

# Fundraising Pack

Welcome to Burning Nights CRPS Support





## Dear Fundraiser,

Thank you for your amazing decision to fundraise in aid of Burning Nights CRPS Support and raise vital funds to support people touched by Complex Regional Pain Syndrome.

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

Through your amazing fundraising efforts, 15,000 patients a year will have somewhere to turn when they need help.

The following pages will give you tips and advice on how to make the most of your fundraising. But we'll also be on hand to support you from ideas, inspiration and know-how to social media posts, branding and a platform to shout about your achievements. We're here to help you achieve your goal!

If you have any questions or need any further support with your fundraising, please feel free to contact the charity's team on **01663 795055** or email us at **fundraise@burningnightscrps.org** Our website also has downloadable sponsorship forms, bunting and poster templates.

Best of luck and thank you for your wonderful support!



*V. Abbott-Fleming*

**Victoria Abbott-Fleming MBE,  
Founder and Chair of Trustees**





# Corben's Story

Corben Roberts, a Transport Planner based in Telford made the decision to fundraise for Burning Nights CRPS Support. As a dedicated runner he chose to run the Rock 'n' Roll Liverpool Marathon. His wife Amy, has been living with CRPS since 2019 and was the primary reason for his fundraising efforts for the charity.

Corben met Amy in 2010 and they married in 2019. Due to a rare disease called Synovial Chondromatosis, Amy underwent a total hip replacement. She was recovering well for approximately six months when it became evident that she had Complex Regional Pain Syndrome.

Before Amy's CRPS diagnosis, they were an active and adventurous couple, who loved hiking and travelling, and Corben says that hasn't changed completely: "Now we have to plan a bit more... but we still do a lot."

Similarly, Amy says that, "As a couple, we're quite determined not to let it get the better of us."

Corben spoke about how the lack of general awareness of CRPS by the medical profession added to the difficulties the couple faced on a daily basis.

Despite the numerous adjustments they've had to make to their life, Amy said that it came as a wonderful surprise to learn that Corben had decided to do a marathon to raise much-needed funds for Burning Nights CRPS Support.

The 'Rock n Roll' Liverpool Marathon took place on October 23rd 2021 and was in fact Corben's first full marathon, which was a special moment for him.

Part of his training for the marathon was by doing 'Red January,' which challenged participants to do one form of exercise every day which began in January and lasted throughout the year. Corben managed to keep going every day since the start of the year, which was just incredible.



Like so many events during the Pandemic, the marathon had been cancelled in May 2020. But the date change didn't deter Corben, but instead spurred him on to keep training hard and to keep on track with his training plan.

Both have found Burning Nights CRPS Support to be a fantastic resource. Amy has attended a virtual peer support group, and Corben follows the motivational social media posts put out by Burning Nights CRPS Support.

When his work schedule allows, Corben intends to join Burning Nights' carer's support network. They both joined the annual conference in November and both found it a great experience.



# Corben's Story

Amy says that "Reading other people's stories is a bit of an insight into how it is for other people living with it and how different it can be."

According to Corben, part of the motivation for doing the run comes from past experiences of having run half-marathons. He says that it was part of their goal as a couple this year to raise awareness about the condition that affects approximately 1 in 3,800 people around the UK.

Remarkably, Corben successfully raised £1,130 which smashed through his initial £500 target.

To help with his fundraising efforts, he posted pictures of his running activities every week on his social media platforms to show his progress so far, and included a link to his fundraising page. Corben also linked his Strava account to his JustGiving page which made it really easy to share his training progress.

To people considering fundraising for the charity, Corben says, "I don't think it matters how much you raise. I feel more committed, and that I need to share our story and tell people what is happening. For me and Amy, raising awareness is really important."

"If someone has cancer or Alzheimer's, everyone knows those conditions and a doctor can easily diagnose them, but with CRPS, you have to actually explain it to some medical people as well as family and friends."

They have also received support from Burning Nights CRPS Support on the best ways to fundraise, with tips on techniques that work to raise the maximum amount possible.

