
Same but Different

About

Ceridwen's images have appeared in publications throughout the world. She is passionate about capturing that moment in time that draws the observer in to want to know more. If it ignites interest or simply makes someone pause then she is happy. Her images of those affected by rare disease or disability have appeared in exhibitions throughout the Uk and include the Houses of Parliament , hospitals, galleries and theatres.

"My own experience with rare disease started the day my youngest son was born. From that moment I became aware that people often see the disease or disability before the child. I founded Same but Different as a way to redress that balance and encourage people to see the person rather than the condition."

RARE AWARE

The project

Same but Different uses the arts for positive social change by working in partnership with organisations, communities and individuals to highlight inequalities and bring communities closer together.

The team create thought-provoking art projects that stimulate conversation, change attitudes and empower those affected.

Through this project we shine the light on rare diseases and its impact on children.

The images and stories in this brochure are only a small, curated sample of those available.

APRIL

April is a brave and determined little character, so friendly and quirky, she charms everyone who meets her. She forever wants to play out in the garden or at the park and loves mud and puddles and paint - anything where she can make a mess. Like most children she enjoys singing and stories, cuddling and Cbeebies! April has two brothers, George and Eli, who she smothers with affection - whether they like it or not! April loves getting together with her cousins and wider family and being thoroughly spoiled by everyone.

HURLERS SYNDROME

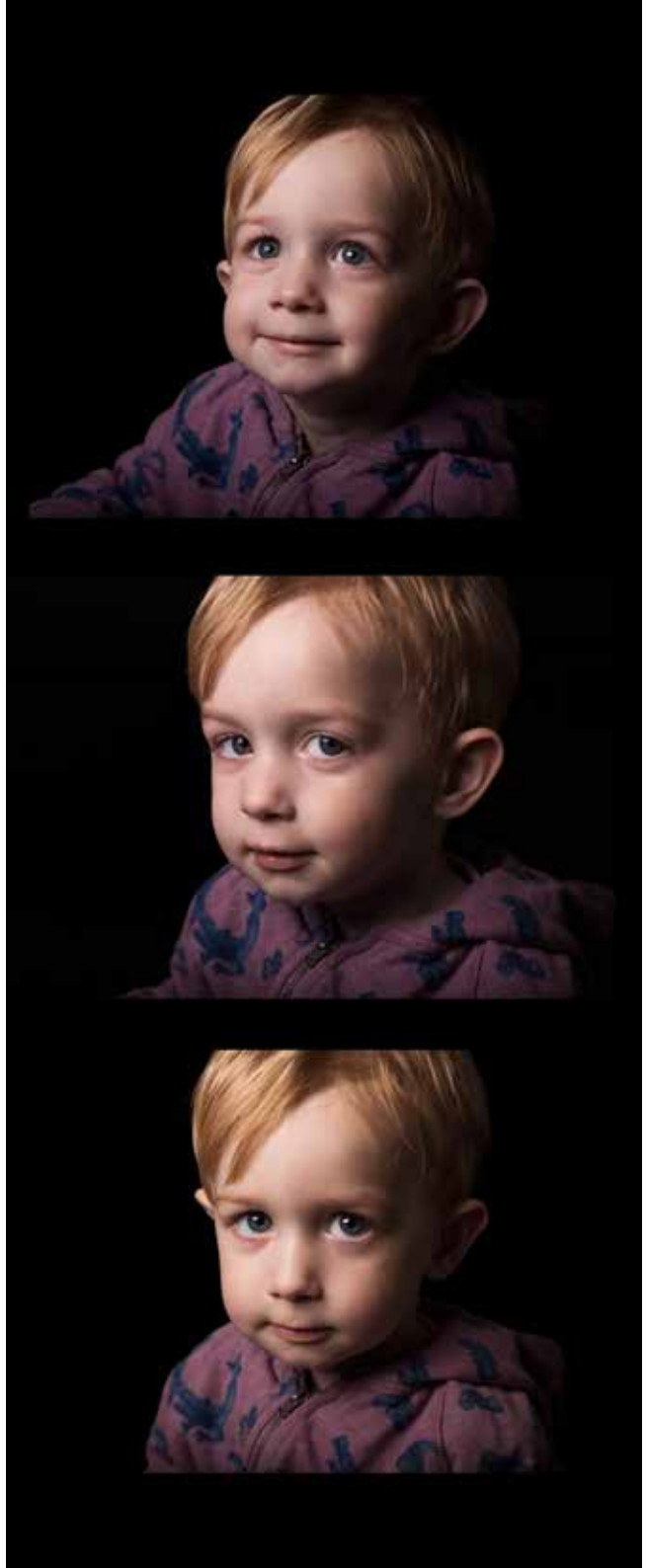
April is a three years old girl who has, but is not defined by, mps1 (Hurlers Syndrome). This is a genetic condition which affects 1/100,000 people.

