



Trustees' Financial Statements

For the year ended 31 January 2017

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Chair's Foreword

At the start of the year Trustees challenged themselves on the impact that they wanted to see. Having set out our expectations on standards of care, our top priority for 16-17 was to reach more professionals, particularly midwives. We also wanted to ensure that key research gaps in the UK were closer to being filled.

Our strategy for engaging more professionals working in antenatal care over the year has been multichannel. We focussed on promoting our existing well-received education products through journal articles, midwifery education online portals and face to face events. Our increased capacity in 16-17 allowed us to expand our presence at midwifery education events in particular. We also collaborated with the Royal College of Obstetricians and Gynaecologists on a multidisciplinary training day on infection in pregnancy. 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 new projects to fill research gaps in the UK. We have now kicked off a project to develop an antenatal education intervention. We have also launched a tender process to appoint economists to estimate 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 have 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 look forward to seeing the publication of the first evidence-based paper on antenatal CMV management in the UK.

Our increased reach in 2016-17 has partly been enabled by our investment in capacity: appointing a consultant project manager, getting more Trustees on board, working with an expert pro-bono adviser 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 now look forward to expanding our reach further with other professional groups in 2017-18.



Caroline Star
Chair, CMV Action
18 August 2017

Trustees' Report for the year ended 31 January 2017

Introduction

The Trustees have pleasure in presenting their annual report on the activities of CMV Action ('the Charity') for the year ended 31 January 2017. 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
Sarah Beadell	Resigned 1 September 2016
Rebecca Blinkhorn	Appointed 19 January 2017
Sarah Dewar	
Liz Estall	
Tom Kelman	
Kate Munson	Appointed 1 April 2017
Jan Pearman	
Sharon Robinson	Resigned 6 February 2017
Amy Taylor	Appointed 1 April 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	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. The Charity is governed by a model 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 five conference calls in-between these meetings. One of the meetings is held on the same day as the AGM of the Charity. All members of the Charity are invited to attend the AGM. At the AGM the Treasurer presents the annual report for the previous year. The Trustees also provide members with information on the current and the future activities the Trustees are undertaking to further the objects of the Charity. The AGM also provides members with an opportunity to ask any questions and provide feedback to the Trustees.

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 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	Continue strategy to change professional behaviour and to raise awareness	Developed and launched CMV training game Multi-channel approach to engagement and education through conferences, training days, 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	Identified and implemented 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) Developed plans 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	Contracted with a project manager and a fundraiser Increased use of third party providers Brought new skills onto our Board of Trustees	Enabled CMV Action to take forward professional development activity that was not feasible working through volunteers alone	The organisation now needs dedicated staff to achieve our objectives

Impact of support activities

We have seen an increase in the number of support volunteers and there are currently 8 available to answer calls and emails or facebook enquiries. 5 are current trustees, 2 were previously trustees and all have children or grandchildren who have been affected by CMV. During the year we received over 150 support requests. The type of support request is gradually changing, with more people contacting us who have had a diagnosis of CMV during pregnancy or are aware of CMV and want to learn how to minimise their risks. This is a change from previous years when more parents were contacting us when their child had been diagnosed with CMV.

Support volunteers work from home and participate in quarterly team conference calls to discuss issues. In April the support volunteers attended a training session delivered by the Helplines partnership tailored to the specific support needs faced by our volunteers including dealing with challenging and emotional calls. This was a useful opportunity to share experience and ideas and discuss how we can best support those who contact us.

In March 2017 we met with our medical expert Dr C Jones who answered a range of medical questions and concerns that had been raised by families and professionals. The meeting was extremely useful in getting a medical perspective and everything discussed was fed back to the volunteers to ensure a consistent and up to date approach.

In 2016/7 we had over 120 requests for our literature and awareness packs.

We have seen our membership grow to 530 and subscribers to our newsletters has increased to 912.

In June 2016 we held our annual party in Manchester. 15 families joined us, many of whom we had supported. This was very successful and a less formal way of giving support.

Impact of awareness and education activities

In order to deliver our top priority for 2016-17 to reach more professionals, particularly midwives, and aided by a £10,000 Big Lottery Grant, we embarked on a programme of attendance at national conferences and events. Educating and influencing our key targets to discuss the risks of CMV with pregnant women commenced with a presentation and exhibition stand at Maternity, Midwifery and Baby (MMB) London, where we were able to reach over 1,000 midwife and student midwife delegates. We followed this with a poster display at MMB Birmingham.

In April, we attended the European Congenital Cytomegalovirus Initiative (ECCI) Conference in Venice where we gave a presentation about the result of our survey of public and professional knowledge of CMV, together with the work of our organisation, to medics and patient information groups from around the world, as well as learning about international advances in CMV care and research.

We held a CMV Awareness Day with Auditory Verbal UK for both families and professionals during National Epilepsy Month and exhibited at Midwifery Society Conferences at Robert Gordon, Canterbury and Lancaster Universities. An exhibition stand at the RCM Legal Births Conference in London in July gave us the opportunity to engage with more professionals working in anti and post-natal care, as did our attendance at the two-day RCM Annual Conference, where we were able to reach over 2,500 midwives and students with our range of information and awareness literature, i-learn module and new CMV board training game.

