



Trustees' Annual Report and Financial Statements

For the year ended 31 January 2023

(Charitable Incorporated Organisation)

Registered charity number: 1171773

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Trustees' Report for the year ended 31 January 2023

Chair's Foreword

During 2022 we saw a gradual return to "business as usual" operations for CMV Action after the restrictions of Covid-19. Whilst we continued to carry out many of our governance meetings by Zoom for much of the year, a return to face-to-face opportunities later in the year was much appreciated for the all the working benefits they allow.

We attended and exhibited at two major health professional conferences during 2022. Firstly, the Primary Care Public Health Conference at the NEC in Birmingham in May, and latterly at the Royal College of Midwives Annual Conference in Newport, Wales in October. Both events afforded us opportunities to speak to and discuss CMV with a wide range of health professionals and we were delighted to receive feedback including one quote: *"I've just had a personal masterclass in CMV. Thank you! That is so useful."* Our new literature, and especially our new tear-off leaflet pad for midwives, was well received. Many copies of this new resource, which carries key messages about CMV, including a summary of the simple hygiene precautions that can reduce risk of infection, are intended for a midwife to hand to pregnant women at their booking appointment, were taken away to be used in midwifery practices and feedback for this, and our other information sources, was very positive.

We also produced a new leaflet "What Families and Childcare Providers Need to Know about CMV" to highlight the issues that women who have children who attend nurseries, and women who work closely with children in childcare settings should be aware of.

The highlight of last year was taking part in the International CMV conference CMV22 which took place in the UK in March. Unfortunately, this had to be held on-line but we were delighted to present at the Public Session which was very well attended by families and professionals.

During the year we have worked collaboratively with medical professionals involved in working with families affected by CMV. We were pleased to chair the CMV Session of the RCOG "An Update on Infections During Pregnancy" day and to deliver both on-line and face-to-face training sessions to teachers of the deaf and other professionals including the Scottish Sensory Service.

We were delighted to welcome three new Trustees – Alice, Graham and Lucy – to our Board. Each brings a range of different skills and experiences which will benefit CMV Action going forward.

In National Awareness Month, June 2022, we collaborated with our international colleagues in the US, Canada and New Zealand to raise awareness of CMV, and many of our supporters shared their family's CMV journey to take part in our on-line "CMV: Faces and Stories" campaign. We also had two articles published in midwifery journals Midwifery Matters and The British Journal of Midwifery.

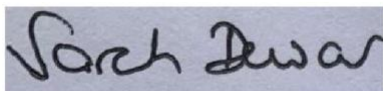
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As a charity we are so grateful to all our wonderful parents and supporters who raise money for us in all sorts of imaginative and sporting ways. Official events included the London Landmarks Half Marathon and the Great North Run. We have received a number of grants in 2022 including ones to translate resource materials into foreign languages as well as funds to support our conference attendance. We will continue to provide support and encouragement to all our current and future fundraisers, as well as looking for other sources of income to enable us to continue and expand our services going forward.

We continued to offer a high level of support to anyone affected by CMV, both by telephone, email or other avenues of support such as social media and a growing Facebook Support Group, giving people an opportunity to share experiences and stories.

We now look forward to 2023 with optimism and confidence, in good shape and firmly determined to continue to make a difference. Thank you to everyone who has supported us in 2022 With the help of professionals and families together we can bring about change.

Sarah Dewar
Chair,
CMV Action

A handwritten signature in black ink on a light blue background. The signature reads "Sarah Dewar" in a cursive, flowing script.

Sarah Dewar
Chair,
CMV Action
18 November 2023

CMV Action
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Introduction

The Trustees have pleasure in presenting their annual report on the activities of CMV Action ('the Charity') for the year ended 31 January 2023. This report sets out the activities for the year undertaken by the Trustees and the volunteers who have supported the Charity over the past year.

