

# COUNTING THE COST OF CMV

The economic impact of CMV



“I was careful when gardening or changing the cat’s litter tray. I avoided food and drink that may have been potentially damaging, but sadly I had no idea about preventative measures I could take to stop catching CMV.”

**Amy Taylor**

Every day in the UK, two to three newborn babies will be affected by cytomegalovirus (CMV), equivalent to almost 1,000 babies every year.

The consequences of contracting CMV infection during pregnancy, known as congenital CMV (cCMV), can be devastating for the baby resulting in lifelong impairments. CMV can cause stillbirth, miscarriage and disabilities and is the leading preventable cause of hearing loss in children. Children who have had cCMV may also develop sensorineural hearing loss (SNHL), cerebral palsy, epilepsy, autism spectrum disorder (ASD) and a range of other conditions.

This places a considerable burden on the NHS, social care, welfare and educational systems, as well as the children and families who live with the consequences of the virus.

The personal cost of cCMV is substantial, and now, for the first time, we know the economic cost is too.

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# THE JOURNEY OF A DIAGNOSIS

Rebecca Wilkins, mum to Emran describes their journey to diagnosis.

My baby boy Emran is born at 37 weeks. Rushed off to NICU, my little 6.1lb baby couldn't eat, regulate his own temperature or control his blood sugars. No tests done. Home within a week.



New born hearing test failed  
... failed again ....and again.

**Midwife:**

"Don't worry it happens all the time. Just see how he goes."

Three months: Is he meant to focus on me yet?

Six months: Is he meant to hold his head up yet? Why does he keep blanking out?



**Health visitor:** "He's fine."

**Doctor:** "He's fine."



**Everyone:**

"Wow he's so chilled, he barely moves."

**1st birthday:** Can't sit up. Why won't he look at his cake?

**2nd birthday:** Hopefully he'll walk soon.

**Me:** Please someone listen to me.



**Nursery:** "Find a good paediatrician and neurologist."

**Diagnosis:**

"Your son has brain damage and epilepsy."

**3rd birthday:** "We now know your son has CMV."

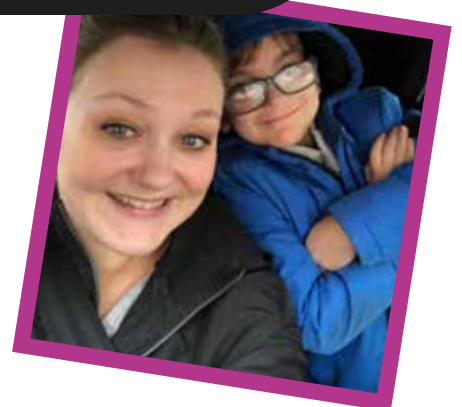


**Doctor:** "There's nothing we can do other than manage his symptoms. He won't get better. Sorry."

**Me:** World crashing and burning.

Emran is losing his hearing in one ear. He's losing his sight in one eye. His seizures are constant. His muscles in his eyes haven't formed. He gets very sick very quick. Chicken pox was scary. That's just the tip of the iceberg.

**Doctors:** "Sorry it took so long to help your son."



## EXECUTIVE SUMMARY

CMV is a common virus. It is usually transmitted via bodily fluids, such as urine, saliva, blood, mucus and tears. It is often passed on through very close contact with young children. Congenital CMV affects more babies every year than Down's syndrome, toxoplasmosis or listeriosis, yet most people have never heard of it.

While most GPs and midwives will advise pregnant women to avoid unpasteurised food and cat litter, few will talk about preventative measures to reduce the risk of catching CMV.

For around one in five babies born with cCMV, the effects will be devastating - leaving them with life-long conditions such as hearing loss, cerebral palsy and epilepsy. The impact is felt far beyond the family home, extending to the NHS, local authorities and wider society.

Progress in tackling the infection rate of cCMV has been slow, and information on how to avoid contracting CMV is not routinely provided in the NHS. Children affected by cCMV will be supported by as many as 20 different health and social care professionals; requiring support from audiology and audio-vestibular clinics, cochlear implant centres, paediatricians, physiotherapists, ophthalmologists, orthoptists, occupational therapists, speech and language therapists, psychologists; psychiatrists, teachers of the deaf, special educational needs support and social workers. This is a huge burden for an over-stretched NHS, local educational authority and social care system.

