



(Charitable Incorporated Organisation)

# Trustees' Annual Report and Financial Statements

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For the year ended 31 January 2020

**CMV Action  
Trustees' Annual Report and Financial Statements  
For the year ended 31 January 2020**

<b>Contents</b>	<b>Page</b>
Chair's Foreword	1-2
Trustees' Annual Report	3-8
- Our Trustees and their advisers	
- Our legal structure and governance	
- Our objectives	
- What we did in the past year	
- Some facts and figures	
- Our fundraisers	
- Financial review	
Financial statements	9-10
- Statement of Financial Activities	9
- Balance sheet	10
- Statement of cash flows	10
Notes to the financial statements	11
Independent Examiner's Report	12

**CMV Action  
Trustees' Annual Report  
For the year ended 31 January 2020**

**Chair's Foreword**

2019-20 was a very exciting year for CMV Action. Following on from the launch of our report "Counting the Cost of CMV", the first complete picture of the economic effects of cytomegalovirus (CMV) in the UK, we were delighted to attend our first ever international conference - the 7<sup>th</sup> International CMV Conference in Alabama, USA in April 2019. We were invited to present and share our research with the audience of worldwide delegates, and the conference afforded us a great opportunity to build international relationships with medics, research and parent-representative organisations alike.

As a respected CMV parent-representative organisation we were pleased to be invited to give evidence at a Public Health England meeting on Residual New-born Bloodspots and CMV Testing. We also became a member of the congenital CMV UK Advisory Board and of the All-Party Parliamentary Group on Baby Loss at Westminster.

Our strategy for engaging more professionals working in antenatal care and the care of children affected by CMV continued with the publication of a number of journal articles, and through midwifery education online portals and face to face events. We also collaborated with hospitals, universities, Royal Colleges and audiology providers in the delivery of presentations, workshops and training sessions. In November 2019, we launched a popular series of CMV webinars for professionals and anyone with an interest in finding out more about CMV. As a result, we have engaged thousands of professionals working in antenatal care, increasing awareness of risks and CMV management guidelines.

Over the year we have seen increasing enquiries about CMV diagnosis in pregnancy. Awareness seems to be growing but many women struggle to get accurate, evidence-based information. We are delighted to continue to be a partner in the RACEFIT project (Reducing Acquisition of CMV through antenatal Education) which is being led by doctors at St. Georges University of London together with experts from Kingston University, University College London and Cambridge University, to assess an educational intervention to reduce the risk of catching CMV infection in pregnancy. We are also excited to be partnering with a number of major universities under the NIHR London In Vitro Diagnostics Co-operative in a project to develop a CMV diagnostic device.

Our continuing work to raise awareness of CMV, reducing the number of babies affected by the virus, and supporting pregnant women and families, simply would not have been possible without all our wonderful community fundraisers who continue to raise money for us in all sorts of imaginative and sporting ways, so a massive thank you to them all. We are also indebted to the hard work of all our volunteers who give their time freely and help us to maximise impact in all sorts of ways.

In June 2019, we were very sad that Caroline Star, our very knowledgeable and able Chair of Trustees stepped down as a Trustee and Chair. Caroline was a fantastic asset to the organisation and will be greatly missed although we are pleased to report that Caroline will critically still continue to be involved in the area of research. A recruitment process to attract new Trustees resulted in the appointment of two great new additions to our Board – Angela Henry and Suzie Mills. Both have personal experience of CMV as well as a wealth of professional skills that will be of great benefit to us.

At the time of writing this report the Trustees are still dealing with the impact of coronavirus on our activities. This has necessarily meant that the Trustees have had to meet successfully remotely since March 2020 and will continue to do so for the foreseeable future. As is the case for other UK charities reliant on public donations and fundraising to support their activities we had to take immediate steps to manage our costs and maintain adequate reserves to continue our activities in coming years. We were fortunate that due to a very successful annual awareness month in June 2020 and donations from fundraising activities allowed as the UK came out of lockdown has allowed us to resume our activities

**CMV Action  
Trustees' Annual Report  
For the year ended 31 January 2020**

more in line with Pre-Covid times, and I am pleased to report that our reserves have actually grown in the seven months since lockdown was announced in the UK in March 2020.

The Trustees are now looking forward to revising our strategy in light of the Covid-19 pandemic and to the rest of 2020 and beyond with a number of exciting opportunities to exploit and maximise the advances we have strived to make in the past year.