He said that completing the marathon was a life-long goal of his and in 2019 when he ran the Great North Run, his t-shirt stated "I run because Amy can't."

"Now I intend to run even further because Amy can do even less."

**Corben raised £1,130 including Gift Aid which smashed his target.**





# How Your Money Helps

## Your generous fundraising means a huge amount to us.

Complex Regional Pain Syndrome literally changes lives in an instant: physically, emotionally and financially. Burning Nights CRPS Support provides support to help CRPS patients, their families and friends. This includes information and advice, legal guidance through our dedicated legal panel, as well as key support services including counselling, befriending and peer support groups.

The money you raise helps support people to rebuild their lives following a diagnosis. Every penny and pound you raise really will make a world of difference. So, set your fundraising target high!



£30



£30 could run our peer support groups for one month, helping people connect with others so they feel less alone

£70



£70 could enable us to provide a free place at our annual national CRPS conference for a CRPS patient and their carer or loved one

£125



£125 could help pay for specialist training for our peer support volunteers; people who have experienced Complex Regional Pain Syndrome and provide emotional and practical support to others

£450



£450 could help us run our volunteer lead helpline for a full year—ensuring we are here to help those who need us most

£700



£700 could pay for a full course of 20 hours of counselling through our CRPS counselling service



# Golden Rules



## Pick and Choose Your Activity

Decide on your fundraising activity. Keep it simple but something you enjoy – take a look at our Fundraising A-Z page to give you some ideas or check out some of our fundraising events.

## Plan it

Whether it's big or small, you'll need to put some thought into planning your event. You can get in touch with us for fundraising materials that will help you plan and advertise your fundraising event.

## Shout about it!

Think about who you'll be asking for donations and how to share your fundraising. Tell everyone about your fundraising event and why you're doing it whether that's on social media, in your email signature or at your workplace or college. Contact your local newspaper/ radio Include key information such as details about your planned fundraising activity and target. Remember to send us any links or adverts that we can share on our social media pages.



## Take pride in your achievements!

Share your pics and tell everyone how you've done. You've done something amazing for people affected by CRPS. We simply can't thank you enough.

## Pay in your money

Time to collect your donations and add up your total. If you've used the charity's own website, JustGiving or Tiltify, your donations will already be with us. If you've collected them yourself then there are plenty of ways to bank the money.

## P.S. Don't forget to thank all your donors and supporters!



# Scarlet's Story

Scarlet was diagnosed with CRPS in 2019 aged just 9 years, and has recently been supported by Burning Nights CRPS Support.

Scarlet chose to fundraise for the charity because she wanted to raise awareness of her condition. She said: "CRPS is a painful and debilitating condition and there is not much awareness of it. It is important that people diagnosed with CRPS and their families can get help and information."

Scarlet made cards, jewellery, loom bands and hamma beads and sold them to her neighbours, at St Wilfrid's Primary School walking day as well as to friends and family. Scarlet's well earned efforts raised £1,200 which could pay for 4 new Befriender volunteers.

She said "I was so happy with how much I made and that people loved the items I was selling – people of all ages. I am glad the money raised will go to a charity that means a lot to me and help others who are suffering."

**Scarlet raised £1,200  
which could pay for 4 new  
Befriender volunteers**





# Fundraising Platforms and Gift Aid

## Online

Online fundraising is easy, safe and an effective way to reach a wide audience. Below are some online platforms for collecting donations.



### Burning Nights CRPS Support website

You can now set up your fundraiser on the charity's own website. Head over to the 'Fundraising' menu at [www.burningnightscrps.org](http://www.burningnightscrps.org) Choose 'Create Your Fundraising Page' and complete the online form. Once approved by our team, you will then be able to share your fundraising page with everyone.

### JustGiving



The best known platform in the UK is also one of the oldest. Its user-friendly interface and clear layout make it easy for you to share updates with your supporters and for them to see how close you are to your target.