Our Trustees, Support Team and their advisers

The names of those individuals who served as Trustees of the Charity during the year and who were appointed subsequent to the year end is as follows:

Trustees

Sarah Dewar	Chair
Liz Estall	
Alice Fletcher-Etherington	Appointed 11 June 2022
Graham Jones	Appointed 11 June 2022
Lucy Kelly	Appointed 11 June 2022
Tom Kelman	Treasurer
Amy Taylor	
Angela Henry	
Suzie Mills	Resigned 12 November 2022

Support Team

Giles King	IT adviser
Sharon Wood	Project Manager

Medical advisers

Dr. Chrissie Jones	Associate Professor of Paediatric Infectious Diseases, Southampton University
Professor Asma Khalil	Professor of Obstetrics and Maternal Fetal Medicine at St George's Hospital, University of London

Other advisers

Banker	Lloyds Banking Group
Independent Examiner	Mohammed Afzaal Bhatti (FCCA) KBM UK Ltd
Legal Advisor	DLA Piper UK LLP

Our legal structure and governance

The Charity is an incorporated association which has been registered as a charity since 11 June 2012 with the Charity Commission for England and Wales. In February 2018 we became a CIO (Charitable Incorporated Organisation) under a relatively new legal structure available for charities or charitable groups that wish to be incorporated. The Charity is governed by a constitution for unincorporated associations as provided by the Charity Commission for England and Wales. The constitution sets out the objects of the Charity and how its activities are to be conducted and governed. A copy of the full constitution can be found on our website www.cmvaction.org.uk.

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The Trustees are all volunteers who undertake many of activities of the Charity, including offering support to pregnant women, parents and professionals. They are assisted by volunteers who have experience of CMV. The Trustees' carried out monthly meetings by Zoom. Our quarterly newsletter and website provide members with information on the current and the future activities the Trustees are undertaking to further the objects of the Charity. The Trustees welcome any questions or feedback from members and stakeholders at all times.

In appointing new Trustees, the existing Trustees undertake a proportionate recruitment process that identifies the skills needed for the role, advertise the role and interview candidates for the role prior to their selection.

Trustees undertake appropriate training to fulfil their role and to keep up to date with the law and regulations surrounding the governance and operation of the Charity. They pay particular attention to the clear guidance provided by the Charity Commission for England and Wales and endeavour to act in accordance with the 6 principles set out in the Good Governance – A Code for the Voluntary and Community Sector.

Our charitable objects

The three charitable objects of the Charity are as follows.

1. To promote and protect the physical and mental health of families affected by congenital CMV through the provision of support, education and practical advice.
2. To advance the education of the medical profession and the general public into congenital CMV and its implications for the family.
3. To promote research into the causes, effects, prevention, treatment and management of congenital CMV and to disseminate the useful results thereof.

What we did in the past year

We would highlight the following actions as being a reflection of our success in the past year in meeting our objectives.

Objective	What we set out to do	What we did	The impact it had	What we learnt along the way
1.To Support families affected by CMV	Appropriately support everyone seeking advice and assistance.	<p>We responded to requests for advice and information by telephone email and social media.</p> <p>We regularly sought advice from our medical experts in relation to medical issues raised in support requests to ensure a correct and consistent approach.</p> <p>Our Private Facebook Support Groups continued to grow and be a useful platform for members to share stories, advice and experiences.</p>	<p>Responses after support is given, as well as feedback on twitter, Facebook and the website demonstrated members deeply value this work.</p> <p>The group currently has 426 members.</p>	<p>Importance of volunteers having regular contact and support.</p> <p>We now respond to a higher level of enquiry requiring medical information as a result of better education of CMV.</p>

