



Trustees' Financial Statements

For the year ended 31 January 2019

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Chair's Foreword

In 2018 - 2019 we focussed much of our capacity on working with our appointed research consultants, the York Health Economics Consortium (YHEC), who we commissioned to deliver a research project to estimate the direct health and productivity costs of CMV in the UK. Through a combination of a full literature review and consultation with key opinion leaders, YHEC generated a robust cost model, revealing that CMV costs the UK £750 million per annum. This figure, considered to be a conservative one due to the lack of evidenced data around CMV, is a staggering sum for a condition that so few have actually heard of.

We were delighted to be invited to share this research with international partners by presenting at the European Congenital Cytomegalovirus Initiative (ECCI) conference held in Brussels in May.

Work then continued to appoint a PR consultant to handle the launch of our lay report based on the research findings, entitled "Counting the Cost of CMV". This report, providing the first complete picture of the economic effects of CMV in the UK, including the economic burdens placed on families, was launched in January 2019 with a flurry of media activity, including interviews on ITV and independent radio channels. The report was sent to a wide range of professional targets and follow up articles have appeared in the professional press. Efforts will continue to bring these costs, and the five recommendations we make to reduce the number of babies affected by congenital CMV, to the attention of policy makers and educationalists in the coming months.

Our strategy for engaging more professionals working in antenatal care continued through journal articles, 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. 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 cytomegalovirus (CMV) infection in pregnancy.

Our research work of 2018 was a significant financial investment for our organisation and 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.

We look forward to 2019 and the opportunity to build and maximise the advances we have made this year.



Caroline Star
Former Chair, CMV Action
16 July 2019

Trustees' Report for the year ended 31 January 2019

Introduction

The Trustees have pleasure in presenting their annual report on the activities of CMV Action ('the Charity') for the year ended 31 January 2019. 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	Chairman Appointed November 2011 Resigned July 2019
Rebecca Blickhorn	Appointed March 2016 Resigned July 2019
Sarah Dewar	Appointed October 2015
Elizabeth Estall	Appointed November 2011
Tom Kelman	Treasurer (Appointed December 2013)
Kate Munson	Appointed March 2017
Jan Pearman	Appointed December 2013
Amy Taylor	Appointed March 2017

The Trustees' advisers are as follows.

Medical adviser	Dr Seilesh Kadambari BSc (Hons), MBBS, MRCPCH Dr. Chrissie Jones, Associate Professor of Paediatric Infectious Diseases, Southampton University
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Banker	Lloyds Banking Group
Independent Examiner	Mohammed Afzaal Bhatti FCCA
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 and undertake all of the day to day activities of the Charity along with volunteers who provide support by assisting those who contact us for support. 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 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	Increased support volunteers to 6 to regularly respond to requests for advice and information by telephone, email and social media Met with medical expert to ensure correct and consistent approach	Feedback on twitter, Facebook and the 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
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 conferences, training days, student midwife training, journal articles and on-line portals	Gained support from medical experts and Royal Colleges for better antenatal education and professional training Raised awareness through multi-channel opportunities, nationally and internationally	Building credibility with key influencers and professional bodies is critical to changing health professional behaviour
3.To support the development and implementation of research into better testing, treatment and management of CMV	Significantly progressed two research priorities	Concluded commissioning of research project to fill a critical gap in the UK on the cost of congenital CMV to the NHS and other public services and launched findings to professional audience and the media. 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)	Both 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.

4.To build the capacity of CMV Action	Improve our financial position and build capacity to deliver our objectives	Continued with our commitment to professional project management Increased use of third party providers Increased volunteer assistance to respond to additional awareness and conference opportunities Continued to develop Trustee skills and experience.	Enabled CMV Action to take forward professional development and research activity that was not feasible working through volunteers alone	The organisation needs dedicated staff to achieve our objectives
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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 another 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 can we can contact to assist with particularly complex medical enquiries.

In the year 1 February 2018 to 31 January 2019 we supported over 600 new families, receiving over 100 calls, 237 requests for support through email and facebook and over 100 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 50 to 600 and our subscribers were up by 120 to 1200.

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.

We ran a Teddy Bear's Picnic campaign during National Awareness Month, encouraging our members and supporters to hold a fundraising picnic, coffee morning or other event, for which we supplied a CMV teddy. Bears were sent all around the UK and one bear travelled all the way to the USA.

Impact of awareness and education activities

Our major project in 2018/9 was the completion of our economic analysis project to research the cost of cCMV in the UK, with our research partners, the York Health Economics Consortium. As initial findings were delivered, we took the opportunity to share with international partners by presenting at the ECCI conference in Brussels in May.

Work then concentrated on producing our lay report based on the research findings, entitled “Counting the Cost of CMV” and a PR campaign to launch the report which took place in January 2019. A good amount of media coverage was achieved, disseminating the first complete picture of the economic effects of cCMV in the UK, including the economic burden placed on families, to a wider audience. The report was also launched to a wide range of professional stakeholders and policy makers, with a supportive statement from the RCM and the opportunity to meet to further discuss our findings.

In order to pursue our objective of raising awareness amongst professionals, particularly midwives, we exhibited and presented at the Primary Health Public Health conference in Birmingham in May 2018, attended by 3,500 practicing clinicians and managers. We also 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 encouraging participation in the CMV E-learning module, which continues to be the most popular module on the RCM i-learn platform.

