STORM|WCB

NEWSLETTER
#8

# There’s nothing more we can do.

This September once again members of the WCB Storm project descended on the Welsh Government Eye Care Conference with two star-studded performances. This year's sketches were performed by myself, Jake, Amy and Tafsila.

As usual, we were asked to create two short sketches, one for the beginning of the day and one for the end. This year, our themes were “There’s nothing more we can do” and “What the Social Model of Disability means to me”.

The first performance, “There’s nothing more we can do”, demonstrated the positive effect of having access to all the services that are available and the negative effect when you don't know what support is out there. This highlighted while for some there isn't a lot more that can be done for other individuals there is a lot more needed to allow them to be confident and independent people.

Our second sketch, at the end of the day, looked at “What the Social Model of Disability means to me”. For me, this was an interesting topic but a hard one to find a creative way of expressing the opinions needed. We began the sketch by quoting the definition of Disabled and Disability, while also explaining what the Medical Model and Social Model means. We wanted to demonstrate that despite the Social Model being the preferred stance the Medical Model still has a place. Through a comical scene replicating a boxing match with the medical and social model as the fighters, we were able to see where the strength of the Social Model lies. We ended the sketch by explaining what the social model means to each of us as individuals.

Both sketches were well received and the feedback we received was very positive all round.

*Megan John*

## An evening with Sir Ian.

On a Friday in September, UCAN Productions members gathered at the School of Optometry for what appeared to be a normal session. We were all very much mistaken. Jane Latham, UCAN Productions' founder, had brought us all together to tell us some news.

Sir Ian McKellen, a.k.a Gandalf, would be donating the proceeds of his West End one-man show to UCAN Productions and nine other performance-based organisations. After receiving the news we were completely speechless. The surprise had this enchanting ability to silence everyone in the room. As a group we were (and still are) completely gobsmacked but incredibly grateful. We believed that the good news had stopped there, well, we were very much mistaken. Not only would UCAN Productions be benefiting from the proceeds, but we had also been invited to the press night for his one-man show.

A few very seemingly short weeks later, a small group of the UCAN Productions core members travelled to London to see his show. We dressed for the occasion and made our way to the Harold Pinter Theatre in the West End. One of the other UCAN Productions members, Jake and I, briefly spoke in an interview with one of the theatre staff about UCAN Productions and what the money would mean, then joined the other invited organisations and had a few celebratory drinks and nibbles before the show.

When walking the short distance from the bar to the theatre, we were greeted with a wall of beautiful noise from the street band. This truly was a wonderful to the theatre experience we were all about to be a part of.

All of my expectations were utterly blown out of the water. His performance was sensational and breathtaking. From starting with a reading from The Lord of the Rings, to his favourite poems and life anecdotes in between in the first act he showcased the man behind the magnificence. And that was only the first act. The second was unsurprisingly focused on McKellen's love and career surrounding Shakespeare. Entwining stories from his own performance experiences with that of Shakespeare's plays. It was a performance we are likely to never forget.

Not only were we astounded by his performance, but after the performance Sir Ian, with a yellow bucket, could be found collecting money for the organisations for whom he is raising funds. Not only we were able to see him even closer up, we met him! Each of us shook his hand, said a hello and a thank you.

By his time we were exhausted but elated. We retired to our respective hotels to reflect on the wonderful day and the marvellous opportunity we had been afforded by Sir Ian. It will stay in our memories forever, alongside our gratitude.

*Amy Gifford*

# Al’s Story.

Hi, I'm Al, I'm 28 and I'm from South Wales. I have been registered blind since birth due to Aniridia and Nystagmus, caused by a rare missing gene that resulted in a condition called WAG-R Syndrome.

At the age of 15 months, I was diagnosed with a Wilm’s tumour, which is a form of kidney cancer. I managed to beat that battle at the age of 3 years old, but my sight battle had barely begun.

As a child my vision was very limited, however I could walk the streets, read books, papers, magazines, see people's faces, and with the use of aids such as magnifiers, etc, I lived a fairly normal childhood, with the exception of having a support teacher on hand. I was confident, and I was full of life.

At the age of about 11 a cataract started to form in both of my eyes, my vision started to become more blurry, but still I could do the things I had always done. About a year later the cataracts were both removed within about 6 weeks of each other and for the next 2-3 years I actually felt like my sight was the best it had ever seemed, though far from perfect vision of course.

At the age of 14 I started to develop Glaucoma in both eyes, but with the help of numerous eye drops and surgeries to control the eye pressures by inserting shunts in to the back of my eyes, I managed to go on for some time without further major loss of sight.

At the age of 17 I left school and by the time I was 18 I started to notice that my sight was getting even worse due to the Glaucoma, by the time I was 20 I was on the waiting list to undergo a limbal stem cell transplant due to epithelial breakdowns on the surfaces the eyes. Following this surgery, I personally saw no significant improvement to my vision, but was told it could take up to 18 months to heal fully. While that stem cell transplant did help with the epithelial tissue breakdown to my eyes, it didn't improve the vision and by the time I was 22 my vision was at the worst it had ever been so far.

With my sight getting worse and worse I became less and less confident and begun to withdraw myself from the outside world far more.

It was at this point that I first became involved with both Cardiff Institute for the Blind and the RNIB. I became both a service user and a volunteer. While still feeling very scared and really lacking in confidence, I soon begun pushing through those feelings because I knew I was around people who understood and who'd probably felt the same once.