CMV Action commissioned York Health Economics Consortium (YHEC) to estimate the economic costs of cCMV in the UK. This model provides a 'snapshot' of the estimated cost burdens of cCMV to the UK in the year 2016 (the most recent complete single year when the model was developed).<sup>1</sup>

Further evidence on the personal cost of cCMV on families came from a parent study where 164 parents completed a financial impact survey. The survey asked respondents to describe the services, equipment and adaptations required; changes to parents' working patterns, and any other financial costs associated with caring for their child.

In recent years there has been a growing awareness of the financial impact of health conditions. The purpose of this research is to establish the economic impact of CMV on both the Government and on the families living with long-term conditions following an infection with CMV. Before this research, there was little knowledge of the economic impact of cCMV.

- Some cCMV infections result in children living with a high degree of disability.

- Around a quarter of parents who responded to our survey require costly special education and additional help from specialist support workers.
- Some parents are forced to leave work, or reduce their hours, in order to be able to care for their child.
- While most specialist equipment costs were covered by either the NHS or local authorities, families reported various additional cost burdens.
- For the families we surveyed, most rely on benefits due to limited ability to work, until their children reach adulthood.
- Costs not included in this report include stillbirths and neonatal deaths due to cCMV. However, the emotional cost to families is huge.

The purpose of the report is to contribute towards filling the evidence gap, show CMV is a serious public health issue, and share our recommendations to reduce the burden.

Ultimately, fewer babies born with cCMV would save the NHS and social services millions of pounds and reduce the cost to society in general.

# CONGENITAL CMV COSTS THE UK £750M A YEAR

We now know cCMV costs the UK a staggering £750m every year and, from the evidence gathered, we believe this figure is a conservative one. Approximately 40% of the costs (£330 million) fall directly on the NHS, social services and educational services.

The remaining £420 million falls on the wider economy through lost work days, as well as the personal costs paid by parents,

including funding specialist equipment and therapies for their children.

As well as facing additional costs, families living with cCMV must also manage the impact of living on a reduced income as many are unable to work due to the demands of caring for a disabled child. Benefits received, such as Carer's Allowance and Tax Credits, do not compensate for the loss of a salary.



## **“It is impossible to maintain a job.”**

“Imogen is severely disabled. She can't walk, talk and is fully dependent on adults. She has cerebral palsy and requires a lot of care. Even now, when I speak to midwives about CMV they usually ask ‘what's that?’ – they have no idea how catastrophic it can be.

“Imogen had so many appointments during the week it became impossible to care for her and maintain a job, especially as a single parent.

“I get quite a lot of benefits with Imogen being so severely disabled. Imogen has cost the NHS and social services a lot of money. Having a disabled child requires a lot of support. The message of prevention must be given to pregnant women. I am shocked at how little professionals know about CMV and wish that, at the same time you are advised to not touch cat litter or eat unpasteurised cheese, professionals would also advise you on the risks of CMV and some preventative measures to avoid catching it.”

**Lynda Quibell, Imogen's mum**



This report reveals a hidden side of a silent infection. A staggering £750 million is being spent annually on the effects of a virus many professionals have little knowledge about.

The majority of these costs are due to the long-term impairments caused by the virus. The most costly condition associated with cCMV, autism spectrum disorder (ASD), was estimated to cost £412m. In contrast, acute treatment of cCMV was a relatively low cost, contributing £1.2m.

For a virus that is rarely discussed in routine antenatal care, and about which there is a lack of awareness among parents and medical professionals alike, this is a considerable economic burden.

We must consider the economic impact of cCMV in light of unfolding policy developments. The health and social care system is facing enormous challenges.<sup>2</sup> Real-term budget cuts and increased demand for NHS services can mean children are not provided with the care they need so parents have to supplement it.

The even more extreme funding pressures on social care present a further threat to disabled people who require support to live safely and comfortably in their own homes.<sup>3</sup>

### **A shocking lack of evidence exists in the UK**

This figure of £750m, as large as it is, is actually a conservative one.