Visit [www.justgiving.com/burningnightscrps](http://www.justgiving.com/burningnightscrps) and click 'Fundraise for us' to set up your page. You can also connect a Strava account with your page to share your training success or your progress.

### Tiltify



If you're a gamer or live streamer then you'll know all about this platform. It's ideal for raising funds while having fun! You can live stream any event and supporters can donate directly to your page, which will come directly to us! Visit [www.Tiltify.com](http://www.Tiltify.com) and click 'Get Started' then head over to the 'Sign up' page. Enter all your details and create your account. Search for Burning Nights CRPS Support and complete the rest of the onscreen details!

## Offline Donations



Remember that offline and in person fundraising is still an essential part of reaching your target even if you have an online page set up, and cash donations still make up a big part of that. You can add those extra donations to your online total! Please contact us for a sponsorship form so you can get the details of those who pledge to support you. This way Burning Nights CRPS Support can claim the Gift Aid and turn every £1 raised into £1.25!

### Gift Aid

Gift Aid allows charities like Burning Nights CRPS Support to claim 25p for every £1 that you donate. That's a whole 25% on top of what you raise! Make sure that when people donate, they complete the Gift Aid declaration on your sponsor form, JustGiving page or on the donation page of our website.

### Matched Giving

Many companies offer matched giving schemes that can double the amount of money you raise. Ask if your employer operates a scheme and if they will match what you raise. Remind them that it's tax efficient for them and that it benefits Burning Nights CRPS Support. If they are able to match your fundraising, remember to let us know so we can look out for their contribution.

