



# Trustees' Annual Report & Financial Statements

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For the year ended 31 January 2014

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## **Chair's foreword for 2013-14 report**

The past two years have been a period of rapid growth and organisational change for CMV Action. The organisation has developed from its roots as a parent support group to establish an ambitious mission – educate, vaccinate, eradicate. As word has spread about the new objectives of the organisation, we have had a fantastic fundraising response from our supporters. Many of these are families who have been personally affected and do not want others to experience the same pain unnecessarily.

So having focussed on setting direction and registering as a charity in '12-13, we now faced questions about how we would achieve our goals. The 2013-14 year is one in which we have focussed on planning for the future. It is also one in which we have improved working practices and efficiency. This means that we can make greater strides towards our goals with the precious time that Trustees and volunteers give.

I would like to highlight some of the key achievements for the organisation during this period. First of all, we are proud to have published an ambitious but credible plan for achieving our objectives.

Then in order to implement the plan we have defined our own approach to building a cohesive and effective Board of Trustees. Each Trustee is responsible not just for collective decision making but for delivering their own challenging portfolio of work. I am grateful for the substantial time, expertise and energy that each Trustee brings to their unpaid role. Partners and supporters are continuously surprised to find out that the organisation is run entirely by volunteers.

The organisation started out as a support group and family support continues to be the bedrock of what we do. This year saw important improvements to the way we support families. We now distribute printed copies of an updated, comprehensive CMV information booklet to all new members. Feedback shows that this is greatly appreciated at a time when families can receive conflicting and confusing information.

Finally, we made a solid start to our awareness-raising agenda. There has been a steady flow of articles in professional publications and local/regional media. The year's activity culminated in a national TV appearance by Kimberley Walsh on behalf of the charity. We have also embraced social media, engaging 5000 people at the peak of our awareness raising activity in January 2014.

I would like to end by saying a huge thank you to our fundraisers, supporters and volunteers - too numerous to name individually. We are very excited about the future and we could not do it without you.



Caroline Star

Chair, CMV Action

**28 October 2014**

## **Trustees' Report for the year ended 31 January 2014**

### **Introduction**

The Trustees' have pleasure in presenting their annual report on the activities of CMV Action ('the Charity') for the year ended 31 January 2014. 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. It also sets out the three year action plan for 2014, 2015 and 2016.

### **Our Trustees' and their advisers**

The following individuals served as Trustees' of the Charity during the year.

Caroline Star	Chairman (from 1 July 2013)
Gaye Tomlinson	Chairman (resigned 30 June 2013)
Sarah Beadell	Head of Fundraising
Liz Estall	Head of Membership Support
Kat Foster	Head of Awareness (appointed 5 December 2013)
Aloysia Jardine	Trustee (resigned 30 June 2013)
Tom Kelman	Treasurer (appointed 5 December 2013)
Mandy Parks	Head of Support (appointed 1 July 2013; Resigned 31 August 2014)
Jan Pearman	Secretary
Becky Scope	Treasurer (resigned 5 December 2013)

The Trustees' advisers are as follows.

Medical adviser	Dr Seilesh Kadambari BSc (Hons), MBBS, MRCPCH
Banker	Lloyds Banking Group
Independent Examiner	Isahack Rahin ACCA

### **Our legal structure and governance**

The Charity is an unincorporated 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](http://www.cmvaction.org.uk).

The Trustees' are all volunteers and undertake all of the day activities of the Charity along with volunteers who provide support by assisting those who contact us for support. The Trustees' aim to meet at least monthly and in the year they met on five occasions and held ten 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 undertook the following activities during the past year to further the charities objects.

- Held a family party in Derby with around 100 attendees, bringing together parents and children to share experiences and most importantly have fun together as part of the CMV community
- Our Secretary wrote an article entitled 'What do you know about Cytomegalovirus' that was published both in The British Association of Teachers of the Deaf magazine and with a few adjustments in the British Society of Audiologists journal (called Audacity). Both articles were accompanied by 1,500 flyers. From there we then had an article entitled 'Congenital CMV: current and future research in the UK by Dr Seilesh Kadambari and Dr Mike Sharland from the Paediatric Infectious Disease Research Group at St. George's Hospital in London published in Audacity.
- Produced a CMV article for Rascals Magazine and the local NCT magazine - Bump, Birth and Beyond – Uckfield, Heathfield and District (East Sussex)
- Produced a chainmail Newsletter Magazine for deaf people in and around Bromley, Kent
- Commented in The Observer on 8 September 2013 on an article about CMV in an adult
- Jennifer Horner produced a 'Bumps' Calendar as a local fundraising initiative in the Yorkshire area. Jennifer sadly lost her unborn son to CMV and wanted to raise awareness. She sold approximately 150 calendars to local supporters. See <http://www.yorkshireeveningpost.co.uk/news/latest-news/top-stories/baring-baby-bumps-in-memory-of-leeds-baby-1-6196324>
- Our Secretary had a further article published in the Motherhood Diaries - The global magazine for parents. See <http://motherhooddiaries.com/cytomegalovirus-what-you-should-know/>
- Kimberley Walsh appeared on All Star Family Fortunes on the 6<sup>th</sup> of January 2014. We received a huge amount of awareness from her appearance on the show and our social media presence saw a positive impact with 22 new likes on Facebook, 100 re-tweets, whilst we engaged with over 5,000 people on Facebook from the 6<sup>th</sup> – 10<sup>th</sup> of January.