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2.To educate professionals, parents-to-be and the general public about prevention of CMV	<p>Continue strategy to change professional behaviour and to raise awareness</p>	<p>Participated in meetings with other professionals and contributed to training sessions for professionals.</p> <p>Multi-approach to engagement and education through channels available during restrictions and beyond.</p> <p>Launched a range of redesigned and updated key literature.</p> <p>Translations of our key infographic into non-English languages commenced.</p> <p>Enjoyed a return to face-to-face exhibiting and health professional conference participation.</p>	<p>Raised awareness through multi-channel opportunities, nationally and internationally.</p>	<p>The charity can use the experience of the families we support to help educate professionals on the need for awareness and change.</p> <p>Building credibility with key influencers and professional bodies is critical to changing health professional behaviour.</p>
3.To support the development and implementation of research into better testing, treatment and management of CMV	<p>Progressed number of research priorities.</p>	<p>Continued to support the delivery of a major piece of research funded by the National Institute for Health Research to test the feasibility and impact of an antenatal education intervention in the UK (GAP-UK).</p> <p>Provided PPI assistance to a number of research projects and clinical trials.</p>	<p>These projects will provide important evidence in the UK for further research and lobbying.</p>	<p>Patient and public involvement is an important aspect of research bids and CMV Action's support can make a significant contribution to bids.</p>
4.To build the capacity of CMV Action	<p>Improve our financial position and build capacity to deliver our objectives</p>	<p>Continued with our commitment to professional project management and fundraising.</p> <p>Welcomed three new Trustees to widen skills and experience on the Board.</p> <p>Continued to develop Trustee skills and experience.</p>	<p>Enabled CMV Action to take forward educational, research and fundraising activities that were not feasible working through volunteers alone.</p> <p>To ensure a sustainable, forward-thinking organisation.</p>	<p>The organisation needs dedicated staff to achieve our objectives.</p>

Impact of support activities

We have six regular support volunteers who are available to answer calls and emails of whom five are current or past trustees and one is a medical professional. All support volunteers have personal experience relating to CMV and have been involved with the charity for some time.

We operate a triage system. Support requests are received by an experienced trustee who will either offer support themselves or refers their query on to a trustee or volunteer depending on their experience and availability. We can also refer families to parents and grandparents who have been supported by CMV Action and have appropriate personal experience. We have two medical advisors, Dr C Jones and Professor Asma Khalil, who we can contact to assist with particularly complex medical enquiries.

In the year 1 February 2022 to 31 January 2023, we supported over 250 families via telephone, email, Facebook, and social media channels such as Twitter and Instagram. This included 92 telephone calls and 77 emails as the first point of contact. Support volunteers will offer support for as long as required so may be involved with an expecting couple or a family for a long period.

We had over 21,000 visitors to our website pages and responded to numerous requests for our literature. All items are downloadable from our website and our key infographic is available in 6 non-English languages. CMV Action has over 650 members and 1,300 subscribers who regularly receive updates and information on CMV. We also have a Facebook group CMV Action UK-family support which currently has over 400 members. This gives families the opportunity to request advice and support each other.

To comply with GDPR we only kept the details of those who consented to their data being retained. Other information is held in an anonymised support log. Details of families we support are never passed to a third party without their permission.

Support volunteers regularly report that the type of support request is gradually changing, and more people who contact us have had a diagnosis of CMV during pregnancy or are aware of CMV and want to learn how to minimise their risks. We regularly support those who have lost their baby. There is now the possibility of treatment during pregnancy in appropriate cases as well as treatment for new born babies. This has resulted in regular communication with our medical advisers to ensure we were giving the most up to date information in line with recent medical research.

Support volunteers work from home using their own computers and phones. Contact with other volunteers is important and support volunteers engage with each other regularly. We discuss what support to give and any concerns our volunteers have. At support meetings we discuss recent challenging or difficult cases and best practise on how to answer the issues raised.

We regularly receive positive feedback on the support we give from both those we support but also from medical professionals.

Impact of awareness and education activities

We were delighted to return to some of our customary face-to-face awareness and education activities with health professionals as the Covid restrictions began to lift during 2022. In May we exhibited at the Primary Care Public Health Conference at NEC Birmingham and in October we returned to the RCM Annual Conference in Newport.