“When Ben was born he was surrounded by doctors. It was clear he was in big trouble. The doctors didn’t know what they were dealing with. They didn’t test for CMV, and information on CMV at the hospital was at least 20 years old. The only reason Ben was eventually tested for CMV was down to an Australian doctor here on secondment.”

**Julia Mills, Ben’s mum**

Sadly, in the UK there is a startling lack of current, robust data.

The model, developed by YHEC, demonstrates how scarce CMV literature specific to the UK is, with prevalence and incidence rates over 20 years old and few large-scale follow-up studies.

The introduction of screening practices would dramatically improve our knowledge and provide the basis for more robust epidemiological and cost data. This data is essential for medical decision-making to assess the cost-effectiveness of both antiviral interventions and preventative measures to reduce infection. These include universal immunisation for when a CMV vaccine is developed and a change in clinical practice whereby pregnant women are routinely advised

on preventative measures to reduce the risk of infection.

### **Babies deprived of a diagnosis**

Acute management, at £1.2 million, is only a small percentage of the overall cost of cCMV. This figure is influenced by the low number of children diagnosed and provides further evidence of the need to secure a firm diagnosis.

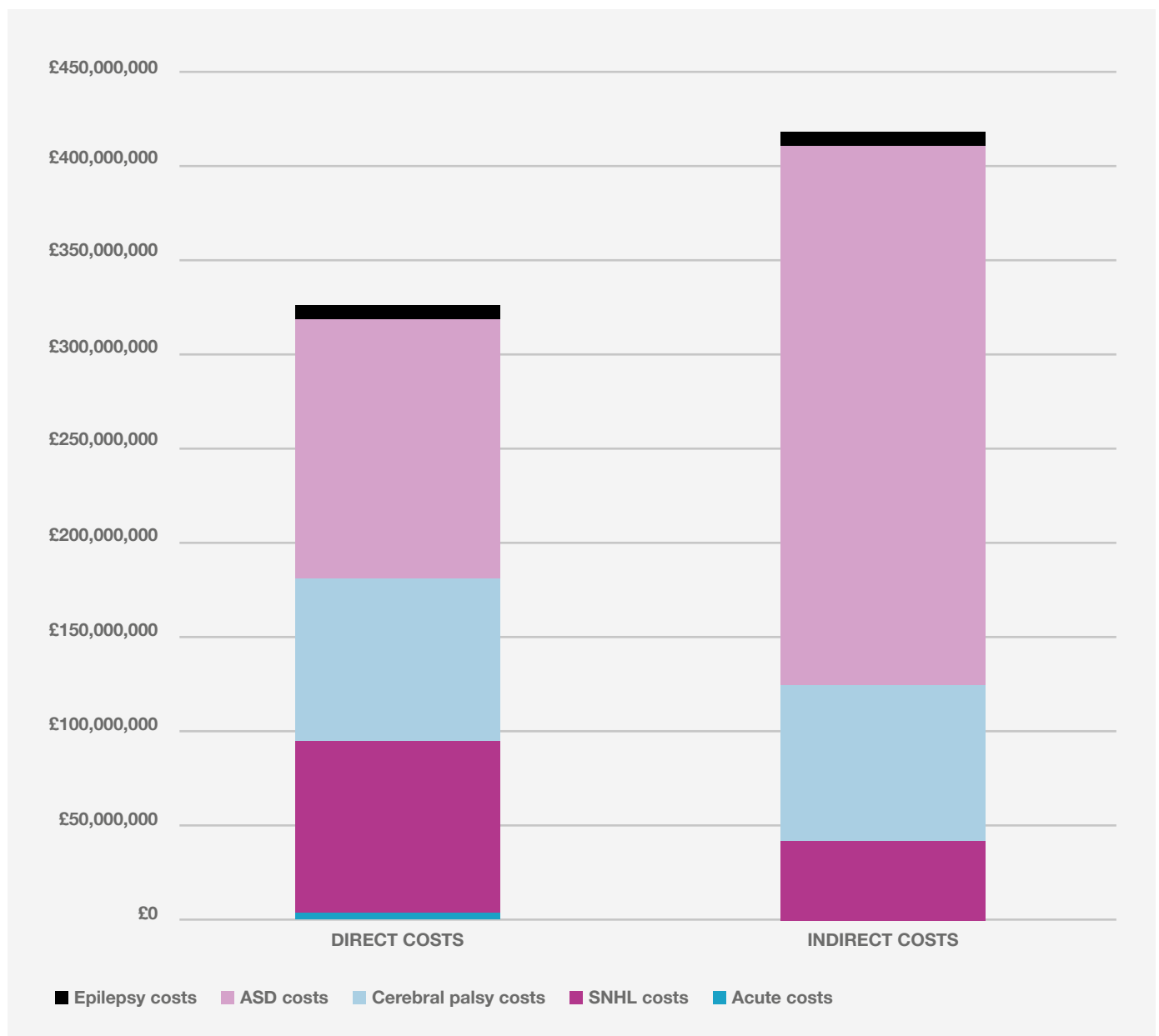
Importantly, many children living with life-long impairments as a consequence of cCMV may never have CMV identified as the cause of their disability. This is due to a lack of testing in clinical practice meaning the likely number of children affected by cCMV is far higher than the data presented here shows.

