more than £60,000 during the year

10 Independent examiner's remuneration

	2023 £	2022 £
Examination of the financial statements	<u>1,440</u>	<u>1,440</u>
Other fees to examiners		
All other services	<u>900</u>	<u>1,320</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

11 Taxation

The charitable incorporated organisation is a registered charity and is thus exempted from taxation of its income and gains falling within section 524 of the Income Tax Act 2007 to the extent that they are applied to its charitable objectives. No tax charge has arisen in the year.

12 Tangible fixed assets

	Furniture and equipment £	Website £	Total £
Cost			
At 1 April 2022	13,544	-	13,544
Additions	<u>-</u>	<u>6,429</u>	<u>6,429</u>
At 31 March 2023	<u>13,544</u>	<u>6,429</u>	<u>19,973</u>
Depreciation			
At 1 April 2022	3,582	-	3,582
Charge for the year	<u>3,386</u>	<u>-</u>	<u>3,386</u>
At 31 March 2023	<u>6,968</u>	<u>-</u>	<u>6,968</u>
Net book value			
At 31 March 2023	<u>6,576</u>	<u>6,429</u>	<u>13,005</u>
At 31 March 2022	<u>9,962</u>	<u>-</u>	<u>9,962</u>

13 Stock

	2023 £	2022 £
Stocks	<u>3,529</u>	<u>4,688</u>

14 Debtors

	2023 £	2022 £
Prepayments	<u>3,207</u>	<u>500</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

15 Creditors: amounts falling due within one year

	2023 £	2022 £
Trade creditors	57	65
Other taxation and social security	291	-
Other creditors	100	-
Accruals	2,341	2,760
	<u>2,789</u>	<u>2,825</u>

16 Funds

	Balance at 1 April 2022 £	Incoming resources £	Resources expended £	Balance at 31 March 2023 £
General				
Unrestricted funds	100,198	58,336	(68,552)	89,982
Restricted funds				
Donation	5,000	-	(5,000)	-
Albert Hunt Trust	-	2,000	(2,000)	-
Local Giving (Magic Little Grants)	-	500	(500)	-
Arnold Clark	-	1,000	(1,000)	-
St James Place Foundation	-	2,000	(2,000)	-
Persimmon Homes Community	-	1,000	(1,000)	-
Total restricted funds	<u>5,000</u>	<u>6,500</u>	<u>(11,500)</u>	<u>-</u>
Total funds	<u>105,198</u>	<u>64,836</u>	<u>(80,052)</u>	<u>89,982</u>
	Balance at 1 April 2021 £	Incoming resources £	Resources expended £	Balance at 31 March 2022 £
General				
Unrestricted funds	71,959	79,169	(50,930)	100,198
Restricted funds				
Donation	6,439	-	(1,439)	5,000
Albert Hunt Trust	2,000	-	(2,000)	-
The National Lottery	-	5,300	(5,300)	-
Total restricted funds	<u>8,439</u>	<u>5,300</u>	<u>(8,739)</u>	<u>5,000</u>
Total funds	<u>80,398</u>	<u>84,469</u>	<u>(59,669)</u>	<u>105,198</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

The specific purposes for which the funds are to be applied are as follows:

During 2023 a restricted grant s were received from:

Alvert Hunt Trust - the purpose of the grant was

Local Giving (Magic Little Grants) - the purpose of the grant was

St James Place Foundation - the purpose of the grant was

Arnold Clark - the purpose of the grant was

Persimmon Homes Community - the purpose of the grant was printing self care packs for 3 different age ranges.

During 2021 a restricted grant of £2,000 was received from The Albert Hunt Trust and one from Abbott Medical, both were utilised in the year.

During 2022 a restricted grant of £5,300 was received form The National Lottery and £2,000 from The Hospisal Saturday Fund for the development of the new website, these were all utilised during the year.

During 2020 a restricted grant of £5,000 was received from a supporter for the purpose of supporting those affected by CRPS in Scotland.. This balance has been utilised during the year.

17 Analysis of net assets between funds

	Unrestricted funds General £	Total funds £
Tangible fixed assets	13,005	13,005
Current assets	79,766	79,766
Current liabilities	<u>(2,789)</u>	<u>(2,789)</u>
Total net assets	<u>89,982</u>	<u>89,982</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2023

18 Comparative Statement of Financial Activities

	Unrestricted funds £	Restricted funds £	Total 2022 £
Income and Endowments from:			
Donations and legacies	73,521	7,300	80,821
Other trading activities	3,648	-	3,648
Total Income	<u>77,169</u>	<u>7,300</u>	<u>84,469</u>
Expenditure on:			
Raising funds	(16,178)	-	(16,178)
Charitable activities	(32,752)	(10,739)	(43,491)
Total Expenditure	<u>(48,930)</u>	<u>(10,739)</u>	<u>(59,669)</u>
Net movement in funds	28,239	(3,439)	24,800
Reconciliation of funds			
Total funds brought forward	<u>71,959</u>	<u>8,439</u>	<u>80,398</u>
Total funds carried forward	<u><u>100,198</u></u>	<u><u>5,000</u></u>	<u><u>105,198</u></u>

Accounts

Charity registration number: 1166522

Burning Nights CRPS Support

Annual Report and Financial Statements

for the Year Ended 31 March 2022

Burning Nights CRPS Support

Contents

Reference and Administrative Details	1
Trustees' Report	2 to 17
Independent Examiner's Report	18
Statement of Financial Activities	19
Balance Sheet	20
Notes to the Financial Statements	21 to 27

Burning Nights CRPS Support

Reference and Administrative Details

Trustees	Mrs Victoria Abbott-Fleming Ms Lisa Davies Mr Thomas Craig Lowe Mr Altaf Patel
Principal Office	1 Alder Brook Chinley High Peak Derbyshire SK23 6DN
Charity Registration Number	1166522
Bankers	National Westminster Bank plc Western Avenue Waterside Court Chatham Maritime Chatham Ken ME4 4RT
Independent Examiner	Andrew J McLaren FCA Beever and Struthers Chartered Accountants One Express 1 George Leigh Street Manchester M4 5DL

Burning Nights CRPS Support

Trustees' Report

The trustees present the annual report together with the financial statements of the charity for the year ended 31 March 2022.

Objectives and activities

Objects and aims

The purposes and objectives of the charity, as set out in its governing document, are as follows:

1) to promote and protect the health of sufferers (patients) of Complex Regional Pain Syndrome (CRPS), their families and carers by the provision of information, advice and support including raising awareness of all aspects of CRPS amongst the public in general but in particular those involved in the diagnosis, treatment and care of those suffering from CRPS; and

2) to assist and support research into CRPS, its causes, treatment and cure and to ensure the useful results of such research are published.

In planning our activities for the year we kept in mind the Charities Commission's guidance on public benefit at our trustees meetings.

This annual report has been made in the aftermath of the Covid-19 Pandemic and is partly at the start of the financial crisis and cost of living crisis. Many activities and fundraising events remained virtual but some did start the transition back to in person events. But the charity continued to power forward and offer online support across our services.

Burning Nights CRPS Support

Trustees' Report

Objectives, strategies and activities

Provision information and support services to people with, affected by, or involved with the diagnosis and treatment of Complex Regional Pain Syndrome

As usual our main focus for all our activities and services lay with promoting and protecting the health of all those whose lives have been affected by Complex Regional Pain Syndrome (CRPS) which includes the sufferers (patients), their families, close friends, loved ones and caregivers, as well as reducing the isolation and loneliness that comes with living with a pain condition like Complex Regional Pain Syndrome (CRPS).

CRPS can also have a definite effect on partners, family members as well as personal relationships, and all those affected may need support. This is evident from the number of partners and family members who contact the charity across our services.

The poor mental health, low self-esteem and low confidence levels as well as loneliness, isolation and confusion that we saw during the years of Covid-19, continued to be evident throughout this year, especially in the scores and responses to our questionnaires in our Counselling and Psychotherapy service and Befriending Service. The demand for all of our support services within our community is continually growing.

We are very grateful to all the amazing supporters who have thought of new ways of raising money and supporting Burning Nights CRPS Support.

We continued to offer education, awareness, information, emotional & psychological support and general advice not only to those whose lives have been touched by CRPS including patients, family members and caregivers but also to members of the public, healthcare professionals and students, legal and financial professionals.

Even though the Covid-19 Pandemic was over, we were in its aftermath where we continued to see the CRPS community having continual problems in accessing NHS mental health services, so we continued to offer our Befriending Service and our Counselling and Psychotherapy Service. In fact, these two services are now our biggest and busiest services. Although in their infancy at the start of this financial year, we received many positive comments about the service.

We received continued requests and registrations for these two main services. Due to the number of requests we received we gradually brought in a total of 5 new volunteer counsellors and psychotherapists. 2 of whom were trainees on placements. But we also realised we had an urgent need for a volunteer therapist for younger clients aged under 18. This was a difficult role to fill as we wanted to ensure they understood the issues that our younger clients could be struggling with as well as having some knowledge or understanding of CRPS or chronic pain.

The Counselling and Psychotherapy Service offers CRPS patients and their family members aged 12 and over up to 20 hours of counselling or psychotherapy and 4 assessments with a counsellor or psychotherapist. We ask the patients to complete a before & after survey so we can monitor the impact of the counselling. We also monitor the number of sessions as well as other information.

The Befriending Service has also seen a continual high number of registrations of people wanting to access this service. People will receive 12 weekly calls or Zoom chats of up to 40 minutes each with one of our trained volunteers. We are continuing to develop the service and we have trained a number of volunteers during the year to become Befrienders.

Burning Nights CRPS Support

Trustees' Report

Maintaining a website and social media presence to promote public awareness and provide support

One of the main projects we began was to overhaul our website which is so central to our charity. Our old website was slowing down and was at its full maximum capacity. It had therefore outgrown our needs. During the year we designed and developed the new website together with the design agency, as the site was being coded from scratch to what design we were wanting.

The website was to contain an online community forum, a small shop with all our information and awareness products, live chat, as well as more information on all our services, the impact and a new membership scheme. This was to offer help and information to those living with CRPS, their families and carers as well as educating and raising awareness of the condition amongst the public, health and legal professionals.

Our blog articles that we produce are well read and patients and families find them useful, with many who print pages to take to their doctors.

Our social media support was also busy once again and we saw a small decrease in Private Messages, but saw an increase in comments and questions in response to our posts. We have a small number of volunteers dedicated to responding to both people's posts/comments and private messages. By being in a different format especially for the Millennials, Gen Z and teens, we aim to reduce the isolation of people with CRPS, their families and friends with our online community activities such as on social media support and our online community forum on our website.

Anyone affected by CRPS, whether they are patients, families, caregivers can contact the charity on six (6) social media channels via direct private messaging to 'speak' to our volunteers for signposting, information and a listening ear. We also receive messages from the general public, health professionals & student healthcare and law firms. They find being able to be in contact with someone who understands the condition extremely helpful.

We have continued to increase our supporters across our social media channels where we have profiles which during 2021-2022 include Facebook, Twitter, Instagram, Pinterest, YouTube and LinkedIn.

