

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
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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.

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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.

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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

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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.

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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

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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.

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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.

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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.

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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.

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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

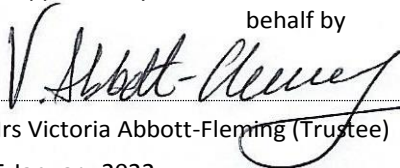
We still receive donations by text message both as a one off and also as a regular donation.

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

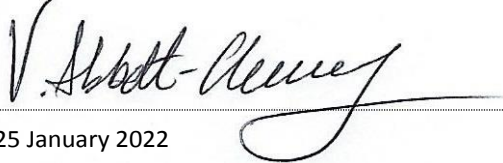
Burning Nights (CRPS) Support
Statement of Financial Activities
For the year ended 31 March 2021

	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