# COSTS OF CONDITIONS

The most common neurodevelopmental impairment resulting from cCMV is sensorineural hearing loss (SNHL). The total costs for children living with SNHL caused by cCMV is estimated to be £130m, with £15m in direct costs to the NHS.

Costs associated with autism spectrum disorder (ASD) are the greatest of all conditions caused by cCMV accounting for approximately 50 to 60% of total costs. Costs to the NHS are substantial at £136m. This is because many children affected

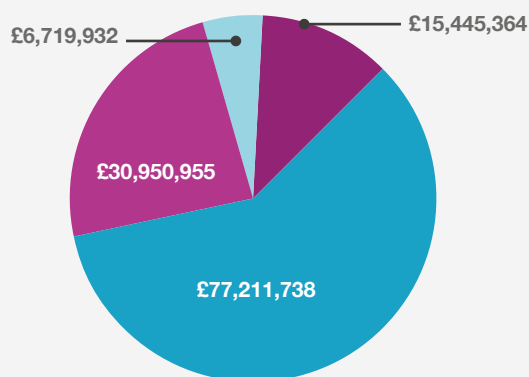
by ASD require support from a number of services including speech and language therapy, occupational therapy and educational support. Alongside this, many children may need specialist educational support.





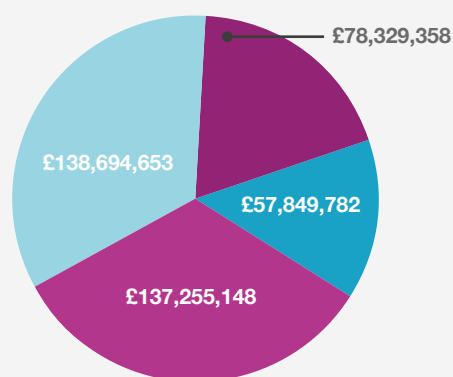
# CAUSED BY cCMV

## SENSORINEURAL HEARING LOSS (SNHL)



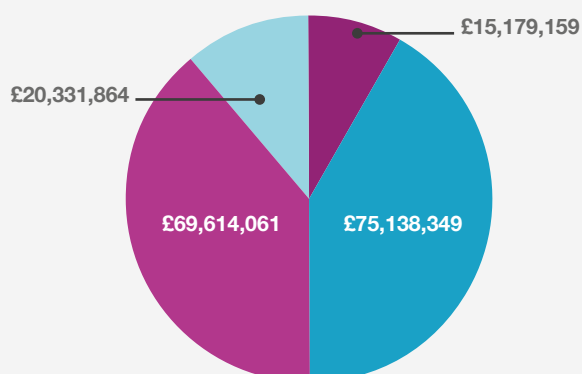
- Direct clinical costs
- Direct non-clinical costs
- Indirect societal costs
- Indirect non-societal costs
- Indirect costs

