



Trustees' Annual Report and Financial Statements

For the year ended 31 January 2021

(Charitable Incorporated Organisation)

Registered charity number: 1171773

**CMV Action
Financial Statements
Year ended 31 January 2021**

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**CMV Action
Trustee's Annual Report
Year ended 31 January 2021**

Chair's Foreword

2020 was a challenging year. CMV Action undoubtedly had to dig deep to overcome the impact of the Covid-19 pandemic.

As a charity we are so grateful to all our wonderful community fundraisers who raise money for us in all sorts of imaginative and sporting ways, and, of course, the pandemic prevented so many of these fundraising opportunities and events from taking place; something which had a marked effect on our income. We are so grateful to those fundraisers who found new and innovative ways to raise money during the year to enable us to continue our services – those who took part in a Virtual 5K run during CMV Awareness Month in June, and the stupendous efforts of Rupert Allhusen who, on Sunday, 6th September, completed a fantastic challenge swimming the channel to raise funds for CMV Action and another charity, the RHF Defibrillator Fund, to name but two.

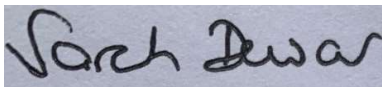
Demands for our services continued despite the pandemic, with the added concern of Covid-19 for parents and parents-to-be resulting in a greater need for us to be there to support those affected by CMV. We have worked hard to continue our work, our influencing, our collaboration and partnerships, just in slightly different ways. We joined the Zoom revolution, using the platform to meet with stakeholders and for the Trustees to regularly discuss operations and contingencies during this difficult year.

We were delighted that Professor Asma Khalil joined CMV Action as a Medical Advisor. Asma is a Professor of Obstetrics and Maternal Fetal Medicine at St. George's Hospital, University of London. We were lucky to be joined by two new Trustees, Suzie Mills and Angela Henry. We were also pleased to welcome Clare Kelly as a volunteer to support our Treasurer in financial matters. Clare is a Finance Manager and member of the Association of Accounting Technicians.

To complement our Facebook page we set up a Facebook Support Group, which already has 200 members, giving people an opportunity to share stories and experiences.

Although some of our awareness work, particularly in respect of reaching health professionals through conferences, workshops etc. was curtailed, with the help of our Medical Advisors, we spent time commencing a full review of our literature and resources. We are excited to be launching two brand new publications in 2021 – CMV in Pregnancy and CMV in Babies and Children. We also worked on a new 3 Year Strategic Plan, with the intention of being in a stable, sustainable position to move forward as soon as restrictions allow.

Whilst restrictions are still very much in place currently, we look forward to 2021 with optimism and confidence that we can make a difference. Thank you to everyone who has supported us in 2020 – together we can bring about change.



Sarah Dewar
Chair,
CMV Action

19 June 2021

CMV Action Trustee's Annual Report Year ended 31 January 2021

Introduction

The Trustees have pleasure in presenting their annual report on the activities of CMV Action ('the Charity') for the year ended 31 January 2021. 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:

Sarah Dewar	Chair
Liz Estall	
Tom Kelman	Treasurer
Kate Munson	
Jan Pearman	
Amy Taylor	
Angela Henry	
Suzie Mills	

The Trustees' advisers are as follows:

Dr. Chrissie Jones, Associate Professor of Paediatric Infectious Diseases, Southampton University

Dr Seilesh Kadambari BSc (Hons), MBBS, MRCPCH

Professor Asma Khalil, Professor of Obstetrics and Maternal Fetal Medicine at St George's Hospital, University of London

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. In February 2017 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 .