April receives fantastic treatment at Manchester Children's Hospital, who are specialists in April's condition and has developmental input from the team in Wrexham Maelor, including play, speech and physiotherapy. She is supported by the MPS society who fundraise for research, provide information and do advocacy work for families as well as organising conferences and events to bring affected families together.

Luckily the progression of the disease has been halted, though not cured, by a bone marrow transplant, which April had at eight months old. This is effective in replacing the enzyme but does not solve any musculoskeletal issues and cannot repair damage already caused.

About the condition

Hurler syndrome is the most severe form of mucopolysaccharidosis type 1, a rare lysosomal storage disease, characterized by skeletal abnormalities, cognitive impairment, heart disease, respiratory problems, enlarged liver and spleen, characteristic facies and reduced life expectancy. Hurlers patients have a missing enzyme which otherwise would breakdown the sugars in their bodies. The sugars build up in all parts of the body and cause deterioration.



MADDOX

“Maddox is a determined, energetic and typical little boy. He is cheeky, naughty and completely wonderful.

He is our eldest child and the journey we have been on so far has completely changed our outlook on life.”

HYPOPHOSPHATASIA

"During birth, Maddox broke several ribs, both wrists and was an extremely poorly little baby. Doctors were unsure as to why he was not improving after birth and following further tests were able to diagnose HPP.
We had thought that Maddox's condition was improving and then to be told his diagnosis was devastating. When symptoms occur in children before 6 months of age, over 70% of children die before they reach 5 years old. At this stage the outcome looked very bleak. Our Doctor spoke to someone who had treated a child in Manchester and was aware of a drug trial that was being carried out in three centres: Manchester, Birmingham and Sheffield. We chose Birmingham and we were transferred there so that treatment could begin.
Due to the impact the trial had on other children ultimately we knew it was our only hope and without this drug he wouldn't be here today.
He was such a poorly baby and they had even discussed the possibility of needing to intubate him to help him breathe and they put him in a different cot in case he needed to be resuscitated.
We have to inject Maddox three times a week. This in itself can be traumatic. It is a small price to pay for seeing him running around and playing like any other two year old. Maddox also has a feeding tube and this can sometimes cause problems, especially in social situations where meals are involved."

About the condition

Hypophosphatasia (HPP) is an inherited metabolic disease that is a serious, progressive and lifelong condition that can damage bones and organs.
This condition disrupts a process called mineralization, in which minerals such as calcium and phosphorus are deposited in developing bones and teeth. Mineralization is critical for the formation of bones that are strong and rigid.

