

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

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for the Year Ended 31 March 2024

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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.

Burning Nights CRPS Support

Report of the Trustees for the Year Ended 31 March 2024

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

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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.

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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.

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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.

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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.

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.

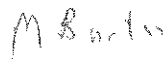
Having satisfied myself that the accounts of the Charity are not required to be audited under Section 144(2) of the Charities Act 2011 and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('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
	<hr/>	<hr/>	<hr/>
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)
	<hr/>	<hr/>	<hr/>
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
	<hr/>	<hr/>	<hr/>
	-	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>