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. The Trustees' met once 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

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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.	We regularly respond to requests for advice and information by telephone email and social media. We regularly seek advice from our medical experts in relation to medical issues raised in support requests to ensure a correct and consistent approach. Additional support was provided in relation to the effects of Covid-19. We set up a Private Facebook Support Group for members to share stories, advice and experiences.	Feedback on twitter, Facebook and the website demonstrates members deeply value this work The group already has 200 members	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
2.To educate professionals, parents-to-be and the general public about prevention of CMV	Continued strategy to change professional behaviour and to raise awareness	Multi-channel approach to engagement and education through channels available during pandemic	Raised awareness through multi-channel opportunities, nationally and internationally	Building credibility with key influencers and professional bodies is critical to changing health professional behaviour

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<p>3.To support the development and implementation of research into better testing, treatment and management of CMV</p>	<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 (RACEFIT)</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>
<p>4.To build the capacity of CMV Action</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 a volunteer to support our Treasurer.</p> <p>Increased use of third- party providers.</p> <p>Drafted and agreed a new 3 Year Strategic Plan for period 2021-2023.</p> <p>Continued to develop Trustee skills and experience.</p>	<p>Enabled CMV Action to take forward professional development and research activity that was 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 trustees and two are medical professionals. All support volunteers 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 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 2020 to 31 January 2021, we supported over 170 new families, receiving over 50 calls, 95 requests for support through email and Facebook and numerous requests for our literature, as well as general support on social media, to new members and follow up calls and emails. Our website had over 50,000 user visits, and over 100,000 unique page views. CMV Action has over 650 members and our subscribers increased by 150 to 1300.

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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. Not surprisingly, due to the worldwide pandemic, this year we had additional queries from people wanting information about Coronavirus and how it might affect babies with CMV which resulted in regular communication with our medical advisers to ensure we were giving the most up to date information in a fast-moving situation.

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 2020 we held a Virtual 5K run event, which supporters completed in their gardens or local areas. One of our Trustees took part in an online interview with CMV Canada, to share ideas and progress.

Impact of awareness and education activities:

Sadly, the impact of the Covid-19 pandemic curtailed many of our awareness and education activities with health professionals with the cancellation of a number of conferences that we had intended attending. However, we were able to take part in an on-line RCOG Conference "An Update on Infections in Pregnancy" when our Chair of Trustees, Sarah Dewar, chaired the session on CMV and we were given access to the European Congenital Cytomegalovirus Initiative Conference (ECCI) held in Paris but which went "virtual" and gave us a great opportunity to access world-leading presentations and papers on CMV.

In October, one of our Trustees was able to give a presentation to colleagues in the fetal medicine team at Birmingham Women's Hospital, something we hope to be able to repeat in different areas of the UK when restrictions allow.

Participation in the CMV E-learning module, which continues to be the most popular module on the RCM i-learn platform as well as being available on the CMV Action website, continued, as did a series of evening Webinars, which reached over 50 professionals.

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.

A review of all our literature and resources commenced and we look forward to launching two brand new publications early in 2021. We believe that the update of our core information will provide a very positive platform for our continuing key aim of educating professionals, parents-to-be and the general public about the prevention of CMV in 2021.

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). The second phase of the project was completed which evidenced that a large scale RCT to determine the efficacy of a digital CMV education intervention is feasible and it is hoped that a further NIHR PRP application for funding will enable this work to be taken forward.

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We assisted in a Huddersfield University Research project into cognition and behaviour in children with CMV, recruiting parents and children to take part in an on-line questionnaire with an excellent response. We also provided the parent perspective in a number of CMV studies and clinical trials which it is hoped 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 were delighted to launch a Private Facebook Support Group to complement our Facebook Page. Membership soon grew, with over 200 now taking part in discussions and sharing experiences.

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 4177 followers, we estimate we reach approximately 900 people.

In terms of Twitter, we have 3307 followers and average 3698 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 those who have given us money and their time to help organise and participate in events that have raised funds in very difficult times. We therefore thank everyone for their continued support without which we would be unable to pursue our objectives.

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 £21,524 from £115,898 to £137,422 and this was due to an increased level of donations and income from fundraising events along with merchandise sales amounting in total to £52,494, whilst our expenses amounted in total to £30,970.

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 2024 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.