*Sarah Dewar*

Chair,  
CMV Action  
**27 October, 2020**

**CMV Action  
Trustees' Annual Report  
For the year ended 31 January 2020**

**Introduction**

The Trustees have pleasure in presenting their annual report on the activities of CMV Action ('the Charity') for the year ended 31 January 2020. 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 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:

Caroline Star	Chair (resigned 29 June 2019)
Sarah Dewar	Chair (from 29 June 2019)
Liz Estall	
Angela Henry	Appointed 18 January 2020
Tom Kelman	Treasurer
Suzie Mills	Appointed 18 January 2020
Kate Munson	
Jan Pearman	
Amy Taylor	

The Trustees' advisers are as follows.

Medical advisers	Dr. Seilesh Kadambari BSc (Hons), MBBS, MRCPCH Dr. Chrissie Jones, Associate Professor of Paediatric Infectious Diseases, Southampton University
Project Manager	Sharon Wood
Banker	Lloyds Banking Group
Independent Examiner	Mohammed Afzaal Bhatti (FCCA) - K B M UK Limited
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 (registered number 1171773). In February 2017, we became a CIO (Charitable Incorporated Organisation) under a 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](http://www.cmvaction.org.uk).

The Trustees are all volunteers who undertake all of the day to day activities of the Charity, including offering support to pregnant women and parents. They are assisted by volunteers who have experience of CMV and by Sharon Wood CMV Actions part time Project Manager. The Trustees' met on three occasions during the year and held six conference calls in-between these meetings. 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

**CMV Action  
Trustees' Annual Report  
For the year ended 31 January 2020**

accordance with the 6 principles set out in the Good Governance – A Code for the Voluntary and Community Sector.

**Our charitable objects**

The three primary charitable objects of the Charity are as follows.

- To promote and protect the physical and mental health of families affected by congenital CMV through the provision of support, education and practical advice.
- To advance the education of the medical profession and the general public into congenital CMV and its implications for the family.
- 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.

Objectives	What we set out to do	What we did	The impact it had	What we learnt along the way
<b>To Support families affected by CMV</b>	Appropriately support everyone seeking guidance and support	Increased support volunteers to 6 to regularly respond to requests for advice and information by telephone, email and social media  We regularly discuss medical issues raised in support requests with our medical experts to ensure correct and consistent approach	Feedback on twitter, Facebook and the CMV Action website demonstrates members deeply value this work  Able to support increased number of people	Importance of volunteers having regular contact and support  Now respond to a higher level of enquiry requiring medical information as a result of better education of CMV
<b>To educate professionals, parents-to-be and the general public about prevention of CMV</b>	Continued strategy to change professional behaviour and to raise awareness	Multi-channel approach to engagement and education through conferences, training days, student midwife training, journal articles and on-line portals/webinars	Gained support for our "Counting the Cost" recommendations from medical experts and Royal Colleges  Raised awareness through multi-channel opportunities, nationally and internationally	Building credibility with key influencers and professional bodies is critical to changing health professional behaviour
<b>To support the development and implementation of research into better testing, treatment and management of CMV</b>	Progressed number of research priorities	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 (RACEFIT)  Became a member of the cCMV UK Advisory Board  Became a member of NIHR CMV Diagnostics Research Steering Group	These projects will provide important evidence in the UK for further research and lobbying.	Patient and public involvement is an important aspect of research bids and CMV Action's support can make a significant contribution to bids.

**CMV Action  
Trustees' Annual Report  
For the year ended 31 January 2020**

<p><b>To build the capacity of CMV Action</b></p>	<p>Improve our financial position and build capacity to deliver our objectives</p>	<p>Continued with our commitment to professional project management.</p> <p>Recruited two new Trustees to the CMV Action Board</p> <p>Increased use of third-party providers</p> <p>Increased volunteer assistance to respond to additional awareness and conference opportunities</p> <p>Continued to develop Trustee skills and experience.</p> <p>Accepted by DLA Piper as pro-bono client.</p>	<p>Enabled CMV Action to take forward professional development and research activity that was not feasible working through volunteers alone</p>	<p>The organisation needs dedicated staff to achieve our objectives</p>
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**Impact of support activities**

We have five regular support volunteers who are available to answer calls and emails. All support volunteers are current trustees and are either medical professionals or have personal experience relating to CMV.

We operate a triage system. Support requests are received by one person who then either offers support 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 are members of CMV Action with appropriate personal experience. We have a medical advisor, Dr C Jones, who we can contact to assist with particularly complex medical enquiries.

In the year 1 February 2019 to 31 January 2020 we supported over 410 new families, receiving over 90 calls, 116 requests for support through email and Facebook and over 69 requests for our literature, as well as general support on social media, at events, to new members and follow up calls and emails. Our membership was up by 35 to 635 and our subscribers were up by 100 to 1300.

To comply with GDPR we only keep details of those who consent 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 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 have also started to receive requests from professionals for substantial quantities of literature.