We continue to provide the latest research, articles and information about all aspects of CRPS, living with the condition and caring for someone with CRPS across all our social media profiles. This is to provide awareness of CRPS and information. We also have active profiles because we also respond to comments and private messages, which helps to reduce the loneliness and isolation of CRPS sufferers, their loved ones, family members and carers. It also offers an understanding and empathy to patients and families.

We also provided information about events that were occurring both from ourselves and from others, any new research or guidelines to continue to raise awareness of CRPS. We regularly receive messages and questions not just for patients and their families and friends but also from health and legal professionals.

Our Closed Facebook group for Parents & Caregivers of Young People with CRPS has gradually increased in numbers and has been very useful for parents, caregivers and guardians who are looking for and finding advice, information and support from others in similar situations as their own.

Burning Nights CRPS Support

Trustees' Report

Publishing of information booklets and products

Gradually throughout the year, we began updating not just the information on our website in anticipation for the new site, but also our information literature had a big overhaul. We also created a new booklet for supporting young people living with CRPS for their parents and guardians.

All of our information literature benefits not just the general public, but crucially to those living with CRPS, their families and carers, healthcare, legal and financial professionals by providing information, advice and support as well as raising awareness of all the aspects of the condition.

As part of our information literature developed and designed 3 packs with 60-75 pages on self-care for CRPS and chronic pain patients - for adults, teenagers and children, their families and caregivers. The self-care packs have information on looking after both their physical and mental health. We incorporated physiotherapy exercises from a physiotherapist, self-care ideas and sleeping tips as well as support helpline numbers. All our sections have activities to be done. These self-care packs are to improve mental health and emotional wellbeing of CRPS patients and their families, by providing information and activities to provide tools such as information and activities enabling them to cope, to improve self-esteem and resilience and to encourage belief and understanding that they can get through each day and their needs matter.

Running online support groups with trained volunteer CRPS patients

We continued with our online CRPS support groups and they were of great benefit to everyone who attended whether they were family members, patients living with the condition, young people or friends of CRPS patients who just wanted to know how to support their friend. They are important for the health of CRPS patients, their loved ones and caregivers and provide a sense of security as well as reduce isolation and loneliness.

These monthly online peer support groups offer a private, safe and confidential space to 'virtually' meet and chat with other members who are affected in similar ways. All our online support groups are volunteer led and who are all CRPS patients themselves. They provide a space for people to learn new skills, meet new people and talk about their experiences.

During our last report (2020-21) we identified the need for online support groups specifically for those aged 18 years and under, as well as one for the loved ones and caregivers. We felt that it is important to continue with these two different online support groups during this year 2021-2022. However due to the decline in numbers we decided to stop running these groups during the summer months and are considering stopping them in the next year. Although these groups had lower attendance numbers than the main peer support group, they have been helpful to those attending.

Burning Nights CRPS Support

Trustees' Report

Organising day conferences and online webinars

During 2021-2022 we held 2 webinars: Getting a Better Night's Sleep and Spinal Cord Stimulation (SCS) for Chronic Pain. It is with thanks to Kate Thorpe for presenting the Sleep Webinar and also Abbott Medical for supporting the webinar on SCS for Chronic Pain. We are extremely grateful for their support during the year. These webinars were well attended and attendees found them extremely informative.

Our annual national CRPS conference went ahead once again this year but in Chester. However as we were in the aftermath of the Covid Pandemic, we decided to hold the conference face to face but also via live stream if anyone was still concerned about Covid. The Government restrictions had been lifted allowing us to hold the conference face to face.

We held our one (1) day annual national CRPS conference during CRPS awareness month of November. As usual we kept it free of charge for those attending either live stream or in person. The attendees were mainly those affected by CRPS including CRPS patients (sufferers), their families and caregivers. At this year's conference we invited health professionals to speak who have an interest and knowledge in protecting the health of CRPS sufferers and their families and carers as well as providing information and support to those people. We also invited legal and disability speakers who are involved with CRPS.

Our attendees were mainly people who live with CRPS, their families, friends and caregivers. But we also had a small number of health professionals who had brought their patients as they were interested to learn more about the condition, treatment options, upcoming research and how it affects people and their families.

Our annual conference really does help to raise awareness of not just the condition, but also about living with it and managing it. Many people who attend find the event useful and insightful. They also gain support from others who attend the conference because they are able to share their own stories of journeys affected by CRPS. The conference also provides help, advice, support and information by trained health professionals giving hope to many patients and families showing there is help out there and there is life after diagnosis.

Burning Nights CRPS Support

Trustees' Report

Running a telephone information and advice Helpline and Live Chat for all members of our community as well as Healthcare Students & Professionals

Our telephone Helpline continued throughout 2021-2022. We still held its usual opening times during the working week ie Monday to Friday. For any calls out of hours there is a voicemail available and we have the phone number of the Samaritans on our contact page on our website as well as on our voicemail. The majority of people who contact the charity's Helpline are CRPS patients, loved ones and caregivers and we receive a range of questions and issues that we are able to deal with. The Helpline is there so others are able to talk to someone who understands what they are going through.

Our Helpline is run by CRPS patients as volunteers. It does benefit those living with the condition as they see it as a lifeline with many people being housebound, vulnerable and isolated. We are there on the end of a phone to help people cope with facing the day and finding a strategy that will work for them. We are also there to chat with the CRPS community when they are finding things difficult or as the start of their long road of acceptance of this condition.

The helpline is also of benefit to those people who care for CRPS sufferers, their family members, friends and loved ones. It is a useful resource used by many healthcare professionals and students including school nurses who see patients and school children and teenagers with this condition.

The Helpline supports callers with information, signposting to other organisations, support and non-medical advice to anyone who contacts the helpline. It also helps CRPS sufferers with their self-confidence and self-esteem as they realise they are not on their own in their journey.

Running an online community forum for mutual support, help, information and an exchange of ideas

Our Online Community Forum has been a great source of help to many. This Online Community forum helps people who maybe don't use social media or who want something that is more reliable. The Community Forum is there to provide peer support, help, peer advice, information as well as camaraderie and social networking.

As a charity we can also use the online community forum to signpost patients and their families to information about our own support services, treatment options available on the NHS and private and general information about the condition, managing the condition and living with it. CRPS patients, their families and carers can also gain support from other patients and their families from posting messages in the forum.

Attendance at exhibitions to promote public awareness

We took part in 2 exhibitions during 21-22 which were the ones that should have run during Covid but were cancelled. These were Guidelines Live and Naidex. We take part in these health and disability exhibitions to raise awareness not just of the charity & its services but also to raise awareness of CRPS and provide information and support to the general public and to those living with CRPS along with their families, loved ones, friends and carers as well as healthcare and legal professionals.

We raise awareness of CRPS at exhibitions so we can educate the public and those involved in caring for, treating and diagnosing those who may be suffering from CRPS is important so we can impart the latest information and research. We can also inform people of our key services that we can offer to patients & families.

Burning Nights CRPS Support

Trustees' Report

Provision of information and education talks to promote understanding and awareness of CRPS

We provided a number of CRPS and chronic pain awareness and information sessions that offered information about the condition, diagnosis, prognosis and treatment as well as ways to manage the condition. This helps with furthering education of CRPS especially to those healthcare students and professionals who are involved in treating, diagnosing and caring for those suffering from CRPS. We also provide these education sessions for healthcare professionals as well as student healthcare who need to be aware of this condition in case a patient comes to them and their department.

We have held meetings with several companies including medical device companies as well as health/medicine companies and law firms to try and raise the awareness of the condition for the protection and benefit of CRPS sufferers, their families and carers. Some of these meetings were very successful and in some cases we have secured future funding.

Supporting research projects that will benefit those affected by CRPS

As a charity we have taken part in assisting and supporting research into CRPS and chronic pain, its causes, treatment and one day a cure in different forms of research. This has included helping researchers find prospective participants.

The Pain At Work (PAW) Toolkit that we were involved in with Dr Blake at Nottingham University has stemmed into further research and a research proposal has been written during 2021-22. We await the response.

All of the research projects that we get involved in and find participants for, to support research into CRPS, its causes, treatment and cure as well as chronic pain and disability are a great way for our community to get involved in. We always ensure the results of such research are published across our social media, website and newsletters.

Campaigning to benefit those affected by CRPS especially patients

We also continued to be involved with a medical device manufacturer, Abbott Medical, who have developed a treatment option for CRPS patients - neuromodulation.

We also continued to be involved with the charity's local Member of Parliament who continues to raise multiple questions about the condition in Parliament. We also encourage patients and families to get involved with their local MP. This is ongoing and if we do manage to get everything that we are asking for from Parliament then this will be a huge benefit to CRPS patients.

Burning Nights CRPS Support

Trustees' Report

Fundraising disclosures

OUR SUPPORTERS

Fundraising and donations

We are almost entirely reliant on donations to fund our work. Without the public's generosity, we would be unable to support people affected by CRPS or work to reduce the time to diagnosis and improve care. We are considering applying for registration with the Fundraising Regulator in the next financial year, but we are open about how we raise our funds.

We train and support our staff to identify and protect people in vulnerable circumstances in accordance with our Safeguarding Policy and our Fundraising Policy. All our direct marketing communications contain clear instructions of how a supporter can easily opt out of receiving any further communication they wish to.

We also ask people to give to us through our regular appeals or by leaving a gift in their Will.

There were a number of fundraising events from our community supporting us which included a number of people taking part in various running, cycling or walking events including The Three Peaks Challenge, as well as a supporter who took on the virtual London Marathon.

Although we didn't receive a charity ballot for the London Marathon, we had someone run in the virtual London Marathon as we had places available.

We continued to receive donations from Facebook fundraisers which we've seen an amazing response to. People have been setting up fundraisers for their birthdays, anniversaries, Christmas, Giving Tuesday etc in aid of Burning Nights CRPS Support.

We still receive donations by text message both as a one off and also as a regular donation.

Organisational Health

We had decided before the Pandemic that we should reduce our reliance on member-generated income (ie income generated by our community) by strengthening our appeal to grant makers and developing more contacts with companies and the impact of the Pandemic simply accelerated the process.

We are grateful to the following for their support:

- CAF COVID Recovery Fund
- The Hospital Saturday Fund

The National Lottery Awards For All and the Albert Hunt Trust had provided their support at the end of the previous financial year for the redevelopment of our new website.

We will also be diversifying our funding further in the next financial year with the launch of our new website.

Corporate Donors

We have also continued to receive donations money from companies from their Dress Down Days, company walking days, Christmas Quiz and as the Charity of the Year.

We had some very productive and successful corporate donor meetings where we managed to secure funding and grants for projects and for the charity including from Abbott Medical. However we started to have talks with other companies at the end of the financial year.

Burning Nights CRPS Support

Trustees' Report

Public benefit

The trustees confirm that they have complied with the requirements of section 4 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Achievements and performance

We were delighted this year when our Founder and Chair, Victoria Abbott-Fleming was awarded an MBE for Services to Charity in June 2021 at the Queen's Birthday Honours List. Her Investiture was in February 2022. This brought the conversation of CRPS and the impact of the condition to the general public.

Although the Covid Pandemic was over, we still received a high number of requests for support, but we were also hit by the start of the high cost of living crisis.

We found that many of our CRPS community were still isolating and vulnerable because of Covid-19 which caused an impact on their mental health. This led to many living in isolation, anxiety and depression.

