



Trustees' Financial Statements

For the year ended 31 January 2018

Contents

Chair's Foreword	2
Trustees' Annual Report	3 to 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	
- Public benefit statement	
Financial statements	9 to 11
- Statement of Financial Activities	9
- Net Assets Statement	10
- Cash Flow Statement	10
Notes to the financial statements	11
Independent Examiner's Report	12

Chair's Foreword

In 2016 Trustees challenged themselves on the impact that they wanted CMV Action to deliver. Having set out our expectations on standards of care, our top priority for 17-18 was to reach more health professionals, particularly midwives. We also wanted to ensure that key research gaps in the UK were closer to being addressed.

Our strategy for engaging more professionals working in antenatal care over the year has been multichannel. We continued to focus on promoting our existing well-received education products through journal articles, midwifery education online portals and face to face events. Our increased capacity created last year together with a successful bid for Big Lottery funding allowed us to expand our presence at midwifery education events in particular. 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.

We have focussed our research strategy on supporting and commissioning new projects to fill research gaps in the UK. We have been a key partner in a project to develop an antenatal education intervention. Very excitingly, we have also progressed our own research project by appointing a team of economists at York University to deliver a study estimating the cost of CMV in the UK and the stark impact of not taking action.

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 that RCOG responded to our call for a scientific impact paper on CMV to help address the significant variations in advice and management practice that families tell us about. Having contributed to the consultation we are delighted that the first evidence-based paper on antenatal CMV management in the UK has now been published and is beginning to be put into practice.

Our increased reach in 2017-18 has partly been enabled by our investment in capacity: appointing a consultant project manager, getting more Trustees on board, working with our appointed researchers and investing in support for our volunteers. We also converted to charitable incorporated organisation status to ensure our structure and constitution are fit for purpose. I would like to say a big thank you to all the community fundraisers who have made these investments possible and all the volunteers who give their time freely and help us to maximise the impact we can have with our resources.

We look forward to an exciting period when current projects come to fruition over the next twelve months.



Caroline Star
Chair, CMV Action
28 October 2018

CMV Action
EDUCATE • VACCINATE • ERADICATE

Congenital CMV is a common virus and one of the main causes of childhood disability in the UK

Connected with **9000** MIDWIVES

COLLABORATED with **10** other charities

COMMISSIONED **YHEC** to research and report on *The Hidden Cost of CMV*

EDUCATED **700** midwives via our iLearning programme

WASH WITH CARE
The CMV virus is destroyed by soap and water

2 to 3 babies every day will be **DAMAGED** by CMV

CMV Action
EDUCATE • VACCINATE • ERADICATE
2017

Sent out **64** AWARENESS PACKS

20k WEBSITE VISITS

Supported over **500** families

www.cmvaction.org.uk info@cmvaction.org.uk 0808 802 0030

Trustees' Report for the year ended 31 January 2018

Introduction

The Trustees have pleasure in presenting their annual report on the activities of CMV Action ('the Charity') for the year ended 31 January 2018. 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
Rebecca Blinkhorn	
Sarah Dewar	
Liz Estall	
Tom Kelman	Treasurer
Kate Munson	Appointed March 2017
Jan Pearman	
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
-----------------	--

Banker	Lloyds Banking Group
Independent Examiner	Isahack Rahin ACCA
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.

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 the number of support volunteers by 2 Met with medical expert to ensure correct and consistent approach Held successful family event	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 expert 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	Supported 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) Launched project to fill a critical research gap in the UK on the cost of congenital CMV to the NHS and other public services	Both ongoing 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 Brought new skills onto our Board of Trustees	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

Impact of support activities

We have five regular support volunteers who are available to answer calls and emails. Four of them 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 additional parents and grandparents with appropriate personal experience. We have a medical advisor, Dr C Jones, who can be contacted to assist with particularly complex medical enquiries.