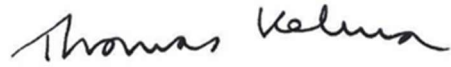
The Trustees have yet to consider and document a formal reserves policy but have agreed, as part of the annual budgeting process that given the current relatively low level of reserves currently held by the Charity and the uncertainty of its income stream which have come under further pressure due to 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.

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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.

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

**Tom Kelman
Honorary Treasurer**

19 June 2021

CMV Action
Statement of Financial Activities
(including income and expenditure account)
For the year ended 31 January 2021

	Notes	2021 £	2020 £
Incoming resources			
<i>Incoming resources from generated funds</i>			
Fundraising events & Donations		51,449	102,113
Merchandise sales		869	1,982
Bank interest		176	418
Total incoming resources		52,494	104,513
Resources expended			
<i>Costs of generating funds</i>			
Fundraising events & Donations		(2,447)	(1,398)
Fundraising trading: costs of goods sold		(57)	(750)
Total costs of generating funds		(2,504)	(2,148)
<i>Charitable activities</i>			
Promote and protect physical and mental health of families		(3,200)	(6,504)
Advance education of medical profession and general public		(0)	(1,176)
Promote research		-	-
Total charitable activities costs		(3,200)	(7,680)
<i>Governance costs</i>			
Trustees' expenses	3	-	(507)
Project management costs		(22,885)	(26,033)
Other expenses		(2,381)	(1,022)
Total governance costs		(25,266)	(27,562)
Total resources expended		(30,970)	(37,390)
Net movement in funds		21,524	67,123
Total funds brought forward		115,898	48,775
Total funds carried forward		137,422	115,898

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 10 form part of these financial statements.

**CMV Action
Balance Sheet
As at 31 January 2021**

	Notes	2021 £	2020 £
Current assets:			
Debtors - prepayments	4	-	1,457
Cash at bank and in hand		139,569	116,480
Total current assets		<u>139,569</u>	<u>117,937</u>
Liabilities:			
Creditors: Amounts falling due within one year - accruals	5	(2,147)	(2,039)
Net assets		<u>137,422</u>	<u>115,898</u>
The funds of the charity:			
Total unrestricted funds		<u>137,422</u>	<u>115,898</u>

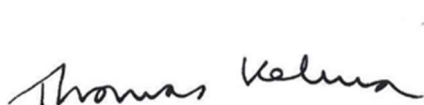
The notes on page 10 form part of these financial statements.

**CMV Action
Statement of Cash Flows
For the year ended 31 January 2021**

	2021 £	2020 £
Reconciliation of changes in resources to net cash inflow from operating activities		
Net incoming/(outgoing) resources	21,524	67,123
Increase in debtors	1,457	(657)
Increase in creditors	108	927
Net cash (outflow)/inflow from operating activities	<u>23,089</u>	<u>67,393</u>
Net funds at 1 February	<u>116,480</u>	<u>49,087</u>
Net funds at 31 January	<u>139,569</u>	<u>116,480</u>

The notes on page 10 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**

19 June 2021

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 to the Republic of Ireland FRS 102 and the Charities SORP (FRS 102) as revised and issued in October 2019 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 3.

3. Trustees' expenses

	2021	2020
	£	£
Includes expenses reimbursed to Trustees as follows:		
In respect of travel	-	379
In respect of reimbursed telephone and postage costs	-	30
In respect of reimbursed subsistence costs	-	98
Total Trustees' expenses	<u>-</u>	<u>507</u>

4. Debtors – prepayments and accrued income

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

Project Manager's fees and expenses	2,147	1,409
Postage costs on merchandise sales	-	356
Trustees' expenses	-	274
Total accruals	<u>2,147</u>	<u>2,039</u>

CMV Action

Independent Examiner's report to the Trustees' of CMV Action Charity No.1171773 For the year ended 31 January 2021

I report to the trustees on my examination of the financial statements of the above charity for the year ended **31 January 2021**.

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.



19/6/21.

Mohammed Afzaal Bhatti FCCA
Independent Examiner

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