However we continued to offer and provide all our support services, expanding some services, slowing others as well as having the majority of our volunteers living with CRPS, showing our beneficiaries that we understand, can empathise and believe what they are going through. Being a patient led organisation is so important, where 75% of our Trustees live with chronic pain or CRPS and over 60% of our volunteers who are also patients themselves.

Here is a roundup of our main areas of focus for 2021-2022:

- Support for all those who have been affected by CRPS (sufferers, their families, friends and carers)
- Campaigning, Advocacy and awareness
- Information and Education
- Research and Studies
- Our Volunteers
- Our Supporters

Burning Nights CRPS Support

Trustees' Report

SUPPORT FOR ALL THOSE AFFECTED BY CRPS

We continue to be there to support, help and inform anyone who has been affected by Complex Regional Pain Syndrome (CRPS), whether they are patients, loved ones, families or caregivers.

We provide direct support through the following services:

- Online Support Groups
- Helpline
- Live Chat
- Social Media
- Email support
- Online Community Forum
- Befriending Service
- Counselling Service

In more detail:

Befriending Service

We continued with our Befriending Service and in fact expanded it to have 6 volunteer Befrienders as we have received a large number of requests to be befriended. We wish to keep expanding this service to have more volunteers to cope with the demand.

This service is one of our bigger support services and consists of a weekly call or online video chat for 40 minutes. Each client receives a total of 12 calls / video chats from one of our trained volunteers who are all CRPS patients themselves.

We will be doing a volunteer recruitment drive during the next financial year to have 10 volunteers who can empathise and be a listening ear for someone affected by CRPS.

During 2021-2022 we provided 66 sessions and started 11 new clients.

Counselling and Psychotherapy Service

We began this service in March 2021 during the Pandemic and initially was going to be a trial of 6 months. However we were inundated with requests for counselling as our community were unable to access NHS mental health services. We have not only continued this service but have expanded it to have 6 (six) counsellors and psychotherapists as we had no fall off in demand for this service.

We offer up to 20 hours of counselling or psychotherapy for anyone aged over 18 along with 4 assessments to keep assessing their anxiety and depression scores. This is far more than the NHS are currently able to offer.

Most of our clients are adults however we received a number of registration forms for young people aged 11 and over, therefore in the next financial year we will have a specific volunteer drive for a young person counsellor.

During 2021-2022 we provided 200 sessions of 1 hour or over and started 25 new clients. Our waiting list has varied from over 18 months to just 3 months, however we have new people wanting to access this service every day.

We have four qualified counsellors, one trainee counsellor and one trainee Psychotherapist. All of whom are volunteers and without them giving up their time, knowledge and skills to support the charity enabling us to offer this important service.

We saw that the average anxiety level of our completed clients started at over 17 which is severe anxiety. This is evident in our own survey. At the completion of 20 hours of counselling this figure dropped to just over 11 which is mild anxiety. This shows a real impact. From our surveys we saw a reduction in anger, fear & frustration in all clients. 100% felt they saw a very definite reduction in suicidal thoughts.

Burning Nights CRPS Support

Trustees' Report

Online CRPS Support Groups

We have continued with online peer support group meetings which were so successful during the Pandemic - as they seem to provide a more accessible service for most people within our community. We are considering the return of our face to face support groups in Manchester and London, but we will find out from our members if this is something people want.

Our main adult online support group maintained its monthly meet, but the young person group and caregivers group had a period without running as we found people weren't in any need of those two groups.

We held a total of 23 online support groups, run by our amazing volunteers who all have CRPS themselves. These groups are a fantastic outlet for people who want to network, find support and to ask for information.

We supported 181 individuals in our online support groups and on average we have a regular number of approximately 15-20 every month attend our main online peer support group.

Email Support

We continued to provide support via email to CRPS patients (sufferers), their families, partners and carers who may have questions or requests for support, help or information.

During 2021-2022 we supported 797 individuals through email.

We received emails regarding various issues such as requests to access our services, CRPS specialist information, CRPS specialist lawyers as well as signposting to other services or organisations.

The support by email helps reduce the loneliness and isolation and increases education for patients, their relatives, families and carers. It also provides them with necessary and important support, advice and knowledge.

Live Chat

We started a Live Chat support in July 2020 during the Pandemic as it provided an alternative digital solution to those who weren't able to use the telephone or any of our other options.

We developed this support service so it is open for 6 (six) days a week.

During 2021-2022 we responded to and supported 369 individuals for almost 19 hours of chat support time. The average chat time was 48 minutes.

Online Community Forum

We continued to offer our Online Community Forum which can be found on our website to offer another digital alternative to social media to reduce the isolation and vulnerability that CRPS sufferers and their loved ones feel once diagnosed with CRPS. It also is a great place for the community to e-meet to exchange help, advice and information between each other.

We have a number of volunteers who support and moderate the Online Community Forum to ensure no spam and that people are following the necessary rules of the forum. They are also there to offer their own personal experiences and ensure the information others provide is correct.

The Online Community Forum is open and available 24/7. We have just over 1,940 participants overall. It is a safe place where patients, their families and partners are able to ask questions and talk about the condition as well as exchange ideas and gain peer support.

The Community Forum is also there to help reduce loneliness and isolation by providing a social interaction with others who can understand what others are going through.

Social Media

We continue to have a very solid presence on six (6) social media platforms where we regularly post articles, events and research opportunities for CRPS sufferers, their loved ones, family members, friends and carers.

We are also able to support everyone affected by CRPS by providing individual responses of support via Private Message and also in the comments of posts.

We responded to almost 600 individual private messages during 2021-2022.

We consistently see an increase in our number of followers and subscribers across all our platforms - Facebook, Twitter, Instagram, Pinterest, LinkedIn and YouTube.

By the end of March 2022, our social media community saw an increase of 8% compared to the previous year (number of followers 52,256 during 2020-21) and we had 56,623 followers and subscribers across the six social media channels.

Our closed online support group on Facebook for parents/guardians who have children and teens with CRPS continues to increase its members and has just over 680 members.

Burning Nights CRPS Support

Trustees' Report

Helpline

The telephone Helpline along with the email support are an integral and important part of the charity and the support services.

We receive calls not just from CRPS patients, their families and friends but also from health professionals and social prescribers needing help, information and signposting.

Many callers asked us for support as they struggled to access NHS services including mental health services and benefits, and many experienced difficulties navigating the education system for children and young people with disabilities.

The Helpline is open for support five days a week.

The helpline is manned by volunteers to the charity who are CRPS sufferers themselves.

During 2021-2022 we responded to 811 calls to our Helpline which was over 101 hours of call time.

We will look into developing our Helpline by recruiting more volunteers and developing a training programme.

CAMPAIGNING, ADVOCACY and AWARENESS

Our Founder and Chair also volunteers with the British Pain Society and regularly raises awareness of the concerns of our patients and families such as waiting times for pain clinics, lack of treatments and limited access to mental health services.

CRPS awareness sessions

We provided a small number of CRPS awareness sessions providing over 9 hours of information to healthcare and legal students and professionals. We delivered other talks both face to face and virtually.

We regularly speak at Derby University to the first year Occupational Therapy (OT) students talking about CRPS and how life is affected by the condition. The talk was delivered face to face once again and it offered the students someone with lived experience who could give them a personal experience of how CRPS affects all aspects of their life.

Education and awareness of CRPS is crucial to improved outcomes, quicker diagnoses and better treatments.

We now need to work together with the NHS, other patient groups and organisations to address the topic of CRPS and how much it does have an effect on the society as a whole just like chronic pain.

We would like to develop online CRPS awareness sessions in the future so people can access them at any time.

Exhibitions

Some of the exhibitions we are usually exhibitors went back to face to face and others were either moved to the next financial year or were held virtually. We were exhibitors at a new exhibition which was primarily aimed at those involved in Primary Care which we found very useful to raise awareness about the charity and the condition.

We attended the virtual exhibitions as exhibitors to raise awareness and provide information about CRPS.

We will continue to be exhibitors at certain health and disability exhibitions to raise awareness of CRPS and the effects of the condition because of the complexity and diverse range of signs and symptoms. If the public and healthcare are made aware of the condition it can provide a better understanding so patients can be diagnosed sooner.

Parliament and Campaigning

We continued working with our local MP to ask questions in the House of Commons about CRPS including mental health support.

We aim to continue working with our MP to carry on asking questions so we can provide answers to CRPS patients & their families.

Burning Nights CRPS Support

Trustees' Report

INFORMATION and EDUCATION

We provide information and education to our CRPS patients, their families and loved ones as well as the general public as well as health professionals and students through our annual national conference, webinars, website and our literature & products.

Annual Conference 2021

Our 7th Annual National CRPS Conference 2022 was our first face to face conference since the Pandemic restrictions were lifted. We held it at the DoubleTree Hilton, Chester on 21st November 2021. We received an Educational Grant from Abbott Medical to support the conference, for which we are extremely grateful.

As well as the face to face conference we also live streamed the event for those who were concerned about Covid-19 and mixing with others.

We had 158 people ticketed/registered for the event and live stream, but sadly only 59 attended either the face to face or live stream. We had CRPS patients and their families from the U.K., we also had attendees from around the world including USA, South Africa, Europe, New Zealand and Australia attending the live stream. For the face to face all were from the U.K. We also had a physiotherapist come along with her patient to gain information, help and support from the speakers but also from the charity.

We brought in 7 health and legal professional speakers all of whom had an interest and/or working knowledge of CRPS, chronic pain or disability. We heard from a pain specialist giving up to date research and information about neuromodulation as a management option of CRPS. We also heard about personalised medicines.

Webinars

Due to the fact that our webinars were well attended during the Pandemic we decided to run a small number of online talks (webinars) during this year.

We held 3 webinars in 2021-2022, including Getting a Better Sleep, Spinal Cord Stimulator for Chronic Pain and Dorsal Root Ganglion Stimulation for CRPS. It is with thanks to Kate Thorpe and Abbott Medical for presenting these webinars.

Overall we supported almost 200 individuals with our webinars.

Website

We want to reach as many people as possible affected by CRPS. Having a dialogue with them will inform them of our plans for projects making a difference across the UK.

We have a great number of unique visits to our website - almost 130,000 during the year. However we know this can be improved upon when we launch our new website later on in the next financial year.

We regularly update and provide information about CRPS for sufferers, their loved ones, families, friends and carers on our website, the blogs and e-newsletter. We added more up to date research in various sections of the website and continued to make updates on the main parts of the website.

The website is extremely valuable to CRPS sufferers, their families, loved ones, friends and carers as well as being informative to the general public about the condition, the health professionals to ensure the condition is properly understood so patients can receive the correct treatment they require and legal professionals can find the information about the condition, current research and treatment options for their clients.

Our main ongoing project was the development of our new website which we were given a number of grants to contribute to the cost.

Literature and Information Products

We continued to regularly update our various information products to ensure they are fully up to date especially after a big update in September 2021. We also developed new booklets to help provide information of all aspects of the living and managing the condition aimed at CRPS patients, their families and friends.

Our main project for 2021-22 was to finish developing our Self Care booklets. This Self Care project was born out of the Pandemic and we found that our community didn't have much information about self care. We developed three different books according to age - adults (aged 18+), teenagers (aged 13-17) and children (aged 8-12).

