Congenital cytomegalovirus (cCMV) is the most common viral and infectious cause of disabilities to newborn babies. It can cause sensorineural hearing loss and deafness, cerebral palsy, verbal, oral and motor dyspraxia, global developmental delay, microcephaly, feeding issues requiring a gastrostomy tube, intellectual disabilities, epilepsy, blindness and death. There are also children with cCMV who are on the autism spectrum however studies have yet to be carried out in this area. For the rest of the family the consequences of cCMV are life changing. Additional pressure on families, separation and divorces between parents, financial hardship, health issues such as anxiety, depression and chronic back problems are just a few examples. Siblings can often find themselves in carer roles, they will often have less time with their parents and are also at risk of having their own health issues such as anxiety.

Cytomegalovirus (CMV) is called a stealth virus for good reason. So many people often carry the virus without ever feeling the effects of it. Despite this CMV can be devastating to anyone with a weakened immune system. The surreptitiousness of the virus is also evident in the fact that often parents won’t be aware that their baby has had the virus until they are diagnosed with a disability after they are born. Ironically this is usually a time in our lives which we expect to be one of the most beautiful – welcoming a new life into the world. Instead families can feel as if their lives have been turned completely upside down and violently shaken. Shattering everything we thought we knew into thousands of pieces which we are then left to try and put back together as best we can.

Some families mourn a miscarriage, others a still birth, and then there are others who might get a day or two with their babies before they die. For many of the more fragile children and their families there are a lot of hospital stays. These families live with the constant and unrelenting fear of not knowing how long their children have. They are the bravest people I know.

For those of us who have not lost our babies we know how lucky we are but our norm becomes filled with appointments with all sorts of early intervention therapists and medical specialists including Audiologists, ENTs, Paediatricians, Neurologists, Psychologists, Ophthalmologists, Infectious disease specialists, Gastroenterologists, Occupational Therapists, Physiotherapists, Audio Verbal Therapists, Speech Therapists, Special needs educators, Counsellors and Social Workers. We become case co-ordinators and fierce advocates for our children, cochlear implant trackers and under the direction of our children’s therapists we also get pretty good with different types of therapy and special education. This becomes our main job, although it is not a job any of us would choose.

The specialists we see for our children do not have a crystal ball and so usually there are not many answers that can be given but our questions and fears are relentless, particularly in the first few years.

Will our baby have an intellectual disability? Will they have seizures? Can my child hear me? Will he be able to hold his head up? Does she have cerebral palsy? Will he ever sit and support himself? Will she be able to feed herself? Is his hearing deteriorating? Will she ever crawl? Will he ever walk? Will she be able to make friends? Will we ever get him out of nappies? Will she ever talk? Does he understand me? Will we ever be able to reason with her? Will the tantrums ever stop? How big is the gap going to be? What kind of life is my baby going to have?

My son, William, is deaf with mild cerebral palsy, motor, oral and verbal dyspraxia and moderate global developmental delay. He and
Under the Microscope

his twin sister, Emmaline, turn 5 in November this year. For the first few years of William’s diagnosis I was often an emotional mess, feeling quite disconnected from friends and family who were getting on with their lives. I found anxiety, depression and weight gain more difficult to manage as life became more overwhelming than I could have ever imagined. I have felt so isolated and alone at times, often the only people I felt really understood were other Mums who have gone through something similar. I know that I am one of many who will always wish that we had been given the opportunity to reduce our risk of contracting CMV by adhering to a few behaviour modifications while pregnant. We missed a 50% chance of preventing our children from having congenital CMV. I look forward to one day celebrating the implementation of a successful vaccine. Until then however I believe it is everyone’s responsibility to make sure that all woman are counselled about congenital CMV before pregnancy. As the Hippocratic Oath says: ‘I will prevent disease when ever I can, for prevention is preferable to cure.’ www.cmv.org.au

– Kate Daly

The real story of congenital cytomegalovirus

Imagine that you, or your partner, have given birth to a baby and you find out that your baby has been exposed to a dangerous virus during the pregnancy. This virus could have a questionable impact on your newborn’s development and prognosis. This virus is cytomegalovirus (CMV) and your newborn has been diagnosed with congenital CMV.

You were never informed of this virus by your physician during pregnancy and were never told of any precautionary measures that could possibly prevent exposure. You may blame yourself for allowing harm to come to your unborn child and may wonder how and where you may have acquired the virus and what you could have done to prevent it.

As you inform friends and family members about your newborn’s diagnosis, they may ask questions about how you contracted this virus and what may happen to your baby. When you express your concern and may not have answers to their questions, they may search on the internet and find information regarding herpes and HIV, which could be confusing and can be taken out of context.

Your family and friends may also read about shedding and contagion issues and assume that your child could infect healthy people and cause them to experience disability or death. You may see a decline in contact from your friends and family. Upon learning of your baby’s diagnosis, family and friends who expressed eagerness to visit and meet your baby may cancel their visits, not call at all or never speak to you again.

You may be disinvited from playgroups out of fear for the other children. There may be an assumption that your child could infect and disable otherwise healthy children in the group. You may have to field questions from babysitters and daycares about your child’s diagnosis and about the perceived impact that your child’s presence may have on the caregiver, the other children, and on their business.

When your child begins preschool or elementary school, there may be concern expressed about your child’s diagnosis. You may have difficulty in explaining to the teachers and staff that your child poses no threat to anyone in the classroom or on the campus.

Over the months and years, you may also experience grief, shame, anger, and depression. You may wonder why other parents and medical professionals didn’t sound their voices louder to warn you to possibly spare you and your child.

Fortunately, you are only asked to imagine this as an experience in your life and in your child’s life.

As a parent of twins born with congenital CMV, I can attest to you that the disease burden of congenital CMV is profound and very real. While emerging research is giving us great insights into the epidemiology, prevention, diagnosis, and treatment of congenital CMV, the true and lasting impact of this virus is felt day after day in families the world over. Whether children are born mildly or severely affected by CMV, they, as well as their families, deserve a public health outcry and development of sound professional and government policy to help stop CMV.

– Janelle Greenlee

Biographies

Kate Daly is the Founder and President of the Congenital CMV Association of Australia, the only not-for-profit organisation in Australia focussing on congenital CMV, representing and supporting families affected as well supporting those working towards a cure. Kate lives in Sydney with her husband and four children.

I started the association in the hope that other parents won’t feel as alone as I did when William was diagnosed and also to raise awareness about CMV so that other parents can have an opportunity I didn’t, to minimise their risk of contracting the virus and giving it to their unborn babies.

Janelle Greenlee is the founding president of Stop CMV, the world’s largest all-volunteer organisation dedicated to CMV. Comprised of families, friends, and medical professionals personally affected by CMV, the mission of Stop CMV is to prevent and eliminate congenital CMV and to improve the lives of all people affected by congenital CMV.