



Role Description

CAMPAIGNING & LOBBYING VOLUNTEER

Organisation Description

Burning Nights CRPS Support is a UK charity working to improve life for all those affected by Complex Regional Pain Syndrome (CRPS).

We raise awareness about CRPS amongst the public, health and legal professionals by providing awareness sessions, so diagnoses can be made quicker and treatment started more rapidly. We also offer support and information through a number of volunteer-led services, including an evidence-based website, support helpline, online forum, email and social media support, annual conference and regional support groups. More recently, we have launched our CRPS Counselling & Therapy Service and Virtual Befriending Service, which have been met with an enthusiastic response.

Charity Reg No. 1166522 (England & Wales)

Location

Online / Remote volunteering, with the possibility of attending events across the UK. Where necessary, certain expenses will be paid by the Charity in accordance with our expenses policy.

Area of the Charity

Campaigning & Lobbying

Minimum Commitment

Minimum 3-4 hours per week. You are not under any contract to perform these tasks nor are you under any obligation to carry out this role. There are no set hours or days for this voluntary role. It is only as and when you are able to volunteer.

Your level of involvement is completely down to you and will depend on what campaigns are running at any one time. You will receive regular updates about what is happening, and how you can get involved, so that you can opt in or out of these activities. There will be opportunities to attend campaigning events with the charity and there may also be times when we will let you know about a specific action that is particularly relevant to your local constituency.

Minimum of 6 months commitment.

Burning Nights CRPS Support (Working to improve life for all those affected by Complex Regional Pain Syndrome (CRPS))

Registered Address: 1 Alder Brook, Chinley, High Peak, Derbyshire SK23 6DN

Tel: 01663 795055

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Web: www.burningnightscrps.org

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Main Purposes of the Role: Why do we need your help?

Campaigners play a vital role in representing the Charity in their local community and nationally, by lobbying on behalf of all people impacted by Complex Regional Pain Syndrome (CRPS). You will be able to use your personal experience and experiences of others impacted by CRPS to try to influence decision-makers to take a particular course of action, which will benefit the CRPS community as a whole. Campaigners act as a voice for the Charity by helping to shape our campaigns, sharing your story and lobbying for change.

As a campaigner, you'll bring your own ideas, local knowledge and personal experience to your campaigns. You'll make decisions about your own local campaign activities and help support national campaign initiatives.

As a Campaigning & Lobbying Volunteer, you will support the efforts of Burning Nights CRPS Support to raise awareness of CRPS and influence policy changes that improve the lives of those affected by the condition, as well as develop your networking and influencing skills along the way. You will engage with stakeholders, contribute to advocacy strategies, and help to shape our campaigns to ensure a stronger voice for the CRPS community.

Key Tasks and Objectives: What will I be doing?

Due to the nature of campaigning, there isn't a set pattern to activity, and sometimes it can be hard to predict when you will be called to action, because the political landscape can change quickly. Here are some ideas of the activities you could be involved in:

- Meet the MP in your constituency and building a relationship with them on behalf of other patients and caregivers to talk about our current campaigns, and keeping up a conversation with them.
- Set up and attend meetings with decision makers.
- Assist in developing and delivering campaign strategies to influence policy and public awareness of CRPS.
- Set up digital petitions, including using social media, to promote campaigns and encourage others to take part and support.
- Research and monitor relevant policies, legislation, and public health initiatives.
- Draft letters, petitions, and briefing documents for MPs, healthcare bodies, and policymakers.
- Use the Charity's insight to identify common or unfair problems that our community come to us for help with. This might involve analysing our data, analysing evidence forms, speaking with volunteers, and creating surveys.
- Engage with others impacted by CRPS, gathering community support for campaigning, this includes speaking with volunteers and staff to understand the problems how it affects clients, and what change would solve the problems, and present this back in a report.
- Engage with government representatives, healthcare professionals, and other key stakeholders.