Burning Nights CRPS Support

Trustees' Report

We also created a new booklet for supporting young people living with CRPS for their parents and guardians. This contained information and tips from other parents on supporting young people with CRPS in all aspects of their life i.e. education, home, friends and medical appointments.

These leaflets and other information literature provide education, awareness and support to everyone affected by CRPS whether they are patients, friends, family members or loved ones.

We continued to distribute our CRPS information leaflets for adult and young people to various NHS hospitals and private clinics across the UK.

We aim to be in contact with more pain clinics during the next financial year to ensure they are aware of our charity and the support services they offer.

RESEARCH and STUDIES

Research

Both Burning Nights CRPS Support and our Founder & Chair, Victoria were heavily involved with Dr Holly Blake at Nottingham University to create a Pain At Work (PAW) Toolkit and the study was finally accepted for print in December 2021. The citation is: **Blake H, Somerset S, Greaves S. The Pain at Work Toolkit for Employees with Chronic or Persistent Pain: A Collaborative-Participatory Study. Healthcare (Basel). 2021 Dec 29;10(1):56. doi: 10.3390/healthcare10010056. PMID: 35052220; PMCID: PMC8775489.**

This was an online digital toolkit designed to provide information, support, advice and guidance for people at work who have chronic or persistent pain. Although this Toolkit was completed during 2020-2021, it wasn't accepted in the Healthcare (Basel) Journal until December 2021. Our Founder & Chair, Victoria Abbott-Fleming MBE, was listed as an author. The direct link to the paper is at: <https://pubmed.ncbi.nlm.nih.gov/35052220/>

The direct for the actual Pain At Work Toolkit can be found at: https://xerte.nottingham.ac.uk/play_24452

Our involvement, especially that of Victoria was included in the BRC Musculoskeletal Theme Conference in February 2022.

We have taken part in assisting and supporting research studies into CRPS and chronic pain, its causes, treatment and cure in 21 research studies from various Universities in the U.K. Ireland and Switzerland.

This has included helping researchers find prospective participants, by sharing their studies on our social media, in our e-newsletters, on our website and occasionally on our blog article section of the website.

We continued to share the results of any research studies or clinical trials we have assisted in across our social media channels, our website, e-newsletter and online community forum.

OUR VOLUNTEERS

We had 39 fantastic volunteers delivering 10 services providing 7,030 hours of support to the charity. Thank You!

Our volunteers are at the heart of the support we provide in the community and we are committed to providing a positive and enjoyable volunteering experience.

Volunteers attend support sessions and meet every two months to share best practice and support each other. For volunteer Befrienders and Counsellors / Therapists they meet every month for supervision and peer support to gain support from each other and to improve the service and ensure volunteers receive up to date training.

Training and Induction

All new volunteers are given a full induction into the charity including essential Safeguarding training. All volunteers also have to complete CRPS awareness training which is a video with subsequent questions to answer.

The volunteer Befrienders and Counsellors also attend four courses which are considered mandatory for their role including suicide awareness, suicide prevention, mental health awareness and self harm awareness.

We regularly offer training courses for all volunteers and ensure the basic courses such as Safeguarding are renewed yearly.

We are committed to ensuring all our volunteers are trained for the role they are to make sure that our community receiving support from our volunteers are fully trained.

Burning Nights CRPS Support

Trustees' Report

Financial review

The Charity has received incoming resources during the year of £84,469 (2021: £54,286) and its outgoing resources for the year were £59,669 (2021: £25,179) resulting in net incoming resources of £24,800 (2021: £29,107).

The balance sheet shows net assets of £105,198 (2021: £80,398 including restricted funds of £5,000 (2021: £8,439)).

Policy on reserves

The aim of the reserves policy is to ensure that the charity's ongoing and future activities are reasonable protected from unexpected fluctuations in its income and expenditure. The board reviewed its reserves policy and agreed that a minimum level of unrestricted general funds, also known as free reserves, of £30,000. This is approximately six months of running costs.

The total reserves at 31 March 2022 was £105,198 (2021: £80,398) of which £5,000 (2021: £8,439) are held in restricted funds. The balance held in unrestricted funds was £100,198 (2021: £71,959) of which £90,236 (2021: £58,611) are free reserves, after allowing for funds tied up in tangible fixed assets.

The trustees consider the excess reserves held are prudent in current economic climate.

Principal funding sources

Burning Nights CRPS Support raises its funds through fundraising activities, grants and donations and also through the sale of branded goods through its online shop.

The Pandemic and the negative impact on our fundraising, accelerated our thoughts and plans on diversifying our income streams.

We continued to receive corporate donations from law firms to join our small legal panel, as well as general corporate donations and grants from medical device companies.

Structure, governance and management

Nature of governing document

Burning Nights CRPS Support was established as a charity and is governed by a constitution adopted on 20 October 2015. It was registered as a Charitable Incorporated Organisation on 13 April 2016.

Recruitment and appointment of trustees

These trustees are appointed in line with the provisions of the Constitution and subject to retirement or re-appointment on a three-yearly rolling basis at the AGM. New trustees are agreed upon by 3 of the current trustees. Apart from the first charity trustees, every trustee must be appointed for a term of three years.

Induction and training of trustees

We have a number of policies in place for trustees including confidentiality, data protection, social media, vulnerable adult and children safeguarding and conflicts of interest. These policies are regularly updated to check for accuracy and updates in the law.

All new trustees are given a full induction into the charity and are given regular training for Safeguarding of Vulnerable Adults and Children.

All trustees give their time voluntarily and receive no remuneration or benefits except exp

Burning Nights CRPS Support

Trustees' Report

Organisational structure

The charity has a Chair who leads the Board and the work of the staff and volunteering team and a Treasurer alongside other trustees without any titles.

Burning Nights CRPS Support is a national UK wide organisation.

Burning Nights CRPS Support maintains working relationships with other charities and umbrella organisations that share common purpose with the charity. None of these relationships is a related party in terms of the SORP.

Statement of Trustees' Responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the applicable Charities (Accounts and Reports) Regulations, and the provisions of the constitution. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The annual report was approved by the trustees of the charity on 23 January 2023 and signed on its behalf by:



Mrs Victoria Abbott-Fleming
Trustee

Burning Nights CRPS Support

Independent Examiner's Report to the trustees of Burning Nights CRPS Support

I report on the accounts of the charity for the year ended 31 March 2022 which are set out on pages 19 to 27.

Respective responsibilities of trustees and examiner

The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

Independent examiner's statement

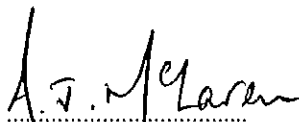
In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the Charities Act 2011; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Andrew J McLaren FCA
Beever and Struthers

Chartered Accountants
One Express
1 George Leigh Street
Manchester
M4 5DL

Date: 23/1/23

Burning Nights CRPS Support

Statement of Financial Activities for the Year Ended 31 March 2022

	Note	Unrestricted funds £	Restricted funds £	Total 2022 £
Income and Endowments from:				
Donations and legacies		73,521	7,300	80,821
Other trading activities		3,648	-	3,648
Total Income		<u>77,169</u>	<u>7,300</u>	<u>84,469</u>
Expenditure on:				
Raising funds		(16,178)	-	(16,178)
Charitable activities		(32,752)	(10,739)	(43,491)
Total Expenditure		<u>(48,930)</u>	<u>(10,739)</u>	<u>(59,669)</u>
Net movement in funds		28,239	(3,439)	24,800
Reconciliation of funds				
Total funds brought forward		<u>71,959</u>	<u>8,439</u>	<u>80,398</u>
Total funds carried forward	15	<u>100,198</u>	<u>5,000</u>	<u>105,198</u>
	Note	Unrestricted funds £	Restricted funds £	Total 2021 £
Income and Endowments from:				
Donations and legacies		42,116	6,510	48,626
Other trading activities		5,660	-	5,660
Total Income		<u>47,776</u>	<u>6,510</u>	<u>54,286</u>
Expenditure on:				
Raising funds		(7,640)	-	(7,640)
Charitable activities		(16,779)	(760)	(17,539)
Total Expenditure		<u>(24,419)</u>	<u>(760)</u>	<u>(25,179)</u>
Net movement in funds		23,357	5,750	29,107
Reconciliation of funds				
Total funds brought forward		<u>48,602</u>	<u>2,689</u>	<u>51,291</u>
Total funds carried forward	15	<u>71,959</u>	<u>8,439</u>	<u>80,398</u>

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2021 is shown in note 15.

Burning Nights CRPS Support
(Registration number: 1166522)
Balance Sheet as at 31 March 2022

	Note	2022 £	2021 £
Fixed assets			
Tangible assets	11	9,962	13,348
Current assets			
Stocks	12	4,688	-
Debtors	13	500	5
Cash at bank and in hand		<u>92,873</u>	<u>67,110</u>
		98,061	67,115
Creditors: Amounts falling due within one year	14	<u>(2,825)</u>	<u>(65)</u>
Net current assets		<u>95,236</u>	<u>67,050</u>
Net assets		<u>105,198</u>	<u>80,398</u>
Funds of the charity:			
Restricted funds		5,000	8,439
Unrestricted income funds			
Unrestricted funds		<u>100,198</u>	<u>71,959</u>
Total funds	15	<u>105,198</u>	<u>80,398</u>

The financial statements on pages 19 to 27 were approved by the trustees, and authorised for issue on 23 January 2023 and signed on their behalf by:

.....
Mrs Victoria Abbott-Fleming
Trustee

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2022

1 Accounting policies

Statement of compliance

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

Basis of preparation

Burning Nights CRPS Support meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Exemption from preparing a cash flow statement

The charity opted to early adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2022

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees's meetings and reimbursed expenses.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Tangible fixed assets

Individual fixed assets costing £0.00 or more are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Stock

Stock is valued at the lower of cost and estimated selling price less costs to complete and sell, after due regard for obsolete and slow moving stocks. Cost is determined using the first-in, first-out (FIFO).

Trade debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that the will not be able to collect all amounts due according to the original terms of the receivables.

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2022

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees's discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Financial instruments

Classification

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

2 Income from donations and legacies

	Unrestricted funds			
	General	Restricted	Total	Total
	£	funds	2022	2021
	£	£	£	£
Donations and legacies;				
Donations	62,371	2,000	64,371	41,626
Gift aid reclaimed	3,150	-	3,150	-
Grants, including capital grants;				
Grants received	8,000	5,300	13,300	2,000
Sponsorships received	-	-	-	5,000
	<u>73,521</u>	<u>7,300</u>	<u>80,821</u>	<u>48,626</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2022

3 Income from other trading activities

	Unrestricted funds	Total 2022	Total 2021
	General £	£	£
Trading income;			
Sales of goods and services	3,648	3,648	2,278
Events income;			
Other events income	-	-	3,382
	<u>3,648</u>	<u>3,648</u>	<u>5,660</u>

4 Expenditure on raising funds

a) Costs of trading activities

	Unrestricted funds	Total 2022	Total 2021
	General £	£	£
Note			
Costs of goods sold	1,796	1,796	-
Events and conferences	301	301	350
Marketing and publicity	2,640	2,640	179
	<u>4,737</u>	<u>4,737</u>	<u>529</u>

5 Expenditure on charitable activities

	Unrestricted funds	Restricted funds	Total 2022
	General £	£	£
Note			
Charitable activities	12,796	-	12,796
Allocated support costs	17,112	10,739	27,851
Governance costs	2,844	-	2,844
	<u>32,752</u>	<u>10,739</u>	<u>43,491</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2022

6 Net incoming/outgoing resources

Net incoming/outgoing resources for the year include:

	2022 £	2021 £
Depreciation of fixed assets	<u>3,386</u>	<u>137</u>

7 Trustees remuneration and expenses

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

During the year 3 trustees were paid expenses for travel and training costs totalling £2,532 (2021: £961).