In the year 1 February 2017 to 31 January 2018 we received 96 requests for support by email or Facebook, and over 45 telephone calls for support (first point of contact). This reflects the initial contact only as follow up support will involve calls and emails. In addition to this we had over 100 requests for our literature and awareness packs. There has been an increase in the number of people contacting us by facebook compared to previous years.

We have seen our membership grow to 558 and people subscribing to our newsletters has increased to 1,079. 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 June we held a Family Day at the Thames Valley Adventure Park. Thirteen families, including 29 children of all ages and abilities, travelled to the park, specially designed for children and adults with all types of special needs to enjoy the fun, freedom and friendship afforded by the opportunity to play and share experiences in a safe and stimulating environment. Everyone brought a picnic, cakes were provided by CMV Action and a support stand was available for attendees to speak to someone if they wished to. Everyone attending had a great time.

We also 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

In order to pursue our top priority for 2017-18 to reach more professionals, particularly midwives, and aided by a £10,000 Big Lottery Grant, we expanded our programme of attendance at national conferences and events.

Educating and influencing our key targets to discuss the risks of CMV with pregnant women, as well as showcasing our CMV Training Board Game and encouraging increased participation in the CMV E-learning module commenced with a programme of Maternity, Midwifery and Baby (MMB) conferences in Bristol, Birmingham, Manchester and Edinburgh. By both presenting and exhibiting at each of these events around the UK, we were able to reach over 2,500 midwife and student midwife delegates.

In May, we attended the annual Primary Care Public Health Conference in Birmingham, attended by a wide range of health professionals. Our presentation to conference, as well as two lunchtime workshops resulted in a large number of visitors to our stand, including students, midwives, GPs and community health workers. Indeed, information was in such demand that we ran out of leaflets on the second day!

An exhibition stand at the RMC Conference in Manchester in October gave us the opportunity to engage with over 3,000 midwife delegates with our range of information and awareness literature and resulted in many useful conversations and contacts during the two-day conference.

This year also saw an approach to universities offering midwifery degree courses around the UK and we were invited to deliver sessions at several of these, including Carlisle, York and the University of West London, with more requests to visit others in the coming year. Work is in hand to extend this programme and to ensure continuance of CMV education for midwifery students by introducing Train the Trainer programmes. In addition to this we were asked to run a repeat series of workshops at Keele University and we were pleased to respond to invitations to attend and present at a number of other hospital and audiology training days and conferences throughout the period.

We believe that work in 2017-18 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 develop plans 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.

The call for CMV Action families to take part in the RACE-FIT (Reducing Acquisition of CMV through Antenatal Education) was very successful with over 20 families coming forward to be interviewed by a researcher from the team. A powerful video featuring personal insights into experiences of living with CMV has now been produced involving some of the families interviewed and CMV Action continues to be involved in production, with advice on methodology and approach.

2017 saw CMV Action's project to estimate the costs of congenital CMV in the UK really begin to take shape. Following a research tender call, interview and selection process overseen by a steering group composed of CMV clinicians, an economist and CMV Action staff, we were delighted to award the project to the York Health Economic Consortium (YHEC) who embarked on the study to generate a robust cost model to estimate the direct health and productivity costs of CMV. The resulting study will provide a firm evidence base for further research, awareness raising, lobbying, campaigning and fundraising.

Both projects will fill important gaps in evidence in the UK. When complete they will make the case for a greater focus on CMV risk reduction and give new practical insights into the most effective way of doing this in the NHS.

Facebook/media coverage

562 families were actively supported through phone calls, emails and social media. In an average week, Facebook is reached by 7 – 8,000 people. Individual posts can be seen by 100 – 6,000 people. Our response rate is 100% and is, on average, 2-4 hours so there is no doubt that the CMV Action Facebook page is very successful and an increasingly popular way of obtaining information and support.

Twitter has a small, but growing, following with tweets up 8.3% on last year, tweet impressions up 50.5% and mentions up 66.7%. We currently have 3,400 followers.

