

# SARA MCCRACKEN

Founder and CEO Angel Eyes NI

## About Sara



My name is Sara McCracken, and I am the CEO and a founder of Angel Eyes NI. I am mum to three children, Rebecca, Peter and Connie (twins). When Rebecca was 9, I fell pregnant with the twins. Right from the get-go the pregnancy was all very different, and they were delivered early at 29 weeks. The twins were very sick, and survival was not guaranteed but after 10 long weeks in neonatal they were well enough to come home. I was aware that the twins weren't focussing and when I spoke to the doctors about this I was reassured that they had a lot of catching up to do and not to worry. It was the first of many times I would be told I was an anxious Mummy - I am sure that sounds familiar to a lot of parents. At four months their eyes started to wobble, a condition known as nystagmus which I had never heard of, and the health visitor referred them urgently to Ophthalmology where they were diagnosed with Ocular Cutaneous Albinism, a rare genetic condition which affects primarily their eyes, skin and hair and registered as severely sight impaired. Fast forward a few years and Rebecca is now 25, engaged to get married next year and a dedicated Orthoptist providing a wonderful service to children and their families. Peter and Connie are in their GCSE year and inspire me with how they overcome challenges and always see the bright side of life.

## From the early days to now...

In the months following their diagnosis, I discovered lots of information on their eye condition but found a lack of support, help and guidance relating to bringing up a child with a vision impairment. I wanted to find other parents/professionals to demystify the support that I needed. I found it very isolating. I was putting on a smile for friends and family, so as not to worry them and wanted everyone to think I was coping just fine. I asked the childrens' social worker to pass on my number to anyone on her caseload that had a visually impaired child. Within a couple of weeks I had spoken to over 20 parents who felt the same way I did! This is how Angel Eyes started - with a handful of parents all in the same boat, and now we **support over 700 families** providing Educational and Family Support.

## Creating change & finding solutions

My role as CEO is to provide clear leadership in delivering our mission, vision and core values, backed by a highly supportive Board of Trustees. We are a small, highly competent team that provide great quality services to our community and want to change systems that don't work, empowering parents and professionals with knowledge relating to sight loss to make a positive impact. My goal is for our children to have the best life they can, and for them to achieve their full potential. I am passionate about our community having a voice to effect necessary change at policy and government level to ensure equality in education and life. We partner and collaborate with other organisations, extending outside the sector of Visual Impairment which keeps us growing, developing and continually raising awareness of paediatric visual impairment.

We are always seeking out solutions that will make a difference and in 2018, in partnership with Ulster University, we developed a **Level 4 Classroom Assistant Qualification: Supporting Pupils with a Vision Impairment in Education**. The first cohort to complete the qualification in 2020 are already impacting change as we address the skills gap identified by our parents and the NI Audit Office SEN Impact Report in 2017 and 2020.

Another key area reported to us by parents and professionals was understanding how exactly VI children see the world. We spent 12 months researching current technological options and soon realised there was no solution to address this, so we set about creating one. With Professor Jonathan Jackson, **Consultant Optometrist and Head of Optometry** from Belfast Health & Care Trust, and Dr Alec Kingsnorth we have developed a solution using modern technology. With funding from Halifax Foundation we were able to develop a prototype **Virtual Reality Sight Loss simulator** that can layer different visual functions to varying degrees. Put together they make up a particular child's impairment, permitting a parent for the first time to see the world as their child does. After demonstrations to professionals and parents we were able to secure further funding, and I am delighted to have received these funds from **The Great Ideas Fund** from National Lottery. Through the **VisualEyes** project we will be able to refine the simulator and deliver vital training to parents and professionals later this year.

To register your interest in the training please click [here](#).



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