## AUTISM SPECTRUM DISORDER (ASD)



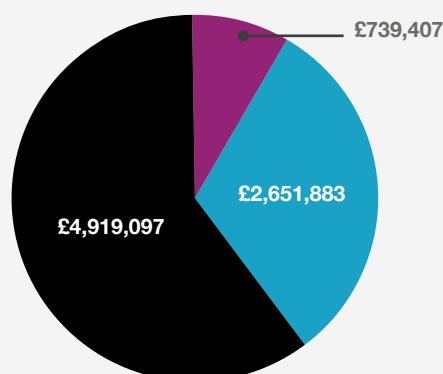
- Direct clinical costs
- Direct non-clinical costs
- Indirect societal costs
- Indirect non-societal costs
- Indirect costs

## CEREBRAL PALSY



- Direct clinical costs
- Direct non-clinical costs
- Indirect societal costs
- Indirect non-societal costs
- Indirect costs

## EPILEPSY



- Direct clinical costs
- Direct non-clinical costs
- Indirect societal costs
- Indirect non-societal costs
- Indirect costs

# THE PERSONAL COST

Families have given further evidence of the significant economic burdens they face due to the consequences of cCMV. CMV Action ran a survey to provide more detail of parents' experiences and the economic impact they face including changes to working patterns.

Economic burden is not purely a matter of income

and expenditure. Financial capability plays a significant role in determining how resilient a household is to changes in its financial circumstances.

As well as having additional costs, families must also manage the impact of living on a reduced income as they are unable to work due to the demands of caring for a disabled child.

"When Emran started nursery, I had to leave work after constantly being called out for seizures, chest infections and other issues. Financially it was hard and we got in quite a bit of trouble. To help with finances we have had to move to a cheaper area two hours away from my family. That was especially hard."

**Bex Wilkins**



## "The economic impact is huge."

"Gabe has cerebral palsy and development delay. We have a hospital appointment pretty much every week, whether it be physio, speech and language therapy, orthotics, audiology or the paediatrician.

"Gabe's impairments cost the NHS a lot of money through his therapies and the equipment he needs. The economic impact on the NHS from cCMV in my opinion is huge and therefore there must be more awareness about CMV and how it can be prevented. "Recently I had to resign from the job I've done for the last 12 years to care for Gabe. Despite wanting to continue to work, it was impossible because I couldn't devote enough time to his therapy.

"We pay for additional physiotherapist sessions to support the ones we receive on the NHS. Physiotherapy is important for Gabe so we pay for the extra support. At £120 a session it is expensive, and we have to find an extra £240 a month to fund it. Thankfully our family helps."

**Stephanie Whitelock, Gabe's mum**

# REDUCED CAPACITY TO WORK

From the survey we can see evidence of the high impact cCMV has on parents' employment, with a significant number having to either give up or reduce their hours at work in order to care for their child. Conditions such as ASD and sensory problems were consistently accompanied by high levels of working hour reductions, while ADHD was associated with high absences from work.

## Funding specialist equipment

While the majority of specialist equipment was funded by the NHS or local authorities, parents were left to fund some significant expenses, including wheelchair accessible cars, home adaptations and equipment. The vast majority of mobility vehicle costs were funded by families, as well as 15% funding adaptations in the home and 50% funding home hearing adaptations.

Alongside substantial one-off costs, families also funded regular and ongoing costs for items such as specialist seats, top-up therapies, extra educational support and travel.



“Our Local Authority is still paying for Calum’s space in an enhanced resource facility for deaf children school, despite the fact that he is at home with me and was only at school for 12 days. The school was not right for Calum, but our Local Authority doesn’t order specialist reports, so are unaware of Calum’s needs. We have so far had to self-fund £3,000 for private assessments.

“The impact on our life has been huge. I have had to close my accountancy business down. My husband’s business has been affected as he needs so much more time off work. Yet the demands on our finances are huge due to us having to prove that Calum needs support. This is alongside paying for private tuition at home and the educational and sensory equipment we have had to pay for.”