Both events afforded us opportunities to speak to and discuss CMV with a wide range of health professionals and to distribute our newly launched literature. Our new tear-off leaflet pad for midwives was particularly well received. A tear-off page provides a summary of CMV and the simple hygiene precautions that can reduce risk of infection and is intended for a midwife to hand to pregnant women at their booking appointment, as a result of hearing from midwives that a barrier to discussing CMV is often simply pressure of time. Many copies of this new resource were taken away to be used in midwifery practices and many more have been ordered since as a result of several CMV articles we had published in midwifery journals.

We were pleased to take part in the CMV Session of the RCOG "An Update on Infections During Pregnancy" day and to deliver both on-line and face-to-face training sessions to teachers of the deaf and other professionals during the year.

Work commenced on translating our literature and resources to reach those where language is a barrier. We added a facility to our website, our key platform for professionals and members of the public alike, to translate content into almost any language in the world. We translated our key infographic into six of the most commonly used non-English languages in the UK – Polish, Romanian, Panjabi, Urdu, Arabic and Bengali – and these are available as downloads in the resource section of our website.

We built on our collaboration with other charities and like-minded organisations through membership of the Pregnancy and Babies Charities Network and the All-Party Parliamentary Group on Baby Loss. We also collaborated with international partners in relation to activities for June's National Awareness Month.

Our Facebook messages reached around 100,000 people which was down on the previous year due to the previous year having a very strong presence around the campaign for screening. We also placed more paid for posts in the previous year. Followers have increased by 3% to 4358. Visits to our Facebook page increased by 81% and likes of the page increased by 100%. The best performing post reached over 15,000 people driving nearly 360 people to visit the website.

Instagram followers increased to 692 (up from 492) and the best performing post reached over 10,000 accounts. Twitter remains consistent with 3361 followers and an average reach per week of 3,000 people.

Our Private Facebook Support Group continues to grow with over 400 now taking part in discussions and sharing experiences.

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Impact of research activities

This year CMV Action continued to support the delivery of a major piece of research funded by the National Institute for Health Research (NIHR) to test the feasibility and impact of an antenatal education intervention in the UK. The RACE-FIT – Reducing Acquisition of CMV through Antenatal Education/CMV GAP).

We were also consulted and partnered, as the patient representative organisation for cCMV, on a number of research applications.

Fundraising Summary

The total funds raised from February 2022 to January 2023 was £42k.

Official events included the London Landmarks Half Marathon and the Great North Run. Due to difficulties filling all places at events we decided not to commit to places in future and have instead sourced places via an agreement with Run for Charity. This gives us access to over 350 fundraising events without committing to places which we cannot fill.

We had 17 people taking part in other events and fundraisers which was up on the 13 people from the year before. However, at around £11.5k the funds raised were slightly lower than the year before. There is no doubt that the post covid environment plus the cost-of-living crisis is having an impact on the willingness of people to both raise money and to donate.

We have successfully received several grants in 2022/23 including ones to translate all our materials into foreign languages as well as funds to support our conference attendance. In all over £14,390 was received.

Our Fundraisers

Apart from the time given freely by the Trustees and the volunteers who assist us on our support line, the Charity relies heavily on donations from individual members of the public and on monies raised from fundraising events to finance its activities. During the past year we are indebted to those who have given us money and their time to help organise and participate in events that have raised funds. We therefore thank everyone for their continued support without which we would be unable to pursue our objectives.

Financial Commentary

The Charity saw its net assets decrease by £14,082 from £144,189 to £130,107 and this was due to a reduced level of donations and income from fundraising events bolstered by the receipt of three grants amounting in a combined income total to £42,433 whilst our expenses amounted in total to £56,515.