Support volunteers work from home using their own computers and phones. Contact with other volunteers is important and support volunteers participate in regular conference calls. We discuss how support is offered and any concerns our volunteers have. We also discuss a recent challenging or difficult case and best practise on how to answer the issues raised.

In CMV National Awareness Month 2019 we ran a “Many Faces of CMV” campaign on social media and the CMV Action website and received an excellent response. The majority of participants agreed that their stories and experiences could be used for future awareness and training purposes. In addition, we attended a “Jennerosity” fundraising day and gave a CMV presentation at the Maternity Mother and Baby conference in Manchester.

**CMV Action  
Trustees' Annual Report  
For the year ended 31 January 2020**

**Impact of awareness and education activities**

Following on from our major project of the previous year - the completion of our economic analysis project to research the cost of CMV in the UK, and the publication of our lay report "Counting the Cost of CMV", we took the exciting opportunity to share with international partners by presenting findings at the 7<sup>th</sup> International CMV Conference in Alabama, USA in April 2019. Attending this high-profile event has been a long-term wish of CMV Action, and we were very grateful to be assisted in this through a very generous donation by a member of CMV Action. We are now planning events to support the 8<sup>th</sup> International CMV Conference which will take place at the University of Cambridge in the UK from the 21<sup>st</sup> of March to the 1<sup>st</sup> of April 2022.

We were also excited to share our report research, and our five recommendations in the report to reduce the number of babies affected by CMV, in a personal meeting with the Senior Policy Manager, Maternity and Neonatal, at the Department of Health when a number of contacts and Government initiatives were discussed to further our objectives.

In order to pursue our objective of raising awareness amongst professionals, particularly midwives, we took part in a number of study days and training events around the country during the year, thus educating and influencing our key targets to discuss the risks of CMV with pregnant women. We encouraged participation in the CMV E-learning module, which continues to be the most popular module on the RCM i-learn platform, and in a series of evening Webinars, which proved to be popular with both a range of professionals and parents/families.

We were delighted that information on congenital CMV has now been approved and included on a number of partners' websites for the first time, including Tommy's and the National Childbirth Trust (NCT). Articles also appeared in several professional journals, including PACEY (the Professional Association of Childcare and Early Years) and the Practising Midwife.

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 believe that research and work carried out in 2019-20 has provided a very positive platform for our continuing key aim of educating professionals, parents-to-be and the general public about the prevention of CMV and we look forward to further expanding our reach next year.

**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 (RACE-FIT – Reducing Acquisition of CMV through Antenatal Education).

Phase 2 of the RACE-FIT project saw the recruitment of a randomised intervention group of women, receiving ante-natal care and attending first-trimester screening, to take part in the full study. The intervention group were shown an educational film about CMV, produced during Phase 1 of the project, with further studies to test an increase in knowledge, perception of risk of CMV and a change in participants' behaviour ongoing. The results of the study, were published in July 2020, and these provide evidence that a large scale Randomised Controlled Trial to determine the efficacy of a digital CMV education intervention is feasible.

CMV Action also became members of the CMV UK Advisory Board to look at the progress in research of a vaccine for CMV and a project by the London In Vitro Diagnostics Co-operative, funded by the NIHR, to develop a rapid low-cost human CMV diagnostic biosensor.



**CMV Action  
Trustees' Annual Report  
For the year ended 31 January 2020**

Each of these projects will fill important gaps in evidence in the UK as well as powerfully making the case for a greater focus on CMV risk reduction and giving new practical insights into the most effective way of doing this in the NHS.

**Facebook/media coverage**

We have a 100% response rate to Facebook contacts, with an average response time of just over 2 hours, which is much appreciated by those seeking information and support. In any week, individual posts reach anything from 300-2000 people. Through our 3899 followers, we estimate we reach approximately 900 people.

In terms of Twitter, we have 3351 followers and average 2500 impressions per week.

**Our fundraisers**

Apart from the time given freely by the Trustees and the volunteers who assist us on our support line, the Charity relies wholly 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 a large number of individuals 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.

**CMV Action  
Trustees' Annual Report  
For the year ended 31 January 2020**

**Financial Commentary**

The past year has been a successful year for the Charity in terms of net income. The Charity saw its net assets increase by £67,123 from £48,775 to £115,898 and this was due to an increased level of donations and income from fundraising events along with merchandise sales amounting in total to £104,513, whilst our expenses amounted in total to £37,390

The Trustees are fully aware that they have a responsibility to apply these reserves to further the objects of the Charity and so are in the process of agreeing a strategy and a financial budget for the coming three years ended 31 January 2023 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 but have agreed, as part of the annual budgeting process that given the current relatively low level of reserves currently held by the Charity and the uncertainty of its income stream which have come under further pressure due to the pandemic then reserves should be maintained at no less than £80,000 in the coming year.