8 Staff costs

The aggregate payroll costs were as follows:

	2022 £	2021 £
Staff costs during the year were:		
Wages and salaries	<u>11,441</u>	<u>6,579</u>

No employee received emoluments of more than £60,000 during the year

9 Independent examiner's remuneration

	2022 £
Examination of the financial statements	<u>1,440</u>
Other fees to examiners	
All other services	<u>1,320</u>

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2022

10 Taxation

The charitable incorporated organisation is a registered charity and is thus exempted from taxation of its income and gains falling within section 524 of the Income Tax Act 2007 to the extent that they are applied to its charitable objectives. No tax charge has arisen in the year.

11 Tangible fixed assets

	Furniture and equipment £	Total £
Cost		
At 1 April 2021	13,544	13,544
At 31 March 2022	13,544	13,544
Depreciation		
At 1 April 2021	196	196
Charge for the year	3,386	3,386
At 31 March 2022	3,582	3,582
Net book value		
At 31 March 2022	9,962	9,962
At 31 March 2021	13,348	13,348

12 Stock

	2022 £	2021 £
Stocks	4,688	-

13 Debtors

	2022 £	2021 £
Prepayments	500	-
Other debtors	-	5
	500	5

14 Creditors: amounts falling due within one year

	2022 £	2021 £
Trade creditors	65	65
Accruals	2,760	-
	2,825	65

Burning Nights CRPS Support

Notes to the Financial Statements for the Year Ended 31 March 2022

15 Funds

	Balance at 1 April 2021 £	Incoming resources £	Resources expended £	Balance at 31 March 2022 £
General	71,959	77,169	(48,930)	100,198
Restricted funds	<u>8,439</u>	<u>7,300</u>	<u>(10,739)</u>	<u>5,000</u>
Total funds	<u>80,398</u>	<u>84,469</u>	<u>(59,669)</u>	<u>105,198</u>
	Balance at 1 April 2020 £	Incoming resources £	Resources expended £	Balance at 31 March 2021 £
General	48,602	47,776	(24,419)	71,959
Restricted funds	<u>2,689</u>	<u>6,510</u>	<u>(760)</u>	<u>8,439</u>
Total funds	<u>51,291</u>	<u>54,286</u>	<u>(25,179)</u>	<u>80,398</u>

The specific purposes for which the funds are to be applied are as follows:

During 2022 a restricted grant of £5,300 was received from The National Lottery and £2,000 from The Hospisal Saturday Fund for the development of the new website, these were all utilised during the year.

During 2021 a restricted grant of £2,000 was received from the Albert Hunt Trust for website development. A restricted grant was also received from Abbott Medical for educational purposes. These grants were utilised during the year.

During 2020 a restricted grant of £5,000 was received from a supporter for the purpose of supporting those affected by CRPS in Scotland.. This balance is remaining in restricted funds and will be utilised in forthcoming year.

16 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds
	General £	£	£
Tangible fixed assets	9,962	-	9,962
Current assets	93,061	5,000	98,061
Current liabilities	<u>(2,825)</u>	<u>-</u>	<u>(2,825)</u>
Total net assets	<u>100,198</u>	<u>5,000</u>	<u>105,198</u>

Accounts

Charity number: 1166522

Burning Nights (CRPS) Support

Report of the Trustees and Unaudited Financial Statements

For the year ended 31 March 2021

Burning Nights (CRPS) Support
Contents Page
For the year ended 31 March 2021

Reference and administrative details	1
report of the trustees	2
independent examiners report to the trustees	13
statement of financial activities	14
statement of financial position	15
notes to the financial statements	16
notes to the financial statements continued	18
detailed statement of financial activities	22

Burning Nights (CRPS) Support
Reference and Administrative Details
For the year ended 31 March 2021

Name of Charity Burning Nights (CRPS) Support

Charity registration number 1166522

Principal address 1 Alder Brook
Chinley
High Peak
Derbyshire
SK23 6DN

Trustees

The trustees and officers' service during the year and since the year-end were as follows:

Mrs Victoria Abbott-Fleming
Ms Lisa Davies
Mr Thomas Craig Lowe
Mr Altaf Patel

Independent examiners ABS Accountancy Ltd
10 Fairfield Road
Buxton
Derbyshire
SK17 7DW

Burning Nights (CRPS) Support
Report of the Trustees
For the year ended 31 March 2021

The Trustees have pleasure in presenting their report and the financial statements for the charity for the year ended 31 March 2021. The Trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2019).

The trustees have considered the Charity Commission's guidance on public benefit, including the guidance 'public benefit: running a charity (PB2)'.

OBJECTIVES AND ACTIVITIES

Objectives and aims

- 1) to promote and protect the health of sufferers of Complex Regional Pain Syndrome (CRPS), their families and carers by the provision of information, advice and support including raising awareness of all aspects of CRPS amongst the public in general but in particular those involved in the diagnosis, treatment and care of those suffering from CRPS; and
- 2) to assist and support research into CRPS, its causes, treatment and cure and to ensure the useful results of such research are published

Objectives, strategies and activities

In planning our activities for the year, we kept in mind the Charities Commission's guidance on public benefit at our trustees meetings.

This annual review was during all of the lockdowns due to the Covid-19 Pandemic. All our usual in person activities had to be altered to the virtual.

Our main focus as usual for all our activities lie with promoting and protecting the health of all those affected by Complex Regional Pain Syndrome (CRPS) which includes the sufferers (patients), their families, friends, loved ones and carers, as well as reducing the isolation and loneliness that comes with living with a pain condition like Complex Regional Pain Syndrome (CRPS). CRPS can also have a huge effect on partners, family members and personal relationships, and all those affected may need support. This is evident from the number of partners and family members who contact the charity.

We identified at the beginning of the Covid-19 Pandemic that loneliness, isolation and confusion needed to be addressed. We found that in the first 6 months of this financial year were during the confusion and lack of understanding of the Coronavirus Pandemic. In fact, we received a 156% increase in requests for services and support. We found that we had an increase of 38% in suicide related calls to the helpline because of the Pandemic and the numerous lockdowns that had been imposed by the U.K. Government.

The Covid-19 pandemic has meant many with CRPS are currently facing difficult changes to their healthcare, with delays, cancelled appointments and treatments. We have been delivering virtual services and webinars, and working with healthcare professionals to provide the guidance people need in these difficult times. The demand for our services within our community is growing, at a time when we are facing a large decrease in income due to events and activities being cancelled. We are very grateful to all the amazing supporters who have thought of new ways of raising money and supporting Burning Nights CRPS Support.

We continued to provide information, emotional & psychological support and general advice not only to those affected by CRPS such as patients, family members and caregivers but also to members of the public, healthcare professionals and students, legal and financial professionals.

Our evidence-based website is central to our charity and our activities as well as our awareness and information products and publications not only to raise awareness of CRPS but they all also provide help and information to those living with CRPS, their families and carers as well as educating and raising awareness of the condition amongst the public, health and legal professionals. However, we identified that our website had started to fail in some areas. Our current website is on the WordPress platform, but it is at maximum capacity regarding plug-ins, slowing it down 30% compared to 2019.

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

It has outgrown our needs. Therefore, we started raising funds for a new website to be developed which would be more suitable to our needs. We contacted website developers in January 2021 to create a new site for the charity.

Patients find the blog articles that we produce extremely useful and helpful, and many print pages off the website to take to their doctors. We have an intention of improving the articles we write and to have more patient lived experiences.

The website and our awareness products such as our CRPS information leaflets for adults and young people, our guide to Dorsal Root Ganglion stimulation for CRPS as well as our folded information cards and bookmarks benefits not just the general public, but more importantly to those living with CRPS (i.e. the patients), their families and carers, healthcare, legal and financial professionals by providing information, advice and support as well as raising awareness of all the aspects of the condition.

Our downloadable information booklets & guides for both adults and young people have been very well received and indeed many people have preferred this option.

The guide booklet for Dorsal Root Ganglion (DRG) Stimulation as a treatment for CRPS that we received an educational grant for has also been very well received and indeed, there has been a 125% increase in downloads than the year before. Due to the Covid-19 Pandemic, we had to stop our local, regional CRPS support groups in Manchester and London. However, we moved these regional groups to online support groups. We held these every month throughout this financial year and at the start of the Pandemic, we held these online groups every couple of weeks. These have been extremely well received as we have had steady numbers in all our groups.

These online support groups have been of great benefit not only to those who have CRPS but also to their friends, family members, loved ones and caregivers who are equally affected by the condition only in a different way. They provide a safe and confidential space to 'virtually' meet and chat with other members who are affected in similar ways. These support groups are important for the health of CRPS patients, their loved ones and caregivers and provide a sense of security as well as reduce isolation and loneliness. All our online support groups are volunteer led. They provide a space for people to learn new skills, meet new people and talk about their experiences.

We are going to continue with the online support groups and to possibly look at restarting some regional groups around the U.K. such as London, once Covid-19 restrictions allow.

We also identified that there was a need for online support groups specifically for those aged 18 years and under, as well as one for the loved ones and caregivers. Although these groups could be joined together, we felt that their needs were different. In summer 2020, we started the Young Person online CRPS support groups for those aged 18 and under. In January 2021, we began the Loved Ones and Caregivers online support groups. Although these groups had lower attendance numbers, they have been helpful to those attending.

Due to the Covid-19 Pandemic and the large number of questions and support requests we were receiving about the risks to CRPS patients, we started our Live Chat service in July 2020. This was an easy way to deal with multiple queries asking the same or similar questions about Covid-19 and its effects on CRPS. We had longer opening times for the Live Chat, indeed we had it open 6 days a week and from 11am to 6pm every day except Saturday when it was open 12-4pm. We decided we are keeping on with the Live Chat service as it has been well supported by our community. We supported 323 individuals through this service during this financial year.

Due to the huge increase in suicide related calls and requests for support, as well as the number of people requesting mental health services, we realised that we needed to create a Virtual Befriending Service and an Online Counselling Service. We started these two new services in February and March 2021 after recruiting some volunteers. At first, we had a number of volunteers offering their time and skills who had been furloughed but gradually they began to return to their working lives once work from home slowed down.

After the initial announcement of the counselling service, we received an influx of patient referrals, which was not what we expected. However, we soon realised that we would need to quickly build a team of counsellors to cope with the number of people requesting counselling.

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

The counselling service offers up to 20 (twenty) hours of counselling and 4 (four) assessments with a qualified counsellor. We ask the patients to complete a before & after survey so we can monitor the impact of the counselling.

The virtual befriending service also received a high number of people wanting to access this service. People will receive 12 weekly calls or Zoom chats of up to 40 (forty) minutes each with one of our trained volunteers. During 2020-2021 we had just one (1) volunteer but we realised we needed to develop this service and train more volunteers.