Fundraising

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 past year has been a year of investment for the Charity in terms of net income. The Charity saw its net assets decrease by £37,694 from £102,355 to £64,661 and this was due to a reduced level of donations and income from fundraising events along with merchandise sales amounting in total to £33,812, whilst our expenses amounted in total to £71,506.

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 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 £30,000 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
28 October 2018

CMV Action
Statement of Financial Activities
For the year ended 31 January 2018

	Notes	2018 £	2017 £
Incoming resources	1		
<i>Incoming resources from generated funds</i>			
Fundraising events & Donations		32,505	61,807
Merchandise sales		1,307	1,131
		<hr/>	<hr/>
Total incoming resources		33,812	62,938
		<hr/>	<hr/>
Resources expended	1		
<i>Costs of generating funds</i>			
Fundraising events & Donations		(761)	(5,123)
Fundraising trading: costs of goods sold		(1,855)	(554)
Grant developer fees		(6,680)	(20,155)
Total costs of generating funds		(9,296)	(25,832)
		<hr/>	<hr/>
<i>Charitable activities</i>			
Promote and protect physical and mental health of families		(2,297)	(6,844)
Advance education of medical profession and general public		(31,963)	(11,347)
Promote research		-	-
Total charitable activities costs		(34,260)	(18,191)
		<hr/>	<hr/>
<i>Governance costs</i>			
Trustees' expenses	2	(804)	(1,826)
Project management costs		(24,813)	(27,971)
Other expenses		(2,333)	(2,939)
Total governance costs		(27,950)	(32,736)
		<hr/>	<hr/>
Total resources expended		(71,506)	(76,759)
		<hr/>	<hr/>
Net movement in funds		(37,694)	(13,821)
Total funds brought forward		102,355	116,176
Total funds carried forward		64,661	102,355
		<hr/>	<hr/>

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

**CMV Action
Balance Sheet
As at 31 January 2018**

	Notes	2018 £	2017 £
Current assets:			
Debtors - prepayments	3	757	7,200
Cash at bank and in hand		64,900	96,459
Total current assets		65,657	103,659
Liabilities:			
Creditors: Amounts falling due within one year - accruals	4	(996)	(1,304)
Net assets		64,661	102,355
The funds of the charity:			
Total unrestricted funds		64,661	102,355

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

**CMV Action
Cash Flow Statement
For the year ended 31 January 2018**

	2018 £	2017 £
Reconciliation of changes in resources to net cash inflow from operating activities		
Net (outgoing)/incoming resources	(37,694)	(13,821)
Decrease/(Increase) in debtors	6,443	(5,200)
Increase/(Decrease) in creditors	(308)	(1,901)
Net cash (outflow)/inflow from operating activities	(31,559)	(20,922)
Net funds at 1 February	96,459	117,381
Net funds at 31 January	64,900	96,459

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

By order of the Trustees

Tom Kelman

**Honorary Treasurer
28 October 2018**

CMV Action
Notes to the financial statements

1. Statement of accounting policies

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.

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

	2018	2017
	£	£
Includes expenses reimbursed to Trustees as follows:		
In respect of travel	497	1,406
In respect of reimbursed telephone costs	307	312
In respect of reimbursed subsistence costs	-	108
Total Trustees' expenses	<u>804</u>	<u>1,826</u>

3. Debtors – prepayments and accrued income

Prepaid exhibition fees	<u>757</u>	<u>7,200</u>
-------------------------	-------------------	---------------------

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

Grant Developer's fees	-	200
Project Manager's fees and expenses	996	664
Trustees' expenses	-	440
Total accruals	<u>996</u>	<u>1,304</u>

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

I report on the accounts of the Charity for the year ended 31 January 2018.

Respective responsibilities of Trustees' and Examiner

The Charity's Trustees' are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the 2011 Act;
- To follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- To state whether particular matters have come to my attention.

Basis of Independent Examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as Trustees' concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent Examiner's statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the 2011 Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Isahack Rahim

Certified Accountant

I & N Consultants Ltd

21 Collette Court, 150 Selhurst Road

London SE25 6NE

28 October 2018