## **Some facts and figures**

The following facts and figures highlight our progress in achieving our objectives over the past year.

- Our membership grew by 21% or a net 47 from 226 to 273
- Over the year we answered over 100 support calls (initial contact), over 50 support emails (again, initial contact)
- Subscribers to our newsletter grew by 34% or 121 from 278 to 399.
- Our reserves increased by 105% or £28,691 from £27,373 to £56,064 due to record fundraising and donations
- In January 2014 we had a record number of visits: 8,421 to our website from a record number of unique visitors: 7,260, due in the main to the success of Kimberley Walsh's appearance on All Start Family Fortunes as highlighted earlier. Kimberley and her team generously donated their prize money to CMV Action and raised awareness on prime time TV.

## **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 review**

The past year has been a very successful year for the Charity in terms of net income. The Charity saw its net assets more than double as they grew by £28,691 from £27,373 to £56,064 and this was due to the level of donations and income from fundraising events and income from the sale of merchandise which together amounted to £35,606 in the year, whilst our expenses amounted to £6,915.

The Trustees' are fully aware that they now have a responsibility to apply these reserves to further the objects of the charity and have agreed their action plan for the coming three years and have also approved a financial budget for the year ended 31 January 2015. This will see the Trustees' apply some of the reserves to further the Charity's objects whilst also continuing to establish 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 least at the current level for the time being and built up further in the coming year. This critical matter will be revisited during the current 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. This matter will also be revisited during the current year.

The Trustees' have identified the main risks the Charity faces and these are the reliance on donations and fundraising with no regular annuity, and the reputational risk that could arise

from giving bad advice to members or issuing incorrect educational material on CMV. The Trustees' have controls in place to manage and mitigate these risks.

The following section sets out how the Trustees' intend to invest some of the reserves and identifies what investment will be made in matters such as the website, research, educational events & material and on public relations.

### **Our action plan for 2014 to 2016**

The Trustees' action plan to further the Charity's objects in the coming 3 years is as follows.

1. To support families affected by CMV by:
  - Improving our ability to match families by asking members to update the database with their child's latest information.
  - Designing a process for regular updating of the database in future.
  - Identifying how we will synthesise relevant research and expertise on the effects of CMV on older children
  - Identifying how we are going to make improvements to our support for existing members after the initial diagnosis stage e.g. better use of the newsletter, celebrating achievements etc.
  - Holding another family party
  - Advertise to members more explicitly that we can advocate and empower parents
  - Implement improvements to our support for support volunteers
2. To educate professionals, parents-to-be and the general public about prevention of CMV by:
  - Developing an awareness-raising strategy, including key messages for each group we are targeting. Identifying how to improve our understanding about gaps in professional knowledge.
  - Build a relationship with key organisations involved in antenatal care e.g. the National Childbirth Trust and the Royal College of Midwives
  - Run the first UK CMV Awareness month to include producing and distributing a pregnancy awareness-raising leaflet and implementing a hand washing campaign
  - Developing branding guidelines, tone/voice for the organisation and updated the website design
3. To support the development and implementation of research into better testing, treatment and management of CMV as follows.
  - Antenatal care: Identified how and when NICE guidelines on antenatal care are due to be updated and how we could influence this. Assessed the current evidence base on CMV prevention and identified gaps.
  - Antenatal screening: Either contributed to a pilot study on antenatal screening or helped to prepare further bids to alternative funders.
  - Neonatal screening: Contributed to design of research on implementation of CMV screening as part of the New-born Hearing Screening Programme. Contributed to stakeholder engagement strategy
  - Infant treatment: Disseminated a position paper in lay terms on length of valganciclovir treatment
  - Professional education: (*Joint activity with prevention work stream*) Identified how we will improve our understanding about gaps in professional knowledge

4. To raise awareness of the need for a vaccine amongst public, professionals and policy makers by:
  - Becoming better informed as a group of Trustees' about current research into vaccine development and the potential vaccine candidates
  - Developing key messages on vaccine development e.g. why it is needed, when it is coming.
  - Starting to integrate key messages on vaccine development into Public Relations opportunities as they arise and our social media presence.
  - Researched how organisations concerned with other conditions have prepared for the introduction of a vaccine.
5. To build the capacity of the organisation to deliver on our objectives by:
  - Researching and reviewing options for increasing the capacity of the organisation e.g. employees, contractors, volunteers.
  - Developing a costed plan of income requirements for the next 3 years
  - Developing a fundraising strategy for the next 3 years
  - Raising money through some big ticket fundraising events managed by CMV Action.
  - Continuing to support our network of fundraisers to maximise the income from one-off and ad hoc fundraising events.
  - Improving our basic working practices, core policies, internal communication.