**Gaye Tomlinson,**  
**Calum’s mum**



# THE COST OF BEN'S

**Ben was born and rushed to NICU where he spent 28 days: £46,000**

Until he was one, Ben had over 40 paediatric appointments.

**Alongside...** specialist consultant appointments, music therapy, physiotherapy, speech and language therapy, occupational therapy (OT), specialist equipment, community nursing.

**Estimated cost to the State: £25,000**



## 1 – 4 YEARS

Specialist consultant appointments, physiotherapy, occupational therapy, music therapy, speech and language therapy, equipment, community nursing.

**Estimated cost to the State: £25,000**

**The family funded:** hydrotherapy equipment NOT funded by NHS/social services, private physiotherapy, cranial therapy.

**Estimated cost to the family: £11,500**



**COSTS TO NHS AND SOCIAL SERVICES:**

£1,700

**COSTS TO FAMILY:**

£22

**TOTAL COST:**

£1,900

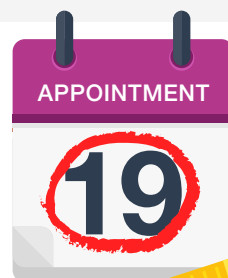
## 5 – 15 YEARS:

18 hospital admissions, specialist consultant appointments, occupational therapy, physiotherapy, wheelchairs, home adaptations.

**Estimated cost to the State: £430,000**

**The family funded:** Home adaptations, heating w/ hydrotherapy pool, equipment.

**Estimated cost to the family: £155,000**



In reality this figure is likely to be much higher because costs like C

# S CARE – 26 YEARS



0,000

20,000

0,000



ntments, speech and language therapy,  
home adaptations, equipment, special school.

washing, activities, mobility cars,



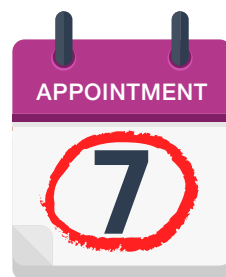
## 21 – 26 YEARS:

Supported housing, equipment,  
benefits – specialist consultations,  
hospital admissions.

**Estimated cost to the State:**  
£500,000

**For the family:** physiotherapy,  
wheelchair maintenance.

**Estimated cost to the family:** £9,000



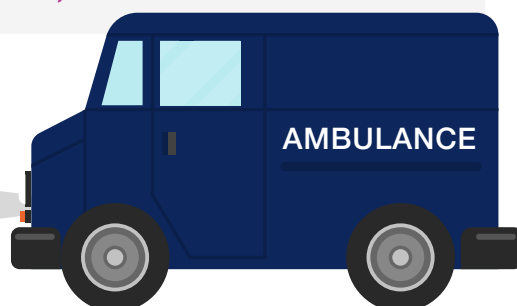
## 16 – 20 YEARS:

Special school, music therapy,  
equipment, specialist consultants.

**Estimated cost to the State:**  
£655,000

**The family funded:** motorised  
wheelchair and ongoing costs,  
activities, physiotherapy,  
wheelchair car.

**Estimated cost to the family:**  
£44,500



Continuing Health Funding and benefits have **NOT** been included.

# COSTS NOT INCLUDED

Our economic model used evidence available but, due to the lack of robust data, not all implications of cCMV were included.

## **Miscarriage, stillbirths and infant deaths**

Congenital CMV can result in stillbirths, infant deaths and may be responsible for early deaths in later life. In addition, parents may decide to terminate a pregnancy due to damage caused by cCMV.

## **Ante-natal costs**

Additional ante-natal costs incurred following pre-natal diagnosis were not included in our model and we were also unable to include costs for many of the development impairments that are difficult to clinically define, such as motor impairment, balance issues or intellectual disability.



“The human cost of cCMV – well you just can’t put a number to it. It has caused our family an immeasurable amount of pain and suffering. The impact it had on our two children was huge. They just couldn’t understand why our baby Annie didn’t come home.

“Since Annie died we have had a little boy. During the pregnancy my wife was so scared about catching another infection. No health professionals seemed interested in talking about it or discussing preventative measures she could take. You never hear about the devastating consequences of cCMV to an unborn child. People should know it can kill a baby.”