*giftaid it*

Matched Giving

# Fundraising Ideas

## A-Z

Here are some ideas for fundraising in aid of Burning Nights CRPS Support

### A

Awareness Day  
Abseil

### B

Birthday Fundraiser  
Bingo

### C

Climb a Mountain  
Car Wash

### D

Dress Down Day  
Dog Walk

### E

eBay for Charity  
Easter Egg Hunt

### F

Fun Run  
Family Day

### G

Gaming/ Live Stream  
Give up alcohol

### H

Half Marathon  
Head shave

### I

Ironman Challenge

### J

Jumble Sale  
Jailbreak

### K

Karaoke Night  
Knit-a-thon

### L

Ladies Day  
Limbo dance

### M

Murder Mystery  
Marathon

### N

Name the Teddy  
Night walk  
Non-uniform day

### O

Online Auction  
Obstacle course

### P

Pub Quiz  
Pet Show  
Paintballing

### Q

Quiz Night  
Quiet time

### R

Raffle  
Raft Race  
Readathon

### S

Sky Diving  
Swearbox  
Street Party

### T

Talent Show  
Triathlon  
Three Peaks

### U

Upcycling  
Unwanted gifts

### V

Virtual London  
Marathon

### W

Walking Wig Party  
Word games

### X

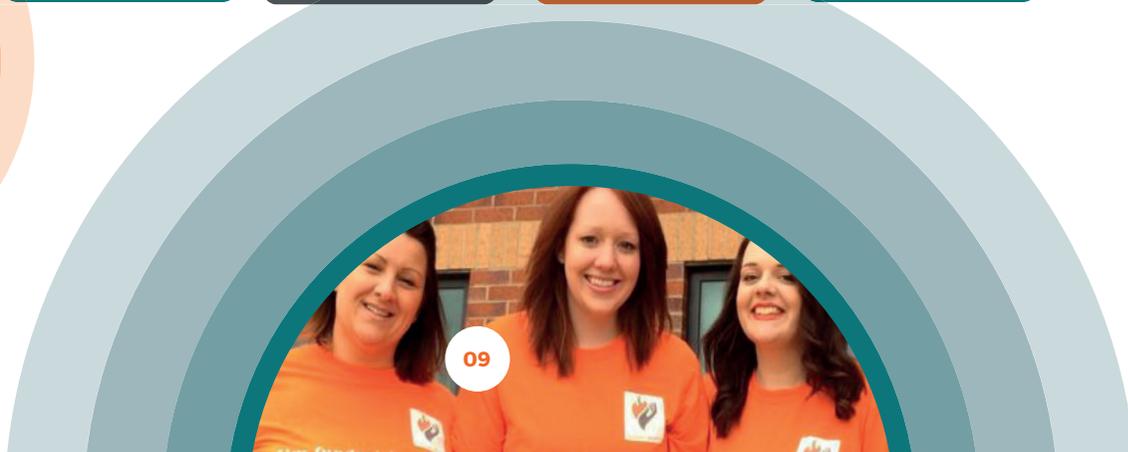
XFactor  
Xbox  
Tournament

### Y

Yoga Day  
Yes day

### Z

Zoom Social  
Event  
Zumbathon





# Keep it safe, keep it legal

**You're doing something fantastic and we want to make sure you stay safe and legal throughout your fundraising event.**

## Safety:

- Get sponsored by and collect donations from people you know and trust.
- Extra care must be taken if your fundraiser involves children. If children are photographed or appearing online in your initiative you must have prior permission from their parent or guardian.
- Ensure that children are supervised and don't let them collect money from strangers.
- If you are holding an event to raise money for Burning Nights CRPS Support, make sure your venue is safe and don't forget crowd control and social distancing.
- Be extra careful about security if you're carrying money around. It's safest to pay in any money you've raised straight away. If this is not possible then always use a locked cash box and keep it with you at all times. However, do not put yourself at risk to defend this money from thieves. Where possible have two people present when money is being counted.

## Legal issues:

- Please do not do house-to-house collections. People find them intrusive and they are illegal without a local authority licence.
- There are strict laws relating to all lotteries and raffles so please be sure that you are familiar with these and operate your auction or raffle accordingly. Note that children under the age of 16 are not allowed to purchase raffle tickets. If you are holding a raffle and your prizes are worth more than £500 you will need a licence from your local authority. Check the Gambling Commission website for details.
- Don't collect money in the street or any other public place without a licence from your local authority or the police. If you are doing something on private property you need to ask the permission from the owner (this includes collections at tube and railway stations and shopping centres).

- Burning Nights CRPS Support cannot accept any liability for your event or anyone who participates in it. Although we're here to help, we aren't responsible for your event and can't accept any liability. If your event involves the general public we advise you to seek advice regarding public liability insurance. There is a range of companies who can provide this. We also recommend that you check with your local authority whether you need any special licences.

## Other issues:

- Please refrain from requesting donations from large companies, other than your employers or small locally based businesses. We may have already requested donations from large companies. If you are unclear, please don't hesitate to give us a call to discuss it further.
- Burning Nights CRPS Support will do its best to provide the materials you need in your fundraising. This includes collection boxes and branded materials. However, you may have to pay a deposit if you need a lot for your event.
- If needed, please contact us for a letter of authorisation for your fundraising. We'll need the names of everyone involved in your fundraising efforts and a contact address.
- It's important that you're clear with your donors that you are fundraising in aid of Burning Nights CRPS Support, not a member of staff nor volunteer and that your activities are not representing or appearing to be organised by Burning Nights CRPS Support.
- If you wish to use a logo to support your fundraising initiative you can use our special 'in aid of Burning Nights CRPS Support' logo. When advertising your fundraiser, remember to include the words: Burning Nights CRPS Support is a registered charity in England & Wales, No. 1166522
- Any printed materials displaying the 'In aid of Burning Nights CRPS Support' logo need approval from the Charity before printing.

**If you need any help, please contact us at [fundraise@burningnightscrps.org](mailto:fundraise@burningnightscrps.org)**

# Paying in your funds

Let's start off by saying a big thank you! You've made a real difference for families facing life affected by Complex Regional Pain Syndrome. Now it's time to get that money to the people who need it.

## Online via our online form

Visit our website [www.burningnightscrps.org](http://www.burningnightscrps.org) and choose 'Donate' then click on 'One off donation'. Don't forget to include the details of your event.