As part of our multi-channel engagement strategy, articles were published in several professional journals and on-line professional education portals, and we were delighted that CMV was included as a topic on the Bounty pregnancy app. Our i-learn module, hosted by and in association with the Royal College of Midwives continues to one of the most popular modules on the RCM i-learn platform and has been accessed by over 700 midwives.

We believe that work in 2016-17 has provided a very firm platform for our continuing key aim of educating professionals, parents-to-be and the general public about the prevention of CMV and now look forward to expanding our reach further in 2017-18.

Impact of research activities

This year CMV Action has had 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 over the year. The RACE-FIT project has launched and recruitment of women and families to gain qualitative insights is well underway. CMV Action have supported recruitment of families affected by CMV and have advised on methodology and insights needed from focus groups with pregnant women.

We have also worked with a volunteer economic adviser to scope a new project aimed at estimating the hidden cost of CMV in the UK. Utilising expert input on a pro bono basis has helped to ensure that the project is defined in a way that will maximise impact. The tender has now been launched and we look forward to working with a contractor in 17-18 to develop a more robust rationale for further action to tackle CMV.

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 month Facebook is reached by around 20,000 people. An individual post reaches between 300 and 600 people and can have up to 200 actions/engagements so there is no doubt that the CMV Action Facebook page is very successful.

We have 3358 followers on Twitter and most of our tweets have around 1000 impressions (number seen) but generally only a couple of engagements (responses). Our engagement rate over 1 month is only .3%/14 clicks (responses). In 1 month we get an average of 25 likes.

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 successful year for the Charity in terms of net income. The Charity saw its net assets decrease by £13,821 from £116,176 to £102,355 and this was due to the continued high level of donations and income from fundraising events along with merchandise sales amounting in total to £62,938, whilst our expenses amounted in total to £76,759.

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 2020 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
18 August 2017

CMV Action
Statement of Financial Activities
For the year ended 31 January 2017

	Note	2017 £	2016 £
Incoming resources	1		
<i>Incoming resources from generated funds</i>			
Fundraising events & Donations		61,807	58,258
Merchandise sales		1,131	1,673
Total incoming resources		62,938	59,931
Resources expended	1		
<i>Costs of generating funds</i>			
Fundraising events & Donations		(5,123)	(4,215)
Fundraising trading: costs of goods sold		(554)	(2,673)
Grant developer fees		(20,155)	(1,200)
Total costs of generating funds		(25,832)	(8,088)
<i>Charitable activities</i>			
Promote and protect physical and mental health of families		(6,844)	(2,642)
Advance education of medical profession and general public		(11,347)	(23,270)
Promote research		-	-
Total charitable activities costs		(18,191)	(25,912)
<i>Governance costs</i>			
Trustees' expenses	2	(1,826)	(1,552)
Project management costs		(27,971)	(8,380)
Other expenses		(2,939)	(2,397)
Total governance costs		(32,736)	(12,329)
Total resources expended		(76,759)	(46,329)
Net movement in funds		(13,821)	13,602
Total funds brought forward		116,176	102,574
Total funds carried forward		102,355	116,176

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

**CMV Action
Balance Sheet
As at 31 January 2017**

	2017	2016
	£	£
Current assets:		
Debtors - prepayments	7,200	2,000
Cash at bank and in hand	96,459	117,381
Total current assets	103,659	119,381
Liabilities:		
Creditors: Amounts falling due within one year - accruals	(1,304)	(3,205)
Net assets	102,355	116,176
The funds of the charity:		
Total unrestricted funds	102,355	116,176

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

**CMV Action
Cash Flow Statement
For the year ended 31 January 2017**

	2017	2016
	£	£
Reconciliation of changes in resources to net cash inflow from operating activities		
Net (outgoing)/incoming resources	(13,821)	13,602
Decrease/(Increase) in debtors	(5,200)	3,000
Increase/(Decrease) in creditors	(1,901)	2,037
Net cash (outflow)/inflow from operating activities	(20,922)	18,639
Net funds at 1 February	117,381	98,742
Net funds at 31 January	96,459	117,381

The notes on page 4 form part of these financial statements.

By order of the Trustees

**Tom Kelman
Honorary Treasurer
18 August 2017**

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

	2017	2016
	£	£
Includes expenses reimbursed to Trustees as follows:		
In respect of travel	1,406	1,067
In respect of reimbursed telephone costs	312	262
In respect of reimbursed subsistence costs	108	223
Total Trustees' expenses	<u>1,826</u>	<u>1,552</u>

3. Debtors – prepayments and accrued income

Prepaid exhibition fees	7,200	-
Accrued income from fundraising events (received in following year)	-	2,000
	<u>7,200</u>	<u>2,000</u>

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

Printing & postage	-	1,265
Grant Developer's fees	200	1,200
Project Manager's fees and expenses	664	650
Website fees	-	90
Trustees' expenses	440	-
Trustees' meeting room hire	-	-
Total accruals	<u>1,304</u>	<u>3,205</u>

Independent Examiner's report to the Trustees' of CMV Action Charity No.1147633

I report on the accounts of the Charity for the year ended 31 January 2017.

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 an 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
18 August 2017
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