**Richard Thompson**



## WE NEED TO TAKE ACTION NOW

GP Christine Glew, wants GPs to help reduce the numbers of babies born with cCMV by providing simple routine advice to pregnant women. Driven by own personal experience, Christine wants her colleagues to know how one simple recommendation could save the NHS millions every year.

"I vaguely remember CMV being covered as part of my paediatric training, and how, if transmitted during pregnancy, it could cause stillbirth, miscarriage and lifelong impairments. I had no cause to think about it again, until years later when my second child was born. After my daughter's birth I took in the low birth weight, tiny head and the knowledge she had failed her hearing test – and had a flashback – this sounds like CMV.

"After Ellie's birth we were referred to a paediatrician to investigate the cause of deafness. I pushed for Ellie to be tested for CMV. The blood test came back negative. I insisted a further urine PCR was taken. The PCR came back positive. This result enabled Ellie to be treated with antiviral medicine just starting within the recommended six-week window. If treated within this time frame, studies have shown it helps to help reduce the impact of SNHL hearing loss.

"Ellie was tube fed from six weeks, had hearing aids at nine weeks and six general anaesthetics in her first year alone. Ellie had her first cochlear implant at 14 months and second at 23 months. Sadly, as Ellie got older, we realised deafness and speech were not the

only consequences of CMV. Ellie has autism, learning difficulties and struggles with eating and sleeping.

"Every day we live with the consequences of CMV. The constant, unending battles to get Ellie the right care and support. The many meetings and hospital appointments, making it impossible to work full time as a GP. My two other daughters have become young carers. The emotional toll on the family is huge. The consequences of CMV extend well into our family budget. I must have driven thousands of miles to take Ellie to appointments – whether that be at Great Ormond Street or to Oxford. The transport and hospital parking costs alone soon mount up.

"Ellie requires a great deal of support from the NHS. She sees speech and language therapists, physiotherapists, occupational therapists, dieticians, paediatricians, ophthalmologists and balance specialists. Some of this support is likely to continue for the rest of her life.

"I really want to get the message out to GPs that ultimately the best way to reduce the future cost burden of cCMV is by fewer babies being born with the

infection. This is why it is vital we as GPs, alongside midwives, advise pregnant women of the simple hygiene measures to reduce the risk of infection. Lower rates of cCMV infection have been reported in countries where risk reduction advice is routinely given. Despite this, information about preventing a CMV infection is not routinely provided by GPs and midwives.

"As GPs we need to do our bit to reduce the transmission of this devastating infection. Simply when we advise our patients not to touch cat litter or eat blue cheese, we should also advise them not to kiss young children on the lips, share cutlery, and to wash their hands after feeding a child or changing nappies. Making women aware of the risks helps them take action to reduce their risk of getting infected with CMV. It is such a simple solution, but sometimes the most effective solutions are the most simple ones."



# CONCLUSIONS AND

The costs associated with the management of cCMV provide strong evidence that to reduce the number of babies affected by cCMV and to provide better long-term

Informed by evidence gathered through this research, we make six recommendations to reduce the infection rate and minimise the future cost burden of cCMV on the NHS, Government and on families themselves.

## RECOMMENDATION 1: Risk reduction advice should be routinely given to pregnant women.



Ultimately the best way to reduce the future cost burden of cCMV is by fewer babies being born with the infection. This is why it is vital midwives are educated to advise pregnant women of the simple hygiene measures to reduce the risk of infection. Lower rates of cCMV infection have been reported in countries where risk reduction advice is routinely given.<sup>4 5 6</sup> Despite this, information about avoidance of CMV infection is not routinely provided by the NHS.

There is a long history of evidence that educational interventions

can prevent congenital diseases. For example, efforts aimed at preventing foetal alcohol syndrome have reduced maternal alcohol consumption in pregnancy<sup>7</sup>, pre-natal vitamin and folic acid supplementation have lowered rates of neural tube defects<sup>8</sup>, and antiviral use in pregnancy has been shown to reduce mother to child transmission of HIV.<sup>9</sup>

We also know that pregnant women are a highly motivated group who are more likely to follow CMV preventative measures than non-pregnant women<sup>10</sup> and that women of childbearing age in the UK want to know more about CMV.