## Bank Transfer

You can transfer your donations via the bank using the following details:

**Name:** Burning Nights CRPS Support  
**Account Type:** Charity/Business  
**Sort Code:** 60-04-18  
**Account No.:** 88213560

## JustGiving, Tiltify or our website

If you've been fundraising using JustGiving, Tiltify or our own website, your work is done! Any donations on your page (even ones made after your event) will be sent directly to us. No need to chase anyone.

## Cheques

These should be made payable to 'Burning Nights CRPS Support' and sent to:

**Burning Nights CRPS Support**  
**1 Alder Brook,**  
**Chinley, High Peak,**  
**Derbyshire SK23 6DN**

Please send the total proceeds of your event in one envelope and include details of your event, any completed sponsorship forms and/or collection boxes. **Please DO NOT send cash.**

**Don't forget** to also return any completed sponsorship forms and/or collection boxes within 10 working days of your event.



# Thanks to donations from people like you, we can help more people like Kerri-Ann

## KERRI-ANN'S STORY:

Kerri-Ann used to live for sport. She loved running and enjoyed high intensity training with her husband every day. She also used to climb Snowdon three times a year. But life as she knew it came to a grinding halt one day in 2018. As she was driving down a dual carriageway, another car slammed into hers head-on. She suffered whiplash, a back injury and muscle damage to her neck and back as well as excruciating pain that spread down her arm into her hand.

At first doctors said her arm was fractured and put it in a plaster cast. But after four weeks of unbearable pain, doctors said she had tendon and ligament problems instead. Kerri-Ann often had pins and needles followed by numbness in her hand, which then turned freezing cold. She was unable to move her wrist or hand and no medication or physiotherapy seemed to ease her agony. She couldn't hold a pen to write or cut her own food up at mealtimes.

Eventually a doctor told her she had complex regional pain syndrome (CRPS), adding that not much was known about the condition or how to treat it. That was devastating for Kerri-Ann, who had already been diagnosed with post-traumatic stress disorder (PTSD) and anxiety from the accident as well as depression due to the pain she was enduring. Her invisible illness made her feel alone and misunderstood at first.

"I felt quite isolated because when people look at you, they don't see there's an issue. Sadly, unless you've had to have an amputation, they don't see there's a problem so they think everything is fine and I have had to say to a lot of my friends: 'Can you please stop saying: when is your hand going to get better?' Because I might have to live with this. I've had this for years and my hand hasn't moved and I know they don't mean anything bad but I've had to educate my own friends and family about this because a lot of people just say: 'Oh it's a bit of pain – it will go in a couple of weeks.'"





## “We all kind of help each other”

Joining a monthly peer support group for people living with CRPS through Burning Nights CRPS Support proved a lifesaver for Kerri-Ann. She has learnt a lot about CRPS from others in the group who have been suffering from this debilitating condition for longer than her. “Just knowing that there are other people out there who have experienced the same feelings as her has been reassuring,” she says.

“They could resonate with how I felt my whole life was just going downhill. I was in a really, really dark place and to talk to other people who have this condition – and some people are a lot worse than me – was quite inspirational. My husband is absolutely amazing – he’s such a support and my 9-year-old daughter is amazing too but to talk to people who can understand the level of pain is very different,” she says. “It’s like another family and it makes you realise that, yes, you might have this awful painful, life-changing condition but actually you’re still a person, you’ve still got your families, you’ve still got a life and everyone is here to support you.”

While some of her friends and work colleagues don’t always realise what she is going through, her newfound friends in the support group do: “If I get upset they understand, if I can’t get my words out they know why and if you’re having a bad day they appreciate that – we all kind of help each other,” Kerri-Ann says. “As long as you’ve got good friends and family, you will get through your dark days.”