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***

**Honorary Treasurer  
27 October 2020**

**CMV Action**  
**Statement of Financial Activities**  
(including income and expenditure account)  
**For the year ended 31 January 2020**

	Notes	2020 £	2019 £
<b>Incoming resources</b>	<b>1</b>		
<i>Incoming resources from generated funds</i>			
Fundraising events & Donations		102,113	46,022
Merchandise sales		1,982	723
Bank interest		418	45
<b>Total incoming resources</b>		<b>104,513</b>	<b>46,790</b>
<b>Resources expended</b>	<b>1</b>		
<i>Costs of generating funds</i>			
Fundraising events & Donations		(1,398)	(1,052)
Fundraising trading: costs of goods sold		(750)	(1,199)
Total costs of generating funds		<b>(2,148)</b>	<b>(2,251)</b>
<i>Charitable activities</i>			
Promote and protect physical and mental health of families		(6,504)	(1,495)
Advance education of medical profession and general public		(1,176)	(33,296)
Promote research		-	-
Total charitable activities costs		<b>(7,680)</b>	<b>(34,791)</b>
<i>Governance costs</i>			
Trustees' expenses	<b>2</b>	(507)	(148)
Project management costs		(26,033)	(23,802)
Other expenses		(1,022)	(1,684)
Total governance costs		<b>(27,562)</b>	<b>(25,634)</b>
<b>Total resources expended</b>		<b>(37,390)</b>	<b>(62,676)</b>
Net movement in funds		67,123	(15,886)
Total funds brought forward		48,775	64,661
<b>Total funds carried forward</b>		<b>115,898</b>	<b>48,775</b>

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 11 form part of these financial statements.

**CMV Action  
Balance Sheet  
For the year ended 31 January 2020**

	Notes	2020 £	2019 £
<b>Current assets:</b>			
Debtors - prepayments	3	1,457	800
Cash at bank and in hand		<u>116,480</u>	<u>49,087</u>
Total current assets		<b>117,937</b>	49,887
<b>Liabilities:</b>			
Creditors: Amounts falling due within one year - accruals	4	<u>(2,039)</u>	<u>(1,112)</u>
<b>Net assets</b>		<b><u>115,898</u></b>	<b><u>48,775</u></b>
<b>The funds of the charity:</b>			
Total unrestricted funds		<b><u>115,898</u></b>	<b><u>48,775</u></b>

**CMV Action  
Statement of Cash Flows  
For the year ended 31 January 2020**

	2020 £	2019 £
<b>Reconciliation of changes in resources to net cash inflow from operating activities</b>		
Net incoming/(outgoing) resources	67,123	(15,886)
Decrease/(Increase) in debtors	(657)	(43)
Increase/(Decrease) in creditors	927	116
<b>Net cash (outflow)/inflow from operating activities</b>	<b>67,393</b>	<b>(15,813)</b>
<b>Net funds at 1 February</b>	<b>49,087</b>	<b>64,900</b>
<b>Net funds at 31 January</b>	<b>116,480</b>	<b>49,087</b>

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

**Tom Kelman**

**Honorary Treasurer  
27 October 2020**

The notes on page 11 form part of these financial statements.

## CMV Action

### Independent Examiner's report to the Trustees' of CMV Action Charity No.1171773 For the year ended 31 January 2020

#### 1. Statement of 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 (the Charities SORP) as revised and issued in March 2015 by the Charity Commission for England and Wales.

#### 2. Statement of accounting policies

##### Going concern

There are no material uncertainties about the charity's ability to continue.

##### 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 2 below.

#### 2. Trustees' expenses

	2020	2019
	£	£
Includes expenses reimbursed to Trustees as follows:		
In respect of travel	379	100
In respect of reimbursed telephone and postage costs	30	28
In respect of reimbursed subsistence costs	98	20
Total Trustees' expenses	<u>507</u>	<u>148</u>

#### 3. Debtors – prepayments and accrued income

Prepaid exhibition fees	<u>1,457</u>	800
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#### 4. Creditors: Amounts falling due within one year – accruals

Project Manager's fees and expenses	1,409	1,112
Postage costs on merchandise sales	356	-
Trustees' expenses	274	-
<b>Total accruals</b>	<u><b>2,039</b></u>	<u>1,112</u>

**CMV Action**

**Independent Examiner's report to the Trustees' of CMV Action Charity No.1171773  
For the year ended 31 January 2020**

I report to the trustees on my examination of the financial statements of the above charity for the year ended **31 January 2020**.

**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.



Mohammed Afzaal Bhatti FCCA  
Independent Examiner

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