## RECOMMENDATION 2: Produce and implement clinical guidelines and pathways for testing, improved diagnosis and management of cCMV.



Paediatricians and other professionals working with families must

understand the guidelines for managing CMV so that more families receive monitoring and support.

As the estimated costs for acute antiviral treatment are relatively minor, more research needs to be conducted to assess whether antiviral treatment can be effective in preventing or reducing the severity of other forms of impairment that develop as a consequence of cCMV. There is evidence to show that the antiviral medicine valganciclovir is effective at reducing SNHL, as well as developmental delays in other neurocognitive functions, in the 24 months following birth.<sup>11</sup>

Currently the treatment is only advised for babies born with symptoms and with central nervous system involvement, with controversy remaining over whether babies with only SNHL should be treated.<sup>12</sup>

Given that a high proportion of the cost burden is attributable to babies born without symptoms, who later develop neurodevelopmental impairments. More research into

# RECOMMENDATIONS

more needs to be done in terms of prevention, diagnosis and intervention, in order outcomes for children affected.

the benefits of this treatment in babies presenting with no symptoms may provide another avenue from which to target the cost burden of the virus. It is only through this that we will be able to bring the UK in line with other countries more advanced in managing CMV infection.

## RECOMMENDATION 3:

Targeted screening for cCMV in children who fail a newborn hearing test to enable affected children to receive treatment much sooner.



There have been significant advances in laboratory technology that enable cCMV to be diagnosed promptly in children who fail their newborn hearing screening test. A pilot study in the UK reported that such screening would be cost-effective.<sup>13</sup> A recent study in the USA indicated that targeted newborn screening would be a cost effective option for detecting and reducing hearing loss caused by cCMV.<sup>14</sup>

## RECOMMENDATION 4:

Universal screening for cCMV to enable affected children to receive treatment much sooner.



There have been significant advances in diagnostic technology and treatments in SNHL. Now, more than ever before, universal screening for cCMV would enable affected children to receive treatment much sooner. A study indicated that universal newborn screening would be cost effective for detecting and reducing hearing loss caused by cCMV in the USA.<sup>15</sup> Although this model is based on the US healthcare system, and not all assumptions are likely to be applicable to the UK, it suggests there is potential for a similar impact in the UK.

## RECOMMENDATION 5:

Invest in research to support clinical decision-making.



Information on cCMV is limited and what does exist is out of date. This is severely hampering our ability to monitor treatments and longer-term outcomes for children affected by cCMV. This means the current situation of 1,000 babies born with cCMV this year, will continue next year, and the year after that, unless something is done.

More investment is needed to gather knowledge and data on which we can make sound, evidence-based clinical decisions. Parents would welcome tests at birth that could provide guidance on the severity of symptoms their child is likely to suffer from. The safety and cost effectiveness of treatment during pregnancy should be evaluated. While this clearly includes research into the efficacy and cost of new drugs, attention should also be given to new diagnostic techniques such as foetal MRI or blood sampling for early identification of babies who may benefit from antiviral treatment.

**RECOMMENDATION 6:**

Develop a vaccine to end CMV.



Our most expensive recommendation, but one that in the long-term

would save billions of pounds, is the development of a vaccine – to eradicate CMV once and for all.

Research into a vaccine for CMV has been massively underfunded for years, causing huge delays in the search for an effective vaccine. Despite this, the prospect of an effective vaccine looks promising with a number of pharmaceutical companies reporting in 2018 that they have vaccines at various stages of development.

With the accelerating pace of research, it is believed a vaccine may be available within 10 years. We recognise that it will take years for CMV to become controlled in a whole community once a successful vaccine becomes licensed; this is why we believe investment in this area should be accelerated now, to reduce the number of years that CMV drains funds from the NHS.

## JUST THINK....

**What could the NHS and social services do with an extra £750m every year?**

**Fund 1,822,500 bed nights<sup>16</sup>**

**Fund 15,510 midwives for a year<sup>17</sup>**

**Fund over 2m health professionals to undertake training on cCMV and other infections in pregnancy.**

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