We held 2 (two) webinars in 2020-2021, including Buteyko Breathing for chronic pain and Understanding and managing anxiety for chronic pain. It is with thanks to Janet Winter and Kate Thorpe for presenting these two webinars.

Our annual national CRPS conference had to be held online because of the Covid-19 Government restrictions. We held our one

(1) Day annual national CRPS conference during CRPS awareness month of November. It was kept free of charge as usual to those

Affected by CRPS including CRPS patients (sufferers), their families and caregivers. At this year's conference, we invited health professionals to speak who have an interest and knowledge in protecting the health of CRPS sufferers and their families and carers as well as providing information and support to those people. We also invited legal, financial and disability speakers who are involved with CRPS.

Our attendees were mainly people who live with CRPS, their families, friends and caregivers. However, we also had a small number of health and legal professionals who were interested to learn more about the condition and how it affects people and their families. Our conference really does help to raise awareness of CRPS especially those involved in the care of those living with CRPS. It also helps provide information and advice by trained professionals giving hope to many patients and families showing there is help out there.

CRPS patients and their loved ones do hugely benefit from this one-day annual conference. Not only do they learn about the condition and living with it, whether they have the condition or whether they care for someone with the condition. They find out what research is going on, the latest treatments available and what support there is.

Our telephone Helpline continued throughout 2020-2021. We still held its usual opening times during the working week i.e. Monday to Friday. For any calls out of hours, there is a voicemail available and we have the phone number of the Samaritans on our contact page on our website as well as on our voicemail. CRPS patients loved ones and caregivers are able to talk to someone who understands what they are going through.

CRPS patients as volunteers run our Helpline. It does benefit those living with the condition as they see it as a lifeline with many people being housebound, vulnerable and isolated. The helpline is also of benefit to those people who care for CRPS sufferers, their family members, friends and loved ones. It is a useful resource and tool used by many healthcare professionals and students including school nurses who see patients and schoolchildren with this condition.

The Helpline supports callers with information, signposting to other organisations, support and non-medical advice to anyone who contacts the helpline. It also helps CRPS sufferers with their self-confidence and self-esteem as they realise they are not on their own in their journey. We saw a large increase in calls of 156% in the first 6 months and during later Lockdowns due to the Coronavirus pandemic. We did become overstretched at points and we did expand our volunteering team to try to combat this huge increase.

Our Online Community Forum has been a great source of help to many. This Online Community forum helps to provide peer support, information and camaraderie. The forum can reduce loneliness and isolation. This is another way that the charity can signpost patients and their families to information about support services, treatment options and general information about the condition and living with it. CRPS patients, their families and carers can also gain support from other patients and their families from posting messages in the forum.

We also received an increase in comments and questions on social media. We have a number of volunteers dedicated to answering people's posts/comments and private messages. By being there, we aim to reduce the isolation of people with

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

CRPS, their families and friends with our online community activities such as on social media support and our online community forum on our website.

Anyone affected by CRPS, whether they are patients, families, caregivers can contact the charity on six (6) social media channels via direct private messaging to 'speak' to our volunteers for signposting, information and a listening ear. We also receive messages from the public, health professionals & student healthcare and law firms.

We have continued to increase our supporters across our social media channels where we have profiles. Those include Facebook, Twitter, Instagram, Pinterest, YouTube and LinkedIn.

We continue to provide the latest information about all aspects of CRPS and living with the condition across all 6 (six) of our social media profiles. Not only to provide information and awareness, but we find that being active and responding to comments and private messages reduces the isolation of CRPS sufferers, their loved ones, family members and carers.

We aim to carry on raising awareness of every side of the condition and provide support to anyone who comments or messages us. We also provided information about events that were occurring both from ourselves and from others, any new research or guidelines to continue to raise awareness of CRPS. We were in contact with a number of healthcare professionals regarding Covid and CRPS, and we kept people up to date about the Pandemic and how it could have an effect on CRPS patients.

Patients and families as well as health and legal professionals are able to post on our social media timelines and ask questions to gain support not only from the charity but also from other people who follow us. We also post patient questions for people as anonymous patient questions and then people can reply by making suggestions or helping to answer their problems.

Our Closed Facebook group for Parents & Caregivers of Young People with CRPS has been of great help to parents and guardians who have been able to find support, advice and information from other parents and carers in the same situations as them as well as finding support and signposting from the charity.

Sadly, because of the Pandemic all our exhibitions either were cancelled or were moved to virtual. We took part in the Naidex virtual disability exhibition which we used to raise awareness of CRPS and provide information and support to the general public and to those suffering from CRPS together with their families, loved ones, friends and carers as well as healthcare and legal professionals. Our aim of raising awareness of CRPS amongst the public and to those involved in caring for, treating and diagnosing those who may be suffering from CRPS is important so we can impart the latest information and research. The virtual exhibition also helped to create awareness for the charity so healthcare professionals know there are essential support services for CRPS patients and their loved ones.

We are aiming to increase the number of people who are aware of this chronic condition and better their understanding of the condition to ensure that in the future people showing signs of this condition are diagnosed sooner to enable treatment to start quicker. Virtual exhibitions are a great way to achieve this.

We also provided a number of CRPS, chronic pain and disability awareness and information sessions that gives information about the condition, diagnosis, prognosis and treatment not only for the public to help educate them about CRPS but also in particular to those healthcare professionals who are involved in treating, diagnosing and caring for those suffering from CRPS. We also provide these education sessions for healthcare professionals as well as student healthcare who need to be aware of this condition in case a patient comes to them and their department.

Education and awareness of CRPS is crucial to improved treatments and outcomes. We now need to work together with the NHS, other patient groups and organisations to address the topic of CRPS and how much it does have an effect on the society as a whole just like chronic pain.

We have held a number of meetings with several companies including medical device companies as well as health/medicine companies and law firms to try to raise the awareness of the condition for the protection and benefit of CRPS sufferers, their families and carers. Some of these meetings were very successful and in some cases we have secured future funding.

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

The charity was also involved in a couple of publications to raise awareness of CRPS and the charity. We believe it will be of benefit to those affected by CRPS as the more awareness we can get out to the public, legal and health professionals, the better it will be for CRPS sufferers, their families and carers.

As a charity we have taken part in assisting and supporting research into CRPS and chronic pain, its causes, treatment and one day a cure in different forms of research. This has included helping researchers find prospective participants.

We were heavily involved with Dr Holly Blake at Nottingham University to create a Pain At Work (PAW) Toolkit. This online digital toolkit was designed to provide supportive information, advice and guidance for people at work who have chronic or persistent pain. This was finally disseminated after this financial year. However it was completed during 2020-2021. Our Founder, Victoria, was listed as an author. (https://xerte.nottingham.ac.uk/play_24452)

These research projects will be useful to anyone living with CRPS and also anyone who is caring for someone with the condition. It will help bring more awareness and focus to the condition as well.

All of our involvement in research is to assist and support research into CRPS, its causes, treatment and cure and to ensure the useful results of such research are published. We always share the results of any research we have assisted in across our social media, our website and our online community forum.

We also continued to be involved with a medical device manufacturer, Abbott Medical, who have developed a treatment option for CRPS patients - neuromodulation.

We also continued to be involved with the charity's local Member of Parliament who continues to raise multiple questions about the condition in Parliament. This is ongoing and if we do manage to get everything that we are asking for from Parliament then this will be a huge benefit to CRPS patients.

Contribution made by volunteers

During 2020-2021, our volunteers spent 11,916 hours listening, talking to, answering questions and providing counselling to CRPS patients and their loved ones who reached out to the charity by email, phone and on our social media channels.

As a small charity, a great and invaluable contribution is made by volunteers. Without the amount of time, energy and knowledge of these volunteers the charity wouldn't have been able to grow as it has done and achieve so much.

We are very grateful for all of their skills that they bring to the charity.

A big THANK YOU to all our fantastic volunteers!

Main achievements of the charity

This year will be a period that none of us will forget. The Pandemic brought fear, worry, isolation and vulnerability to our community. In the early part of 2020, there was misunderstanding as well as a lack of information about the effects of Covid-19 on Complex Regional Pain Syndrome (CRPS). Although we consulted numerous consultants we struggled to find adequate answers for our community.

Eventually we were told by a senior consultant that having CRPS didn't mean that our patients would result in a serious form of Covid-19.

We continued to provide compassion and reassurance to our community, to try and help our community come together and to share knowledge.

SUPPORT FOR ALL AFFECTED BY CRPS

We continue to be there for people affected by Complex Regional Pain Syndrome (CRPS), whether they are patients, loved ones, families or caregivers. We provide direct support through the following services:

Online Support Groups

- Helpline
- Live Chat
- Social Media
- Email support
- Online Community Forum

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

As of the start of 2021, we also now provide support through two new services:

- Befriending Service
- Counselling Service.

It is with thanks to our amazing volunteers who run our support services that we continue to be there for even more people affected by CRPS every year. This year was no exception, and we have increased our support for those with the condition by launching 2 more online support groups, developed and started Live Chat support, as well as starting a virtual Befriending Service and a CRPS Counselling Service.

In our Impact Survey 2020-2021 we found that 67% of our supporters felt they had contacted the charity more than usual.

In the same Survey we found that 90.5% were either very satisfied or satisfied with their recent communication with us. 90.5% also said it was easy or very easy to access our support services for what they needed. Finally 86% said they would rate our support as Excellent and 86% would recommend Burning Nights CRPS Support to others.

During 2020-2021, we supported 1,057 individuals through our online support groups, webinars and annual conference.

Due to the isolation and loneliness the Government lockdowns due to the Pandemic, had left some of our community who had been shielding, we started and developed a virtual Befriending Service.

This service is a weekly call or Zoom chat for 45 minutes. Each client receives a total of 12 calls from one of our trained volunteers who are all CRPS patients themselves.

Befriending Service

Initially we had just one volunteer however we did a volunteer recruitment drive and in the next financial year we have 6 volunteers.

The volunteer took on one client to phone each week and she got a lot out of the weekly calls. The calls were a way for her to talk about her condition and her life to someone who understood what she was going through.

Counselling Service

As this service only started in March 2021 we only had 3 clients with just 1 counsellor. The counsellor provided a total of 6 hours of counselling up to the end of March 2021. However we had only advertised this service on one occasion and we had over 15 referrals from patients.

We will continue to develop this service with more counsellors to cover the ever increasing numbers of people needing mental health support who have been affected by CRPS.

CRPS Support Groups

Although our Regional support groups in Manchester and London had to be stopped due to the Covid Pandemic, we moved our main support group online.

At first we had just one main online group however we soon identified that the young people affected by CRPS needed a different group so they could talk amongst their peers about things that are more important to them such as schooling, college or relationships.

We also realised that there should also be a Loved Ones and Caregivers support group so they could discuss what was relevant to them such as how to care for someone with CRPS.

We held a total of 23 online support groups, run by our amazing volunteers who have CRPS themselves.

We will continue with our online support groups going forward and we are looking into having speakers in to offer professional support to our patients and their loved ones.

We supported over 850 individuals in our online support groups and on average we have a regular number of approximately 15-20 every month.

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

Email Support

We also provide regular support by email. CRPS patients (sufferers), their families, partners and carers all have the ability to contact the charity for support, advice and information by email or via the contact form on our website.

