CMV Action

PROTECTING BABIES • EMPOWERING FAMILIES

CMV Connect Project

Our first year: what families told us and what we did

June 2025-May 2026

Thank you

CMV Connect has been running for just over a year. In that time, families from across the UK have joined our communities, attended sessions, shared their experiences and told us what they need. This short evlaution summary is our way of saying: we heard you, and here is what we found.

What we did this year

We set up four WhatsApp communities which now have over 107 families and individuals. We ran six online sessions - including peer drop-ins, an expert session and a wellbeing session. We mapped where families are across the UK. We worked with doctors and researchers to understand how to reach newly diagnosed families earlier. We also worked with families and ran a Family Advisory Panel. **And we listened, a lot.**

What we did (in numbers)

107+ families in our WhatsApp communities

21 families attended online sessions

33 families mapped across the UK - from Scotland to Northern Ireland to the South West

0 families knew of a local face-to-face cCMV group near them

41 support service contacts

Over 150 hours of volunteer time given to the project

4 families gave their time to the Family Advisory Panel

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Having people to talk to that understand.

It's gratitude mixed in with trauma - you're grateful but also heartbroken at the same time.

So reassuring and nice to know we're not in this alone - there is support out there

What you told us

We asked families how CMV Connect had made a difference. Eight families completed our End of Year survey. Here is what they said:

All said CMV Connect had made a big difference
8 out of 9 were very satisfied with the project overall
All 9 feel less isolated and part of a supportive community
All 9 feel more informed about cCMV and more confident talking to health professionals
8 out of 9 said their emotional wellbeing had improved
8 out of 9 had given support to other families - and received it back

We know not everyone fills in surveys, and that does not mean your experience matters less. We have heard from many more families through conversations, sessions and messages.

We have never, ever met anyone else with a child with CMV. Not a single person I've ever met knows what CMV is.

It has made the first year far less lonely and scary. The most difficult thing after diagnosis was feeling alone with the thoughts and fears. Speaking to other families who really 'get it' has been so amazing particularly when you are having a hard day.

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What we learned

We learned that what matters most is finding each other. Not big events or complicated programmes - just a space where you can say something and someone else says 'me too'.

We learned that you are carrying a lot. Appointments, EHCPs, equipment, professionals who have never heard of cCMV, and all of this while caring for your child and your family. We know filling in a form or attending a session is sometimes just one thing too many - and we want to make it easier.

We learned that many of you want to do more - to help other families, to raise awareness, to make sure the next family to get this diagnosis has an easier time than you did. Several of you already are: speaking at medical conferences, doing fundraising, sharing your stories in campaigns. We want to build a proper structure to support that.

We also learned that there is no face-to-face cCMV support anywhere near most of you. That needs to change. It is a Year 2 priority.

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What is coming next

We will be continuing everything that is working - the WhatsApp communities, the online sessions, the wellbeing offer and making sure families with lived experience are at the heart of our work and decisions, and we will be seeking funding to do more:

In-person meetups in areas where we know families are

A formal Ambassador programme for families who want to represent CMV Action

A warm handover pathway so that newly diagnosed families are connected to peer support from day one

Better ways of capturing your feedback that do not add to your load

A note on your voices

The quotes in this document are from real families. We have not changed what you said. We are grateful to everyone who shared their experience.

If you have thoughts on anything in this document, or want to be more involved in shaping CMV Connect, please get in touch with Debbie at CMV Action at debbierennie@cmvaction.org.uk