**Public benefit statement**

Membership of the Charity is free as the Trustees' want to provide free access to our services and support. The work undertaken by the Trustees' and volunteers to further the objects of the Charity provide a public benefit by educating the public, raising awareness and supporting research into eradicating CMV.

**By order of the Trustees**

**Tom Kelman  
Treasurer  
28 October 2014**



**CMV Action**  
**Statement of Financial Activities**  
**For the year ended 31 January 2014**

	<b>Note</b>	<b>2014</b>	2013
		£	£
<b>Incoming resources</b>	<b>1</b>		
<i>Incoming resources from generated funds</i>			
Fundraising events		<b>26,188</b>	17,407
Donations		<b>9,315</b>	1,655
Merchandise sales		<b>103</b>	-
<b>Total incoming resources</b>		<b><u>35,606</u></b>	<u>19,062</u>
<b>Resources expended</b>	<b>1</b>		
<i>Costs of generating funds</i>			
Fundraising events		<b>(1,101)</b>	(1,151)
Donations		<b>(772)</b>	(120)
Fundraising trading: costs of goods sold		<b>(399)</b>	-
Total costs of generating funds		<b><u>(2,272)</u></b>	<u>(1,271)</u>
<i>Charitable activities</i>			
Promote and protect physical and mental health of families		<b>(495)</b>	(479)
Advance education of medical profession and general public		<b>(1,244)</b>	-
Promote research		<b>(216)</b>	-
Total charitable activities costs		<b><u>(1,955)</u></b>	<u>(479)</u>
<i>Governance costs</i>			
Trustees' expenses	<b>2</b>	<b>(1,278)</b>	(424)
Other expenses		<b>(1,410)</b>	(1,522)
Total governance costs		<b><u>(2,688)</u></b>	<u>(1,946)</u>
<b>Total resources expended</b>		<b><u>(6,915)</u></b>	<u>(3,696)</u>
Net movement in funds		<b>28,691</b>	15,366
Total funds brought forward		<b>27,373</b>	12,007
<b>Total funds carried forward</b>		<b><u>56,064</u></b>	<u>27,373</u>

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

**CMV Action  
Balance Sheet  
As at 31 January 2014**

	<b>Note</b>	<b>2014</b> £	2013 £
<b>Current assets:</b>			
Debtors - prepayments	<b>3</b>	<b>2,651</b>	-
Cash at bank and in hand		<b>57,738</b>	27,373
Total current assets		<b>60,389</b>	27,373
<b>Liabilities:</b>			
Creditors: Amounts falling due within one year - accruals	<b>4</b>	<b>(4,325)</b>	-
<b>Net assets</b>		<b>56,064</b>	27,373
<b>The funds of the charity:</b>			
Total unrestricted funds		<b>56,064</b>	27,373

The notes on page 9 form part of these financial statements.

**CMV Action  
Cash Flow Statement  
For the year ended 31 January 2014**

	<b>2014</b> £	2013 £
<b>Reconciliation of changes in resources to net cash inflow from operating activities</b>		
Net incoming resources	<b>28,691</b>	15,366
Increase in debtors	<b>(2,651)</b>	-
Increase in creditors	<b>4,325</b>	-
<b>Net cash inflow from operating activities</b>	<b>30,365</b>	15,366
<b>Net funds at 1 February</b>	<b>27,373</b>	12,007
<b>Net funds at 31 January</b>	<b>57,738</b>	27,373

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

**By order of the Trustees**

**Tom Kelman  
Treasurer  
28 October 2014**

## 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 2005 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

	<b>2014</b>	2013
	£	£
Includes expenses reimbursed to Trustees' as follows:		
In respect of travel	966	375
In respect of reimbursed telephone costs	278	49
In respect of reimburses subsistence costs	34	
<b>Total Trustees' expenses</b>	<b><u>1,278</u></b>	<b><u>424</u></b>

#### 3. Debtors – prepayments

Deposit for 2014 ball	1,021	-
Deposit for 2014 great south run and swim	1,630	-
<b>Total prepayments</b>	<b><u>2,651</u></b>	<b><u>-</u></b>

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

Trustees' expenses	110	-
2014 Ball deposits paid in advance	4,215	-
<b>Total accruals</b>	<b><u>4,325</u></b>	<b><u>-</u></b>