We were delighted that information on congenital CMV has now been included on a number of partners’ websites for the first time, including Tommys and the National Childbirth Trust (NCT). Articles also appeared in several professional journals, for example MIDIRS Midwifery Journal.

We believe that research and work carried out in 2018-19 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 two research priorities aimed at advancing new research:

- 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 (RACE-FIT)
- To deliver a project to fill a critical research gap in the UK on the cost of congenital CMV to the NHS and other public services

Both priorities have been progressed significantly over the year, with the delivery of the latter taking place as detailed in the section above.

Phase 1 of the RACE-FIT (Reducing Acquisition of CMV through Antenatal Education) project resulted in the production of a film, featuring the narratives of families who generously shared their stories of how CMV affected their child. This film is now being tested in a randomised controlled trial to understand if this can increase knowledge and understanding about CMV and whether it is effective at helping women to modify their behaviour to try to reduce the risk of catching CMV infection in pregnancy. Women who are having antenatal care at St. George’s Hospital are being asked if they would like to take part in the trial.

Both 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 us 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 2 hours 50 minutes, which is much appreciated by those wanting information and support. In any week, individual posts reach anything from 300-2000 people. Through our 3672 followers, we estimate we reach approximately 900 people.

In terms of Twitter, we have 3409 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 objects.

Financial Commentary

The Charity saw its net assets decrease by £15,886 from £64,661 to £48,775 and this was due to a the further investment in our research into counting the cost of CMV. The level of donations and income from fundraising events along with merchandise sales rose compared to last year amounting in total to £46,790, whilst our expenses amounted in total to £62,676.

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 and a financial budget for the coming three years ended 31 January 2021 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 then reserves should be maintained at no less than £50,000 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.



Tom Kelman
Honorary Treasurer
14 October 2019

CMV Action
Statement of Financial Activities
For the year ended 31 January 2019

	Notes	2019 £	2018 £
Incoming resources	2		
<i>Incoming resources from generated funds</i>			
Fundraising events & Donations		46,022	32,505
Merchandise sales		723	1,307
Bank interest		45	-
Total incoming resources		46,790	33,812
Resources expended	2		
<i>Costs of generating funds</i>			
Fundraising events & Donations		(1,052)	(761)
Fundraising trading: costs of goods sold		(1,199)	(1,855)
Grant developer fees		-	(6,680)
Total costs of generating funds		(2,251)	(9,296)
<i>Charitable activities</i>			
Promote and protect physical and mental health of families		(1,495)	(2,297)
Advance education of medical profession and general public		(33,296)	(31,963)
Promote research		-	-
Total charitable activities costs		(34,791)	(34,260)
<i>Governance costs</i>			
Trustees' expenses	3	(148)	(364)
Project management costs		(23,802)	(24,813)
Other expenses		(1,684)	(2,773)
Total governance costs		(25,634)	(27,950)
Total resources expended		(62,676)	(71,506)
Net movement in funds		(15,886)	(37,694)
Total funds brought forward		64,661	102,355
Total funds carried forward		48,775	64,661

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

**CMV Action
Balance Sheet
As at 31 January 2019**

	Notes	2019 £	2018 £
Current assets:			
Debtors - prepayments	4	800	757
Cash at bank and in hand		49,087	64,900
Total current assets		<u>49,887</u>	<u>65,657</u>
Liabilities:			
Creditors: Amounts falling due within one year - accruals	5	(1,112)	(996)
Net assets		<u>48,775</u>	<u>64,661</u>
The funds of the charity:			
Total unrestricted funds		<u>48,775</u>	<u>64,661</u>

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

**CMV Action
Statement of cash flows
For the year ended 31 January 2019**

	2019 £	2018 £
Reconciliation of changes in resources to net cash inflow from operating activities		
Net (outgoing)/incoming resources	(15,886)	(37,694)
Decrease/(Increase) in debtors	(43)	6,443
Increase/(Decrease) in creditors	116	(308)
Net cash (outflow)/inflow from operating activities	<u>(15,813)</u>	<u>(31,559)</u>
Net funds at beginning of year	<u>64,900</u>	<u>96,459</u>
Net funds at end of year	<u>49,087</u>	<u>64,900</u>

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

These financial statements were approved by the board of trustees and authorised for issue on 14 October 2019, and are signed on behalf of the board by:



**Tom Kelman
Trustee**

CMV Action
Notes to the financial statements
For the year ended 31 January 2019

1. Statement of compliance

Convention

These financial statements have been prepared in compliance with FRS 102, 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland', the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (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.

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.

3. Trustees' expenses

	2019	2018
	£	£
Includes expenses reimbursed to Trustees as follows:		
In respect of travel	100	497
In respect of reimbursed telephone costs	28	307
In respect of reimbursed subsistence costs	20	-
Total Trustees' expenses	<u>148</u>	<u>804</u>

4. Debtors – prepayments and accrued income

Prepaid exhibition fees	<u>800</u>	<u>757</u>
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5. Creditors: Amounts falling due within one year – accruals

Project Manager's fees and expenses	<u>1,112</u>	<u>996</u>
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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 2019.

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

22/11/2019

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