CHARLIE

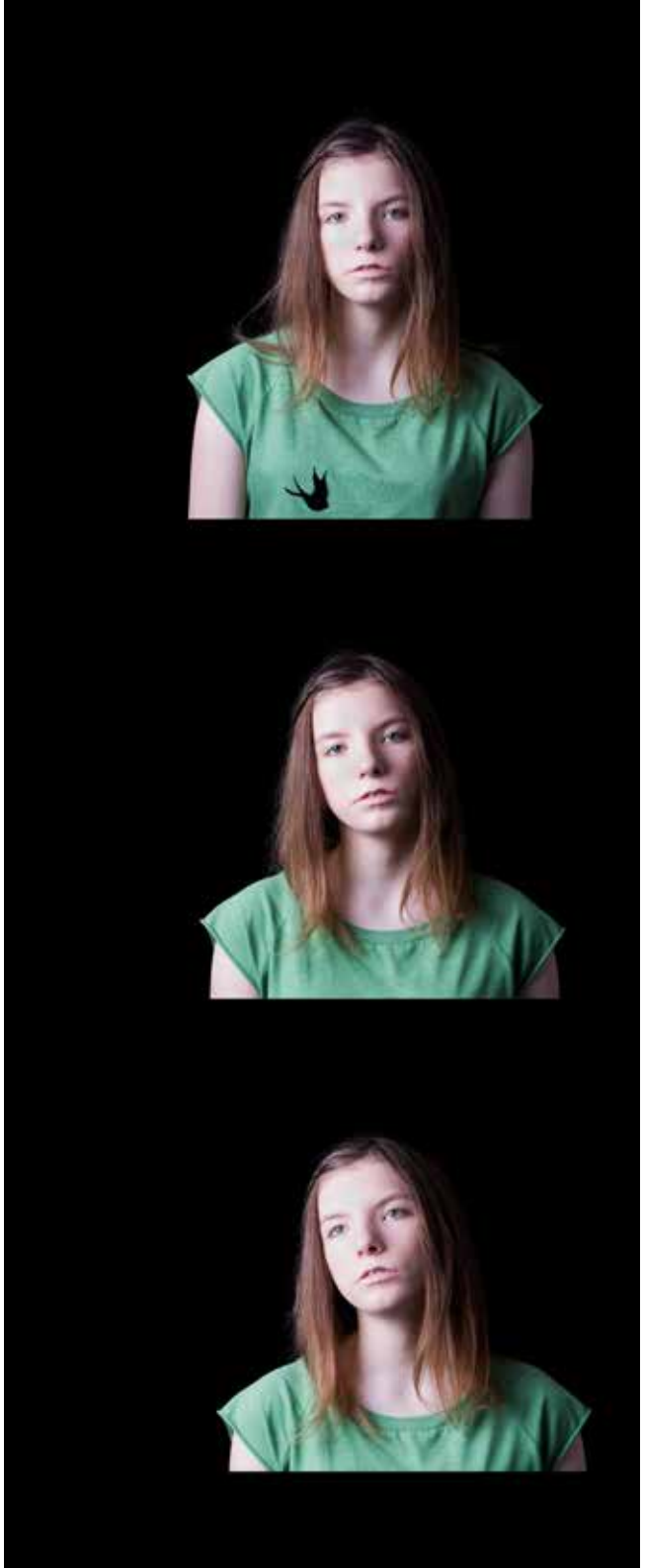
"Charlie is a happy little boy who loves Peppa Pig and cuddling his blanket, and on the day of our photo session he was celebrating his second birthday. Whilst he was more than happy to take part and enjoyed being photographed, he was also recovering from his latest admission to hospital."

ME CP2 DUPLICATION SYNDROME

"It is hard to say exactly how the condition will affect Charlie because there can be huge variances between the way it affects each individual.
We believe that Charlie has quite a small duplication but that does not necessarily mean his symptoms will be less. He is already experiencing some gross developmental delay as he is very much behind his peers; he only started crawling two months ago.
Something just didn't feel right in the way he is very happy in his own little bubble and just very content.
For me that was alarm bells because he just wasn't interested in doing all the stuff that 'normal' children do. When we were given his diagnosis, they could tell us very little. We were handed a rare disease leaflet and told to go home and love our son and that was it.
We are in a position at the moment where we have to wait and see if he develops seizures.
Having someone to support you emotionally and knowing that they understand the affect of a rare disease is really important.
It is not something you realise until it happens.
You feel really alone after diagnosis, nobody really understands what you're going through.
Having someone there who knows exactly what you're going through, and you can talk to, is invaluable. Sometimes just being able to have a good cry together really helps, it's a big release.
All I want is for people to see Charlie as the little boy he is and hopefully treat him the same as every other child."

About the condition

MECP2 Duplication Syndrome is a duplication of the MECP2 protein/gene and it's located on the XY chromosome. What it means for Charlie is that people affected by this condition usually have global developmental delay, are non-verbal and can be prone to seizures later in life due to the build-up of protein. Many with the condition suffer from recurrent respiratory infections.



KATJA

Katja is a kind and loving girl who absolutely adores music and can always be heard singing around the house. She is an avid reader and spends a lot of time writing short stories herself. She has an infectious warmth and happiness about her and loves being around her family and friends. Although she faces, and has faced, many challenges and prejudices in her life, Katja does not let this hold her back.