During 2020-2021 we supported 797 individuals through email.

We can deal with any number of different types of email from requests for treatment information, private specialists' details and information, signposting to other services as well as people wanting to have contact with other people who are in similar situations as them.

The support by email helps reduce the loneliness and isolation of patients, their relatives, families and carers. It also provides them with necessary and important support and knowledge. The feedback we have received from our patients and families has been extremely positive and is a valuable resource for information and advice.

Live Chat

In July 2020 we started the Live Chat support, because from our May 2020 website survey revealed 45% of our community had requested this type of service.

We developed this support service so that it was open Monday to Saturday from 11am to 6pm except for Saturday where it was from 12 noon to 4pm.

In 2020-2021 during the 8 months the Live Chat was live, we responded and supported 323 individuals.

The average chat time was 43 minutes.

Online community forum

The charity continued to maintain its Online Community Forum on our website to try and help reduce the isolation and vulnerability that CRPS sufferers and their loved ones feel once diagnosed with CRPS.

We have a small number of volunteers who help support and moderate the Online Community Forum.

We provided support on the online community forum which is available 24/7. We have approximately 1,850 participants overall. This is a safe place where patients or their families and partners can request support, ask questions and generally talk about their condition. Our volunteers who oversee the online community as moderators attempt to respond within 2-3 working days to ensure CRPS sufferers, their families and friends receive adequate support from the charity.

Social Media

The charity continues to have a good solid presence on six (6) social media platform profiles where we continue to provide the latest information, research, guidelines and support services for CRPS sufferers, their loved ones, family members, friends and carers. The charity supports everyone affected by CRPS by providing individual private responses of support via Private Message and also in the comments of posts.

We supported 1,357 people through social media private messaging during 2020-2021.

We consistently see an increase in our number of followers across all our platforms - Facebook, Twitter, Instagram, Pinterest, LinkedIn and YouTube. We receive feedback that many people and groups are beginning to recognise our charity as an organisation to support and as an organisation who can provide support, information and the latest research and guidelines.

By the end of March 2021, our social media community saw an increase of 8.2% compared to the previous year (47,971 2019-20) and we had 52,256 supporters across the social media channels.

Our closed online support group on Facebook for parents/guardians who have children and teens with CRPS continues to increase its members.

Helpline

We have continued to develop our Help, one to support CRPS patients, their families and caregivers. We still maintain our current hours of Monday - Friday 10am-4pm.

Burning Nights (CRPS) Support

Report of the Trustees Continued

For the year ended 31 March 2021

The helpline is manned by volunteers to the charity who are CRPS sufferers themselves. Our Helpline continues to be a vital resource and source of information and support not only to CRPS patients but also health and legal professionals who have questions about the condition or questions about our essential services.

We receive many testimonials from our service users.

During 2020-2021 we answered 732 calls to our Helpline. Many calls were received in the first part of the year due to the Pandemic, which at times overstretched our team of volunteers but we continued dealing with all enquiries with the help of more volunteers.

Due to the Pandemic and increased loneliness we had a 38% increase in suicide related calls which we dealt with but calls took longer.

We will continue to develop our Helpline to improve how we support those who contact us.

AWARENESS & CAMPAIGNING

CRPS awareness sessions

The charity provided a total of 5 CRPS awareness sessions during 2020-2021, providing over 8 hours of information.

We now are a regular speaker at Derby University for the first year OT students talking about CRPS and how life is affected by the condition. This year was held for the first time virtually, although we didn't get the same level of interaction, we did create a good discussion around CRPS and the different ways it can affect people.

Other talks were also online and included healthcare teams i.e. Podiatrists, Occupational Therapists and Physios.

We are going to consider offering online CRPS awareness sessions not only for healthcare and legal professionals but also for schools, colleges and universities.

Exhibitions

Our usual exhibitions for disability and primary care initially had been postponed in the early part of 2020 due to the Pandemic, with future dates given. However sadly those dates were pushed back and the disability exhibition eventually put on a virtual exhibition.

We did attend the virtual exhibition as exhibitors to raise awareness and provide information. Although this wasn't as well attended as a physical exhibition, we did get people 'visiting' our online booth and asking questions.

We want to continue exhibiting to raise awareness of CRPS because of its complexity and diverse range of signs and symptoms. If the public and healthcare are made aware of the condition it can provide a better understanding so patients can be diagnosed sooner.

Parliament and Campaigning

We continued working with our local MP to ask questions in the House of Commons about CRPS including mental health support.

We aim to continue working with our MP to carry on asking questions so we can provide answers to CRPS patients & their families.

INFORMATION

We provide information to our CRPS patients, their families and loved ones through our annual national conference, webinars, website and our literature & products.

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

Annual Conference 2020

Due to the Covid restrictions, our 2020 one (1) day 6th Annual National CRPS conference was moved online on Sunday 15th November 2020. We received an Educational Grant from Abbott Medical to support the conference, for which we are extremely grateful.

143 people were ticketed for the event and we had a 90% turnout on the day of the conference. Not only did we have CRPS patients and their families from the U.K., we also had attendees from around the world including USA, Canada, Europe, New Zealand and Australia.

We brought in 7 health and legal professional speakers as well as accessibility products who all had an interest and/or working knowledge of CRPS, chronic pain or disability and who provided those who attended with information and support.

We heard from a pain specialist giving information about the various treatments available including neuromodulation.

Our attendees were also pleased to hear from a benefits advisor who discussed all the possible benefits available to our attendees such as disability benefits as well as carers benefits.

Webinars

Due to the Pandemic and everything being run online, we decided to run a few webinars some of which were paid for and others were free. We held 2 webinars in 2020-2021, including Buteyko Breathing for chronic pain and Understanding and managing anxiety for chronic pain. It is with thanks to Janet Winter and Kate Thorpe for presenting these two webinars. Kate went on to present two (2) more webinars in the next financial year.

Website

We continued to improve and update the information about CRPS for sufferers, their loved ones, families, friends and carers through our website, the blogs and e-newsletter. We added more up to date research in various sections of the website and continued to make updates on the main parts of the website.

We had 244,967 unique visitors to the website which was an increase of 10.65%.

The website is of benefit to CRPS sufferers, their families, loved ones, friends and carers as well as informing the general public about the condition, the health professionals to ensure the condition is properly understood so patients can receive the correct treatment they require and legal professionals can find the information about the condition, current research and treatment options for their clients.

In our November 2020 Survey, 89% found the information on the website excellent or very good. This is one of the testimonials we received from a patient:

“I mentioned Burning Nights CRPS Support and your fantastic website and how informative it was to my specialist as when I was diagnosed. I wasn’t told anything about the condition. I told that her without your help and fantastic website I would never have known anything about CRPS. I would just like to say thank you personally to you for everything you and your website do to raise awareness of this awful condition”

- **Bex, CRPS patient**

Literature and Information Products

We have continued to update and create various booklets and literature to help provide information of all aspects of the condition to CRPS patients, their families and friends. These booklets are to try and help patients & families understand the condition in an easy but informative way.

The guide booklet for Dorsal Root Ganglion (DRG) Stimulation as a treatment for CRPS that we received an educational grant for, continues to be a popular leaflet to download and we have seen a 125% increase in downloads than the year before. We were also asked to provide our digital guide to the DRG to a neuromodulation healthcare group for them to disseminate.

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

These leaflets and other information literature provide information and support to everyone affected by CRPS whether they are patients, friends, family members or loved ones.

We still continue to distribute our CRPS information leaflets for adult and young people to various NHS hospitals and private clinics across the UK.

Media and Publications

The charity was invited to make comments on a couple of newspaper articles mainly concerning the updated NICE guidelines for chronic primary pain.

We also had 2 volunteers of the charity share their personal experiences and stories included in journals/magazines and newspapers. They also included links to the charity in them.

From these publications we received an influx of calls and emails from new CRPS patients and family members asking for help and support.

RESEARCH

We have taken part in assisting and supporting research into CRPS and chronic pain, its causes, treatment and cure in 10 different research studies from various Universities in the U.K. and Australia.

This has included helping researchers find prospective participants, by sharing their studies on our social media, in our e-newsletters, on our website and occasionally on our blog article section of the website.

Both Burning Nights CRPS Support and our Founder & Chair, Victoria were heavily involved with Dr Holly Blake at Nottingham University to create a Pain At Work (PAW) Toolkit.

This online digital toolkit was designed to provide supportive information, advice and guidance for people at work who have chronic or persistent pain. This was completed during 2020-2021. But wasn't disseminated or accepted on paper format until after this financial year. Our Founder & Chair, Victoria Abbott-Fleming MBE, was listed as an author. Here is the direct link: (https://xerte.nottingham.ac.uk/play_24452)

We also share the results of any research we have assisted in across our social media, our website and our online community forum.

OUR VOLUNTEERS

We had 44 fantastic volunteers delivering 10 services providing 11,916 hours of support to the charity. Thank You!

Training and Induction

Some of the trustees and volunteers completed webinar training and face to face training for fundraising, grant writing, governance and suicide awareness training.

We have ensured that all new volunteers go through a formal induction and training, and also dependent on their role, they receive training in safeguarding, mental health awareness, suicide awareness and suicide prevention.

OUR SUPPORTERS

Fundraising and donations

There were 21 fundraising events registered with us which included a number of people taking part in the 2.6 Challenge, Lands End to John O'Groats by bike, running, cycling, giving up chocolate, virtual events and even a hair & beard colour transformation.

Although we didn't receive a charity ballot place for the virtual London Marathon, we had someone run in the virtual London Marathon in their own place in aid of the charity.

We continued to receive donations from Facebook fundraisers which we've seen an amazing response to. People have been setting up fundraisers for their birthdays, anniversaries, Christmas etc in aid of Burning Nights CRPS Support.

Burning Nights (CRPS) Support
Report of the Trustees Continued
For the year ended 31 March 2021

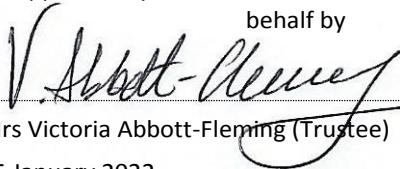
We still receive donations by text message both as a one off and also as a regular donation.

Corporate Donors

We have also continued to receive donations money from companies from their Dress Down Days, company walking days, Christmas Quiz and as the Charity of the Year.

We had some very productive and successful corporate donor meetings where we managed to secure funding and grants for projects and for the charity including from Abbott Medical.

Approved by the Board of Trustees and signed on its
behalf by

A handwritten signature in black ink, appearing to read 'V. Abbott-Fleming', is written over a horizontal dotted line.

Mrs Victoria Abbott-Fleming (Trustee)

25 January 2022

Burning Nights (CRPS) Support
Independent Examiners Report to the Trustees
For the year ended 31 March 2021

I report to the trustees on my examination of the accounts of the charity for the year ended 31 March 2021.

