

Join our board as chair of trustees: Lead us towards a sustainable future

Are you a visionary leader who is passionate about driving positive change? We are seeking an experienced and dynamic Chair of Trustees to lead our charity through a period of financial and strategic transformation.



This role is an opportunity to make a meaningful impact on the lives of those affected by congenital cytomegalovirus (CMV), ensuring our charity's continued success and sustainability.

About CMV Action

CMV Action is the only charity in the UK providing support and information to families affected by congenital 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

As Chair of Trustees, you will provide visionary leadership to our board, steering our charity towards a sustainable future. You will work closely with our trustees, staff, and stakeholders to ensure that our decisions align with our values and contribute to our long-term success.

Responsibilities:

- Set a proactive and purpose-driven agenda for the charity, guiding us in exploring new possibilities and adjusting paths towards our self-chosen outcomes.
- Build and nurture strong relationships with our board, staff, and community partners, fostering a collaborative culture that enhances our charity's impact.
- Ensure that the board and charity operate with the highest standards of transparency, honesty, and integrity in all actions and decisions.
- Guide the board to make informed decisions supported by robust research and expert insights, achieving the best possible outcomes.
- Lead the charity's commitment to equity, ensuring that all those affected by CMV, regardless of their needs, have fair access to the support and resources we offer.

What we're looking for

We are seeking a Chair who shares our core values and brings the following skills and experience:

- A track record of setting strategic goals, driving organisational growth, and steering organisations towards positive change.
- Strong interpersonal and communication skills, with the ability to inspire and motivate others, build partnerships, and foster a cohesive, united board.
- Experience in financial oversight, charity governance, or strategic planning, with the ability to provide direction and make informed decisions that support long-term sustainability.
- A reputation for integrity and transparency, with a commitment to ensuring that our charity's actions reflect our values and ethical standards.
- A deep commitment to promoting diversity, equity, and inclusion, ensuring our work remains accessible to everyone affected by CMV and reflective of their unique needs.

While prior experience on a charity board is an advantage, it's not essential. If you're committed to making a difference and ready to bring your unique skills to our team, we'd love to hear from you!

Why join us?

- Your leadership will be instrumental in helping us towards a secure future and expand our impact, ensuring we continue to serve those affected by CMV.
- Work alongside a dedicated group of trustees and team who are driven to make a difference and work collaboratively to achieve our mission.
- Play a pivotal role in shaping the direction of our charity, championing our values, and guiding us towards a sustainable, impactful future.

What this role involves

- Chair 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).
- Two of these quarterly meetings will be in-person (currently held on a Saturday in central London). Papers are circulated a week in advance and generally require two hours of advance reading.
- Chair monthly finance meetings with the treasurer, trustees and book-keeper, so you can help the charity drive the strategic vision 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.
- Meet with team members and represent the charity at events and meetings with key stakeholders.

To ensure a smooth transition, our current Chair of Trustees will offer ongoing support to the incoming Chair, for as long as needed. This continuity will provide valuable guidance and stability as we move forward together.

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 'Chair of Trustees Application'.

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