MOEBIUS SYNDROME

"Katja was born with Moebius Syndrome, a rare congenital disease which causes paralysis in some of the cranial nerves; especially those that control the muscles of the face, eyes and ears. This means that Katja is unable to smile, frown or blink and has some difficulties with her hearing. She is also unable to move her eyes from left to right, which affects her co-ordination and balance, and she suffers from muscle weakness causing scoliosis of the spine. However, this does not stop her always trying her best at things and she recently gained her green belt in Karate and her Grade 2 Piano.

Those that take the time to look past her exterior will know that she is quietly strong and determined, and handles things with admirable dignity and without complaint (most of the time!). Her family is extremely proud of her and the things that she has already achieved for herself."

About the condition

Moebius syndrome is a rare neurological condition that primarily affects the muscles that control facial expression and eye movement. The signs and symptoms of this condition are present from birth. Weakness or paralysis of the facial muscles is one of the most common features of Moebius syndrome. Affected individuals lack facial expressions; they cannot smile, frown, or raise their eyebrows. The muscle weakness also causes problems with feeding that become apparent in early infancy.




GRACE

“Her smile and bubbly personality hides the fact that at such a young age she has already been through so many challenges.
Grace is a wonderful child whom we love very much. We encourage her to try everything and allow her to make her own decisions (within reason!).”

PERIVENTRICULAR LEUKOMALACIA

"Grace has multiple issues - starting at her head, she has a brain injury called PVL, Periventricular leukomalacia, her spine finishes above her sacrum, Sacral Agenesis (SA), around T12, her spleen is on the wrong side, she has a heart murmur and she had a cyst on her lung which was removed, her intestines were rotated but that was also fixed (at 7 days old)! As a result of her SA, the nerves which control her bowels and bladder didn't ever develop and so she is incontinent. As of today, her PVL has caused some developmental delay; she can't do her buttons and seems a lot younger than she is.
So how does this affect us, to be honest it kind of doesn't! I know that probably doesn't make sense, but it is just life with Grace for us. We get up in the night to change her pull-up so her bedding doesn't smell and so she doesn't get sore. She has her pull-ups changed throughout the day at school. When she comes home, she is like any other normal child. She plays, watches tv or reads. Then she goes to bed. Grace's sister started Tae Kwon Do and Grace wanted to go too so she recently had her first lesson, which she really enjoyed.

I am still changing nappies even though she is 7. Sometimes she gets wet through at school, or catches her clothes on a dirty pull-up so she needs to change clothes in school and has started to worry about people noticing. She doesn't keep up with her friends and again, she has started to notice.
The other morning I told her to drink her milk to help her bones grow and she asked me if her spine will grow....."

About the condition

PVL is a type of brain injury that is most common in premature babies. The white matter surrounding the ventricles of the brain is deprived of blood and oxygen leading to softening. The white matter is responsible for transmitting messages from nerve cells in the brain so damage to the white matter can cause problems with movement and other body functions. The most common symptom is cerebral palsy, a condition that affects coordination and movement.

NINA

"Nina is an extremely affectionate, selfless, imaginative and gentle child – shy to strangers but extroverted to loved ones. She has always had a very particular and unique interest in all things bird related, and loves reading books and playing'pretend' with people she knows very well and trusts. She dislikes light, loud noises, balloons, and finds it unsettling to be in small crowded places. She loves placing herself in other people's shoes, and imagining fictional scenarios for those people that she acts out."

PHOTOPHOBIA

"Due to Nina's extreme photophobia and difficult eating habits, her social life has been severely affected, and she is unable to participate in many of the outdoor activities that other children participate in, or even in indoor activities where the light is too bright. Additionally, Nina must take a daily anti-inflammatory injection and a variety of medicines, due to the severe pain she suffers from her condition, which has meant that eating food is also painful for her. Her days are spent eating and drinking very small amounts of food at constant intervals, so she can get the nutrition required for her development.

Nina is also limited in her capacity to travel abroad, because of the number of medicines we need to take with us, including Nina's daily injections, her special formula and other medicines that need to be refrigerated.

Nina's sleeping patterns have been severely affected as well, because she is not exposed to sunlight, due to her photophobia, the doctors believe that her melatonin levels are affected and therefore she is unable to sleep well at night.