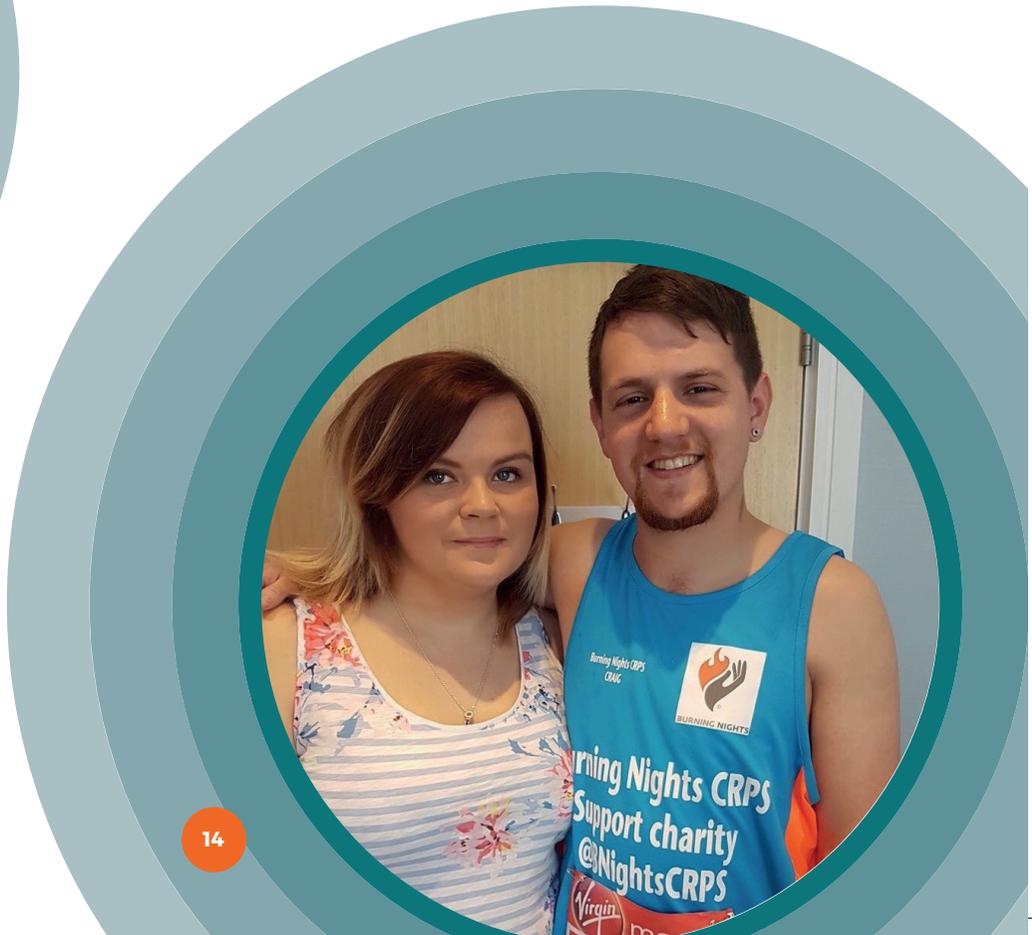


# FINAL THANK YOU

## You are truly amazing!

The fact that people like you are taking the time to fundraise means the world to Burning Nights CRPS Support and the many people affected by CRPS who turn to us for help. Together, we can all give people with CRPS, their families, caregivers and loved ones the hope and support they deserve.

**We are incredibly grateful.**





It would be great if you could follow us over on our socials!



**Facebook:**

Burning Nights CRPS Support



**Instagram:**

@burningnightscrps



**Twitter:**

@BNightsCRPS



**YouTube:**

Burning Nights CRPS Support



**Pinterest:**

/bncrps



**LinkedIn:**

Burning Nights CRPS Support



**TikTok:**

@burningnightscrps

# Contact us

Need more information?

We are here to help you every step of the way.

Visit our website: [www.burningnightscrps.org](http://www.burningnightscrps.org)

Email us: [fundraise@burningnightscrps.org](mailto:fundraise@burningnightscrps.org)

Call us: 01663 795055

Write to us: 1 Alder Brook, Chinley, High Peak, Derbyshire SK23 6DN

Burning Nights CRPS Support

Charity Reg No. 1166522 (E & W)



**BURNING NIGHTS**