

Join our board as a trustee: help us navigate a path to a sustainable future

Are you passionate about making a difference and equipped with the skills to guide a small charity through challenging times?

CMV Action are seeking proactive and committed trustees to join our board and support us in building a sustainable future.



About CMV Action

CMV Action is the only charity in the UK providing support and information to families affected by congenital cytomegalovirus (CMV). Congenital CMV is the most common viral infection that can affect babies before birth, with potential long-term health impacts such as hearing loss, developmental delays and vision loss. It can also cause miscarriage and stillbirth.

As many as 1 in 200 newborn babies are born with congenital CMV. The majority of these will not have any symptoms. However, around 1 in 1,000 born in the UK every year will have permanent disabilities as a result of congenital CMV – around 900 children every year. As congenital CMV is a relatively unknown condition, it is a common misconception that it is rare. It is in fact more common than Down's syndrome, Toxoplasmosis, Spina Bifida or Cystic Fibrosis.

Despite the prevalence and potential severity of congenital CMV, awareness and knowledge are alarmingly low among healthcare professionals, parents and the general public. One of our key roles, therefore, is to develop and deliver resources and training for healthcare professionals, run public awareness campaigns, and collaborate with researchers and policy makers to improve outcomes for those affected by congenital CMV.

CMV Action was registered as a charity in 2012 and became a CIO in 2018. It is the only UK charity offering advice and support to families affected by congenital CMV. It is run by trustees, a part-time consultant operations manager (0.6FTE), a part-time consultant fundraiser (0.4FTE), a part-time consultant book-keeper (0.1 FTE), a volunteer IT consultant, and a support team run by volunteers with lived experience.

We are a fully remote team, and the majority of our work takes place online with our beneficiaries and stakeholders in the UK. We run an online community support group for families on Facebook and 482 of our members are based in the UK. We also provide a telephone helpline and email support to families and healthcare professionals in the UK. We offer these services, using our network of medical advisers, who are all experts in the field of CMV, leading research and supporting the medical needs of families affected by the virus.

The charity relies heavily on community fundraising and donations, which has steadily reduced over the last four years. This decline can be attributed to a number of factors including the rising cost of living, economic uncertainty, and the lingering effects of the COVID-19 pandemic.

For any further information on CMV Action, visit www.cmvaction.org.uk

The role

We are seeking trustees who resonate with our core values and can bring their expertise to guide our charity through this critical time. As a trustee, you will:

- **Provide strategic guidance:** Help us make proactive, evidence-based decisions to stabilise our finances and develop a sustainable funding strategy.
- **Collaborate with key stakeholders:** Work closely with our board of trustees, contract team, volunteers and the community we serve to foster strong, impactful relationships.
- **Champion accountability:** Uphold our commitment to honesty, transparency, and integrity in all our actions and decisions.
- **Support inclusivity:** Ensure our work is accessible and equitable for everyone affected by congenital CMV, reflecting our commitment to inclusivity.

What we're looking for

We welcome application from everyone, and are particularly interested to hear from individuals who share our values and can bring the following skills and experience to our board:

- **Proactive and strategic thinkers:** You are purposeful about the directions you choose and willing to explore new paths to drive our charity towards self-chosen outcomes.
- **Experience in finances, fundraising, marketing or strategy planning:** Your expertise in charity finance, fundraising strategy, business development, or organisational change will help us build a sustainable future.
- **Collaborative leaders:** You excel in building strong relationships and working effectively with a diverse range of people and organisations.
- **Evidence-based decision-makers:** You value research and expert advice, using robust evidence to guide strategic decisions that achieve the best outcomes.
- **Committed to accountability and transparency:** You act with integrity, ensuring our charity operates openly and ethically.
- **Advocates for inclusivity:** You are dedicated to ensuring that our work is accessible and equitable for all, embracing the diverse needs of the community we serve.

Why join us?

- **Make a lasting impact:** Your guidance and expertise could be the key to securing our charity's future and ensuring we can continue to make a difference for those affected by congenital CMV.
- **Be part of a passionate team:** Join a collaborative group of trustees, volunteers and contractors who are committed to working together to overcome challenges.
- **Shape our future:** Play a pivotal role in steering our charity towards a sustainable future with purpose, accountability, and inclusivity.

What this role involves

- Attendance at quarterly meetings which will be held remotely during the evenings or at a convenient time for the group (meetings usually take place in December, March, June and September).
- Attendance at two in-person meetings (currently held on a Saturday in central London). Papers are circulated a week in advance and generally require two hours of advance reading.
- Working with fellow trustees in themed sub-groups where you can offer expert advice and guidance to drive the strategic vision of the charity forward.
- Commitment to be a trustee for a term of three years initially, with a view to review this at the end of the second year.

How to apply

If you are inspired by our mission and values and believe you can help us build a sustainable future, we would love to hear from you.

Not sure if this role is right for you? For an informal chat, please contact Sarah Dewar, Chair of Trustees, by emailing recruitment@cmvaction.org.uk

To apply, please submit your CV and a covering letter by 9:00 on Monday 4th November to recruitment@cmvaction.org.uk using the subject line 'Trustee Application'.

Together, we can turn challenges into opportunities and ensure a brighter future for those affected by congenital CMV.