We feel that the majority of people do not understand the complexity of Nina's condition, and therefore do not take her needs into consideration when dealing with her. We have also heard a lot of jokes from the public about the fact that Nina wears sunglasses, when using the public transport, walking on the streets, etc. While we have grown used to it, and even take it in good humour ourselves, we worry how people will treat her when we are not around to offer comfort or protection."

About the condition

Nina suffers from extreme photophobia and a variety of gastro-intestinal problems, and has development delay. She is visually impaired. When Nina was already 2.8 years old, the rheumatology team found an abnormality in Nina's Adam 17 gene that could explain all her symptoms. The abnormality of the Adam 17 gene is believed to increase pro-inflammatory cytokine production, possibly leading to her symptoms, and is the only known registered case in the medical literature.

IZZY

"Izzy is a beautiful little girl and she's very happy, most of the time. She can get quite anxious and frightened about things as I think she has a lot of sensory processing problems. The biggest challenge she has is communication. What I wouldn't give to have a conversation with her. I know what she wants most of the time and she makes herself understood. She loves life. She's luckily, blissfully unaware of the challenges that she faces and that's a good thing for her really."

PITT-HOPKINS SYNDROME

"Izzy has Pitt-Hopkins syndrome, she's 8 years old and was diagnosed just before her 2nd birthday. Initially, when she was born we didn't think there were any problems with her but then as she became a little bit older, towards her 1st birthday, it was as if sometimes she was a bit vague and the lights were on but nobody was home. She wasn't quite understanding things as her brother did. I took her to the paediatrician and he felt that there was a slight developmental delay but I think at that point that I knew there was something a bit more than that.

As a parent, her diagnosis destroyed me and it still does every day. There was a time when we were in a very bad place, but you've got to dust yourself down and think, ok we can either let this destroy us or we can live as best a life as we can, and that's what we decided to do. We make the best of it every day and make the most of her life.

Having an ultra rare condition makes everything that bit more difficult. If you go for any sort of medical help, whether it be therapists or doctors, usually we end up as the specialists.

It can be very difficult for siblings. I had the children very close together because I wanted them to be strong brothers and sisters. The plan did work and didn't work, obviously they've still got each other, I know that, but it's an awful lot of responsibility for Thomas. He's only 21 months older than her but I feel he's had to grow up slightly quicker than I'd have liked him to."

About the condition

Typically people with Pitt Hopkins syndrome have global developmental delay, absence of speech and they can have dysmorphic features like a wide nose, deep set eyes and low set ears. Izzy also has problems with her balance. Quite often children with the condition have seizures, hyperventilation and apnea. The blood test for Pitt-Hopkins has only been around since 2007, so there are very few children or young adults diagnosed with Pitt-Hopkins.

PERCY

"Percy is a very sociable little boy who loves attention. His two brothers are so close to him and he loves to spend time playing with them. His bubbly personality and bright smile really makes sure he captures the hearts of anyone he meets."

PRADER WILLI SYNDROME

"Percy has Prader Willi syndrome and when we were given his diagnosis we were devastated but in some strange way a bit relieved as his diagnosis could have been so much worse. Prader Willi syndrome causes the person who has it to have a constant desire to eat"
The family are having to make huge changes to their lifestyle to accommodate Percy's condition.
"Typical events like Christmas and Easter usually revolve around food and we have to change this as food will become such a huge issue for Percy.
We are introducing gifts instead of easter eggs etc. and are having to make huge changes in the home too. All food is being moved to a special locked room outside the main part of the house. We will be installing surveillance equipment to make sure we are aware if Percy tries to leave the home in search of food, so driven will his desire for food be.
Percy will never live independently and will always need supervision. When he is in school he will have to be monitored in case he tries to get hold of food and when he is older he will likely have to live in sheltered housing where access to food is closely controlled. To be told that you have a child with this condition is heart-breaking but to know that he may forever be in pain, pain through hunger, and that there is nothing we can do to stop it is the hardest part."

About the condition

Prader Willi is a rare genetic condition that, amongst other issues causes the person who has it to have a constant desire to eat.
They are driven by a permanent and all consuming feeling of hunger and can easily lead to dangerous weight gain.
People with this syndrome also can have restricted growth and low muscle tone.
There is currently no cure for Prader Willi and as with any condition, it can affect people differently.

Contact

These stories and accopanying images are only a curated selection. To discuss this project or any other projects please contact the team.

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