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- Help to organise awareness of issues. This might involve creating material, such as newsletters, social media infographics or presentation or writing something for social media or newspaper, which could be used to explain the problems to others (such as local councillors or members of the public).
- Help to organise getting the organisation to engage in a solution, which may be an event, reports or meetings. This may include helping the Charity carry out research about how certain issues affect our clients, which might involve doing a survey with clients to find out how a change in benefit is affecting them.
- Acting as a patient representative on a hospital board or group.
- Support online and offline lobbying efforts, including social media advocacy and email campaigns.
- Help to organise and promote campaign events, petitions, and parliamentary meetings.
- Collaborate with people with lived experience to ensure their voices are central to our advocacy work.
- Assist in evaluating the impact of campaigns and identifying areas for improvement.
- Promoting Charity campaigns on social media.
- Create social media, articles or leaflets/flyers to raise awareness of the issues and to invite people to.
- Completing surveys or sharing your personal experiences on a given issue in order to support a campaign.
- Engaging the local press to raise awareness of a campaign or issue.
- Attending a training day, lobbying event or day of action.
- Sharing your experience with fellow campaigners after you have taken a particular action.
- Keep the trustees in the loop with responses you receive from political representatives or councillors.

The important thing about this role is that you can make it your own – we'll work with you to shape it. We want to make sure you have the opportunity to have your say on our campaigns, and that you're confident and happy with the activities you're taking part in.

Key Skills or Qualifications

- Strong communication skills – written and verbal, with the ability to tailor messages for different audiences.
- Passionate about the work of Burning Nights CRPS Support and contributing to its impact.
- To have had a personal experience of being affected by CRPS, whether you have had a CRPS diagnosis yourself, a family member or friend.
- Knowledge of or interest in policy, healthcare, and disability rights.

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- Willingness to learn and enthusiasm to interact with a variety of audiences, including politicians.
- Interest in public speaking and sharing your experiences.
- A personal, approachable and friendly manner.
- Be non-judgmental and politically impartial, respect views, values and cultures that are different to your own.
- Have good IT skills.
- Be willing to learn about and follow the aims, principles and policies, including confidentiality and data protection of Burning Nights CRPS Support.
- Be willing to undertake training in your role.
- Ability to research, analyse, and summarise policy documents and reports.
- Confident in engaging with policymakers and advocating for change.
- Organised, proactive, and able to work independently as well as part of a team.

Key Benefits

- Use your skills to contribute to achieving the aims of Burning Nights CRPS Support and become a valued part of our charity.
- The opportunity to take action, have a positive impact, and help bring about real, lasting change.
- The satisfaction of knowing that you are making a valuable contribution to the lives of those affected by CRPS.
- The chance to develop your communication, problem solving and public speaking skills.
- Gain valuable experience in campaigning and lobbying.
- Contribute to a supportive and rewarding work environment.
- Expand your professional network and enhance your career prospects.
- Learn about a range of issues and the impact on people impacted by CRPS.

Training and Support

- Full induction to our organisation.
- Relevant and ongoing training for your volunteer role and, after 3 months volunteering, all volunteers are eligible for additional courses (reasonable cost).
- Regular updates on Charity activities.
- Ongoing support, advice and guidance from the Volunteer Co-ordinator Team or Trustees, contactable by email, Slack message or phone call.

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- Peer support from fellow volunteers.
- You will receive information at the start of any national campaign or action, detailing ways to get involved.
- You will be provided with any equipment necessary to carry out your role.

How To Apply

If you think you could be the person we are looking for, we would love to hear from you. We invite anyone to apply for our volunteering opportunities, regardless of ability or experience.

Find current volunteer opportunities and apply for roles through recruitment platforms [Charity Job](#) and [Reach Volunteering](#). To find out more and register your interest, you can also fill out the [application form](#) on the Burning Night CRPS Support website or get in touch by phone or email.

Please note that you will be asked to submit a copy of your CV before interview and all volunteers are subject to two reference checks. All volunteer roles that involve interaction with vulnerable service users require an up-to-date DBS check, which the Charity will cover the cost of.

Contact information

Tel: 01663 795 055 (UK)

E: admin@burningnightscrps.org / victoria@burningnightscrps.org

W: www.burningnightscrps.org

A: 1 Alder Brook, Chinley, High Peak, Derbyshire SK23 6DN (UK)



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