Responsibilities and basis of report

As the charity trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the 2011 Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Basis of independent examiner's report

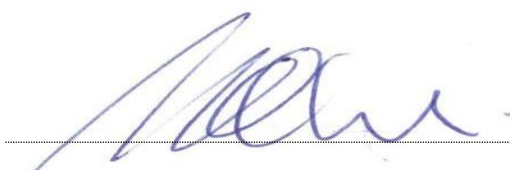
My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiners statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1) accounting records were not kept in respect of the Charity as required by section 130 of the 2011 Act; or
- 2) the accounts do not accord with those records; or
- 3) the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



ABS Accountancy Ltd
10 Fairfield Road
Buxton
Derbyshire
SK17 7DW

25 January 2022

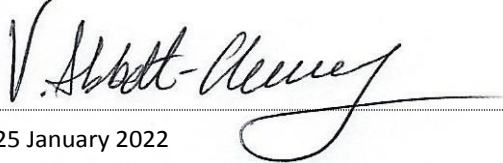
Burning Nights (CRPS) Support
Statement of Financial Activities
For the year ended 31 March 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 £	2020 £
Income and endowments from:					
Donations and legacies	2	42,116	6,510	48,626	52,922
Other trading activities	3	5,660	-	5,660	11,155
Total		47,776	6,510	54,286	64,077
Expenditure on:					
Raising funds	4/5	(882)	-	(882)	(11,617)
Charitable activities	6	(23,537)	(760)	(24,297)	(35,954)
Total		(24,419)	(760)	(25,179)	(47,571)
Net income		23,357	5,750	29,107	16,506
Reconciliation of funds					
Total funds brought forward		48,602	2,689	51,291	34,785
Total funds carried forward		71,959	8,439	80,398	51,291

Burning Nights (CRPS) Support
Statement of Financial Position
As at 31 March 2021

	Notes	2021 £	2020 £
Fixed assets			
Tangible assets	14	13,348	685
		13,348	685
Current assets			
Debtors	15	-	4,200
Cash at bank and in hand		67,110	46,404
		67,110	50,604
Creditors: amounts falling due within one year	16	(60)	2
Net current assets		67,050	50,606
Total assets less current liabilities		80,398	51,291
Net assets		80,398	51,291
 The funds of the charity			
Restricted income funds		8,439	2,639
Unrestricted income funds	17	71,959	48,602
Total Funds		80,398	51,291

The financial statements were approved and signed on its behalf by



25 January 2022

Burning Nights (CRPS) Support
Notes to the Financial Statements
For the year ended 31 March 2021

1. 1. Accounting Policies

Basis of accounting

The financial statements have been prepared under the historical cost convention, except for investments which are included at market value and the revaluation of certain fixed assets and in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), and the Charities Act 2011.

Burning Nights (CRPS) Support meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern.

Along with many Charities, the charity closed its online shop and moved all services online on 17th March 2020 because of COVID-19 restrictions. The vast majority of staff and volunteers managed a slightly reduced service working from home throughout all the lockdown periods. The Charity ran all the support services from their own homes.

In order to reduce outgoings, all non-essential costs etc. were deferred; however, additional steps were introduced in order to maintain the health, welfare and safety of all staff and volunteers, many of whom fall under the Clinical Vulnerable bracket; as well as that of our customers. As a result, all staff and volunteers dealing on a face to face basis now undergo regular Lateral Flow Tests (LFT).

At the time of approving the financial statements, the Treasurer has a reasonable expectation that the organisation has the adequate resources to continue in operational existence for the foreseeable future, even in the light of the impact COVID-19 has had on the charity. Thus the Treasurer will continue to adopt the going concern basis of accounting to prepare the financial statements.

Funds

Unrestricted funds consists of the general purposes fund and designated funds. Designated funds are funds established by the trustees from time to time for specific projects or purposes, are not in any way restricted and any surplus or deficit will be transferred to/from the general purposes fund when the designated fund is closed.

Restricted funds (income and endowments) are funds subject to specific restrictions imposed by donors or by the purpose of any appeal. The purpose and use of designated, restricted income and endowment funds is set out in the notes to the financial statements.

Donated goods, services and facilities

Income and endowments

Voluntary income including donations, gifts, legacies and grants that provide core funding or are of a general nature is recognised when the charity has entitlement to the income, it is probable that the income will be received and the amount can be measured with sufficient reliability.

Donations and legacies

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Burning Nights (CRPS) Support
Notes to the Financial Statements Continued
For the year ended 31 March 2021

Costs of generating funds

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees' meetings and reimbursed expenses.

Allocation and appointment of costs

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes.

Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that the charity will not be able to collect all amounts due according to the original terms of the receivables.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Burning Nights (CRPS) Support
Notes to the Financial Statements Continued
For the year ended 31 March 2021

Recognition and measurement

All financial assets and liabilities are initially measured at transaction price (including transaction costs), except for those financial assets classified as at fair value through profit or loss, which are initially measured at fair value (which is normally the transaction price excluding transaction costs), unless the arrangement constitutes a financing transaction. If an arrangement constitutes a financing transaction, the financial asset or financial liability is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Financial assets and liabilities are only offset in the statement of financial position when, and only when there exists a legally enforceable right to set off the recognised amounts and the charity intends either to settle on a net basis, or to realise the asset and settle the liability simultaneously.

Financial assets are derecognised when and only when a) the contractual rights to the cash flows from the financial asset expire or are settled, b) the charity transfers to another party substantially all of the risks and rewards of ownership of the financial asset, or c) the charity, despite having retained some, but not all, significant risks and rewards of ownership, has transferred control of the asset to another party.

Financial liabilities are derecognised only when the obligation specified in the contract is discharged, cancelled or expires.

2. Income from donations and legacies

	Unrestricted funds	Restricted funds	2021	2020
	£	£	£	£
Donations received	37,116	4,510	41,626	45,422
Grants received	-	2,000	2,000	-
Sponsorships received	5,000	-	5,000	7,500
	42,116	6,510	48,626	52,922

3. Income earned from other activities

Unrestricted funds	2021	2020
	£	£
Fund raising events	3,382	7,657
Shop income	2,278	3,498
	5,660	11,155

4. Expenditure on generating donations and legacies

Unrestricted funds	2021	2020
	£	£
Subscriptions	532	-
	532	-

5. Expenditure on other trading activities

Unrestricted funds	2021	2020
	£	£
Fund raising events	350	3,730
Support costs	-	7,887
	350	11,617

Burning Nights (CRPS) Support
Notes to the Financial Statements Continued
For the year ended 31 March 2021

6. Costs of charitable activities by fund type

	Unrestricted funds	Restricted funds	2021	2020
	£	£	£	£
Staff costs	6,579	-	6,579	2,958
Support costs	16,958	760	17,718	32,996
	23,537	760	24,297	35,954

7. Analysis of support costs

	2021	2020
	£	£
Management	961	15,434
IT	11,542	-
Governance	5,212	28,407
	17,718	43,841

8. Net income/(expenditure) for the year

This is stated after charging/(crediting):

	2021	2020
	£	£
Depreciation of owned fixed assets	137	59
	137	59

9. Staff costs and emoluments

Total staff costs for the year ended 31 March 2021 were:

	2021	2020
	£	£
Salaries & Wages	6,579	2,958
	6,579	2,958
	2021	2020
Support Staff	1	1
	1	1

10. Trustee remuneration and related party transactions

During the period, the charity made the following transactions with trustees:

£961.44 (2020: £3,221) of expenses were reimbursed to during the period.

No trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

No trustees have received any other benefits from the charity during the year.

Burning Nights (CRPS) Support
Notes to the Financial Statements Continued
For the year ended 31 March 2021

11. Comparative for the Statement of Financial Activities

Income and endowments from:	Unrestricted funds	Restricted funds	2020
	£	£	£
Donations & legacies	49,217	3,705	52,922
Other trading activities	11,115	-	11,115
Total	60,372	3,705	64,077
Expenditure on:			
Raising funds	(3,730)	-	(3,730)
Charitable activities	(34,063)	(1,891)	(35,954)
Total	(37,793)	(1,891)	(39,684)
Net income	22,579	1,814	24,393
Total funds brought forward	33,910	875	34,785
Total funds carried forward	56,489	2,689	59,178

12. Tangible fixed assets

Cost or Valuation	Computer Equipment
£	£
At 01 April 2020	744
Additions	12,800
At 31 March 2021	13,544
Depreciation	
At 01 April 2020	59
Additions	37
At 31 March 2021	196
Net book values	
At 31 March 2021	13,348
At 31 March 2020	685

13. Debtors

Amounts due within one year:	2021	2020
£	£	£
Other debtors	-	4,200
	-	4,200

Burning Nights (CRPS) Support
Notes to the Financial Statements Continued
For the year ended 31 March 2021

14. Creditors

	2021	2020
	£	£
Trade creditors	65	-
PAYE & social security	(5)	(2)
	<u>60</u>	<u>(2)</u>

15. Movement in funds

	Balance @ 01/04/2020	Incoming resources	Outgoing resources	Balance @ 31/03/2021
	£	£	£	£
<i>General</i>				
Restricted	2,689	6,510	(760)	8,439
Unrestricted	48,602	47,776	(24,419)	71,959
	<u>51,291</u>	<u>11,286</u>	<u>(25,179)</u>	<u>80,398</u>

16. Analysis of net assets between funds

	Tangible Fixed assets	Net current assets/(liabilities)	Net Assets
	£	£	£
Unrestricted funds			
<i>General</i>			
Unrestricted	13,348	67,050	80,398
Total	<u>13,348</u>	<u>67,050</u>	<u>80,398</u>

Previous Year

	Tangible Fixed assets	Net current assets/(liabilities)	Net Assets
	£	£	£
Unrestricted funds			
<i>General</i>			
Unrestricted	685	50,606	51,291
Total	<u>685</u>	<u>50,606</u>	<u>51,291</u>

Burning Nights (CRPS) Support
Detailed Statement of Financial Activities
For the year ended 31 March 2021

	2021	2020
	£	£
Donations and legacies		
Donations	12,060	11,419
Donations (Non-Gift Aid)	29,566	34,003
Grants Receivable	2,000	-
Sponsorships	5,000	7,500
	48,626	52,922
Other trading activities		
Fund Raising Events	3,382	7,657
Shop Income	2,278	3,498
	5,660	11,155
Total incoming resources	54,286	64,077
EXPENDITURE		
Raising donations and legacies		
Subscriptions	532	-
	532	-
Other trading activities		
Fund Raising Events Costs	(350)	(3,730)
	(350)	(3,730)
Charitable activities		
Staff Costs - Wages & Salaries	(6,579)	-
	(6,579)	-
SUPPORT COSTS		
Management		
Staff Costs - Wages & Salaries	-	(2,958)
Trustee - Expenses	(961)	(3,221)
Volunteer Expenses	-	(1,673)
Computer Software & Maintenance	-	(7,582)
	(961)	(15,434)
IT		
Computer Software & Maintenance	(11,545)	-
	(11,545)	-
Governance costs		
Conferencing Costs	-	(7,887)
Depreciation Of Owned Assets	(137)	(59)
Telephone & Fax Expenses	-	(183)
General Insurance	(274)	(263)
Postage & Stationary Expenses	(2,138)	(3,960)
Sundry Expenses	(327)	(2,030)
Advertising Expenses	(179)	(9,859)
Professional & Legal Fees	(35)	(1,017)
Printing Expenses	(1,659)	(2,800)
Bank Charges	(214)	-
PayPal fees	(249)	(349)
Total resources expended	(25,180)	(47,572)
Net Surplus	29,107	16,506