The Trustees are fully aware that they have a responsibility to apply these reserves to further the objects of the Charity and so have agreed a strategy for the coming three years ended 31 January 2026 for this purpose. This will see the Trustees continue to apply some of the reserves to further the Charity's objects whilst also continuing to retain reserves to mitigate risk and to fund innovation and future developments.

The Trustees have yet to consider and document a formal reserves policy.

The Trustees have yet to consider and document a formal investment policy but have sought security and liquidity in preference over yield given the low level of reserves currently held by the Charity and the low level of reward offered by deposit takers.

The Trustees have identified the main risks the Charity faces, and these are the reliance on donations and fundraising with no regular annuity, and the reputational risk that could arise from giving bad advice to members or issuing incorrect educational material on CMV. The Trustees' have controls in place to manage and mitigate these risks.

The Trustees have considered the going concern status of the charity in light of the pandemic and have no reason to believe that the charity will be unable to meet its debts and conduct its activities for the foreseeable future beyond the twelve months from the date of signing this annual report.

Tom Kelman

A handwritten signature in black ink that reads "Thomas Kelman". The signature is written in a cursive style with a large 'T' and 'K'.

**Honorary Treasurer
18 November 2023**

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Year ended 31 January 2023

CMV Action
Statement of Financial Activities
For the year ended 31 January 2023

	Notes	2023			2022		
		£	£	£	£	£	£
		Restricted	Unrestricted	Total	Restricted	Unrestricted	Total
Incoming resources	1						
<i>Incoming resources from generated funds</i>							
Fundraising events, donations, grants		14,390	27,531	41,921	2,622	44,921	47,543
Merchandise sales		-	-	-	-	137	137
Bank interest		-	511	511	-	42	42
Total incoming resources		14,390	28,043	42,433	2,622	45,100	47,722
Resources expended	2						
<i>Costs of generating funds</i>							
Fundraising events & Donations		-	(1,420)	(1,420)	-	(1,352)	(1,352)
Fundraising trading: costs of goods sold		-	-	-	-	(212)	(212)
Total costs of generating funds		-	(1,420)	(1,420)	-	(1,564)	(1,564)
<i>Charitable activities</i>							
Project management costs		(5,000)	(23,779)	(28,779)	-	(23,634)	(23,634)
Community fundraiser costs		(2,500)	(10,044)	(12,544)	-	(8,283)	(8,283)
Other direct costs		(6,890)	(4,914)	(11,804)	(2,622)	(4,475)	(7,097)
Total charitable activities costs		(14,390)	(38,737)	(53,127)	(2,622)	(36,392)	(39,014)
<i>Governance costs</i>							
Trustees' expenses	3	-	-	-	-	-	-
Depreciation of fixed assets		-	(1,968)	(1,968)	-	(377)	(377)
Total governance costs		-	(1,968)	(1,968)	-	(377)	(377)
Total resources expended		(14,390)	(42,125)	(56,515)	(2,622)	(38,333)	(40,955)
Net movement in funds		-	(14,082)	(14,082)	-	6,767	6,767
Total funds brought forward		-	144,189	144,189	-	137,422	137,422
Total funds carried forward			130,107	130,107	-	144,189	144,189

All of the above results are derived from continuing activities.

There were no other recognised gains or losses other than those stated above.

The notes on page 13 to 14 form part of these financial statements.

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**CMV Action
Statement of Financial Position
As at 31 January 2023**

	Notes	2023 £	2022 £
Fixed Assets	4		
Tangible Fixed Assets		1,119	532
Intangible Fixed Assets		2,872	2,200
Total Fixed Assets		3,991	2,732
Current assets:			
Debtors - prepayments	5	-	709
Cash at bank and in hand		128,220	141,588
Total current assets		128,220	142,297
Liabilities:			
Creditors: Amounts falling due within one year - accruals	6	(2,103)	(840)
Net Current Assets		126,117	141,457
Net assets		130,107	144,189
The funds of the charity:			
Total unrestricted funds		130,107	144,189
Total restricted funds		-	-
Total unrestricted funds		130,107	144,189

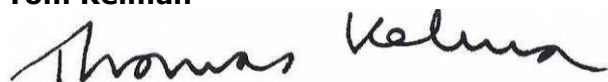
**Statement of Cash Flows
For the year ended 31 January 2023**

	2023 £	2022 £
Reconciliation of changes in resources to net cash inflow from operating activities		
Net incoming/(outgoing) resources	(14,082)	6,767
Purchase of Tangible and Intangible Fixed Assets	(3,227)	(3,109)
Depreciation of Fixed Assets	1,967	377
Decrease / (Increase) in debtors	710	(709)
(Decrease) / Increase in creditors	1,263	(1,307)
Net cash (outflow)/inflow from operating activities	(13,369)	2,019
Net funds at 1 February	141,588	139,569
Net funds at 31 January	128,220	141,588

The notes on page 13 to 14 form part of these financial statements.

The financial statements were approved and authorised for issue by the Trustees and signed on their behalf by:

Tom Kelman



**Honorary Treasurer
18 November 2023**

**CMV Action
Notes to the financial statements**

1. Statement of accounting compliance Convention

The financial statements are prepared in accordance with applicable accounting standards in the United Kingdom and under the historical cost convention and comply with the current Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) and the Charities SORP (FRS 102) and the Charities Act 2011.

2. Statement of accounting policies

Going concern

There are no material uncertainties about the charity's ability to continue undertaking its activities in the coming twelve months from the date on which the financial statements were approved by the Trustees.

Recognition of income

Income attributable to the financial year is recognised as follows:

- Fundraising activities – where possible the income arising from fundraising activities is recognised at the time of the event, if this is not possible to determine then the income is recognised when it is physically received by the Charity as cleared funds.
- Donations – the income arising from donations is recognised when it is physically received by the Charity as cleared funds.
- Merchandise sales – the income arising from merchandise sales is recognised when it is physically received by the Charity as cleared funds.

Resources expended

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. A further analysis of the expenditure on Trustees' expenses is given in note 3. below.

Tangible and Intangible fixed assets and depreciation and amortisation

Tangible and Intangible fixed assets with a cost more than £500 are capitalised at cost. Depreciation and amortisation of fixed assets is charged at rates estimated to write off their costs or valuation (less any residual value) over their estimated useful lives commencing in the month of acquisition and over three years using straight-line rates of depreciation and amortisation.

3. Trustees' expenses

As a result of the Trustees not travelling to meet each other and conducting their meeting over Zoom over the two-year impacted by Covid there were no Trustees expenses incurred in either year.

CMV Action
Notes to the financial statements (continued)

4. Fixed Assets – Tangible and Intangible

	Tangible £	Intangible £	Total £
Cost			
At 1 February 2022	709	2,400	3,109
Additions	1,019	2,208	3,227
At 31 January 2023	1,728	4,608	6,336
Depreciation			
At 1 February 2022	177	200	377
Charge in year	432	1,535	1,967
At 31 January 2023,	609	1,735	2,345
Net book value as at 31 January 2023	1,119	2,873	3991
Net book value as at 31 January 2022	532	2,200	2,732

5. Debtors – prepayments and accrued income

	2023 £	2022 £
Prepaid exhibition fees	-	709

6. Creditors: Amounts falling due within one year – accruals

	2023 £	2022 £
Project Manager's fees and expenses	888	-
Community Fundraiser Fees	1,215	840
Total accruals	2,103	840

**Independent Examiner's report to the Trustees' of CMV Action Charity
No.1171773**

I report to the trustees on my examination of the financial statements of the above charity for the year ended **31 January 2023**.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Charity's financial statements carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

1. accounting records were kept in respect of the charity as required by section 130 of the Act; or
2. the financial statements do accord with those records; or
3. the financial statements do comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



20/11/2023.

Mohammed Afzaal Bhatti FCCA
Independent Examiner

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