So I began taking part in activities and courses with Cardiff Institute for the Blind, I also became a volunteer and ended up co-running Visual Awareness courses and becoming a committee member in a County Steering Group. I also started to organise some of the events for a youth group that I was a part of and I was even asked to attend numerous meetings for both Cardiff Institute for the Blind and the RNIB, to give input and feedback, both as a service user and as a volunteer. It was as though I had a purpose again, as though I had a new lease of life.

Then, after about 10 months or so, once again more eye operations came along. I had orbital decompression's and had a cornea transplant lined up. Due to the amount of hospital visits, etc, I felt I had too much going on and withdrew from Cardiff Institute for the Blind and from the RNIB. In no time at all I was back to my depressed, non-confident old self.

The cornea transplant went ahead when I was about 25 and the vision did improve a little, but nowhere near where my vision acuity was as a child. The regular hospital appointments continued frequently. Lately though, I've been thinking a lot about things and have decided that, at least for now, I've had enough of constant operations and hospital appointments. I'm finally realising that I have to start to accept that my vision is never really going to improve much more now. So it's time to start accepting that this is my life from now on and it's time to start living again. Don't miss understand me, I don't mean to put you off seeking treatment yourself, just that sometimes it's ok to feel like you've been put through enough.

The big problem with me is that I've always struggled with being seen and treated as 'different'. My pride has always got in the way of me being comfortable using things like a cane, etc, in front of people, for instance. This is still something I'm very much struggling with and by letting my pride get to me, I feel like I'm isolating myself further from the world in the process and that's making my depression even worse too.

So, if you've read my story then firstly, sorry that it's so long. Secondly and most importantly, the point I want to make is, if you have ever felt anything similar, then you are certainly not alone. I really implore you to take deep breaths and say 'screw you' to your pride and take small steps towards freeing yourself from the prison of your own mind. Reach out to Cardiff Institute for the Blind or the RNIB or any other sight charity, just see what they can do to help you become the best you that you can be, I promise you will be surprised and you will feel much better for it once you have taken that first step. Sight loss is a terrible thing, but it doesn't mean it's the end of who you are, it's just really, really hard coming to terms with adjusting, that is one of the scariest parts of any sight loss, but reaching out for help really does make a big difference.

Have a great day, thanks again for reading my story.

*Allyn Stansfield*

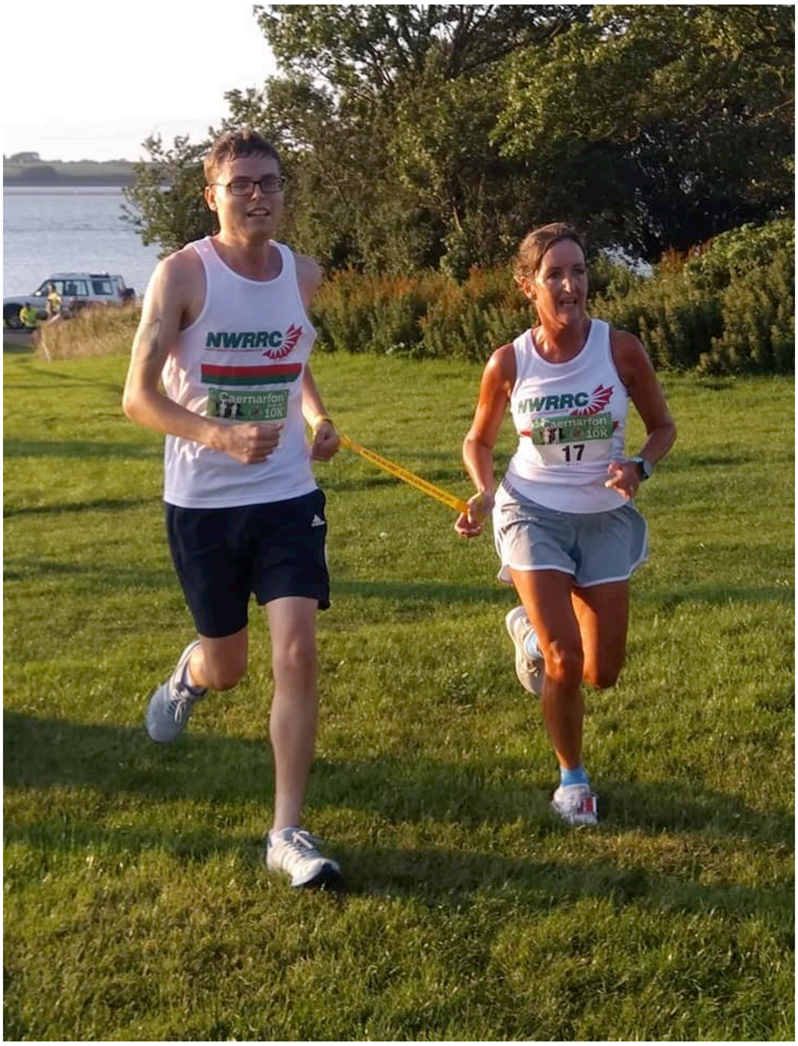
# Dan Owen’s and his Running Story.

Hi I’m Daniel, I’m 26 and I have retinitis pigmentosa; resulting in night blindness, light sensitivity, loss of peripheral vision and limited blurred central vision. I live in North Wales and despite being a fairly nice place to live there is very little to do in the area, which becomes even more restrictive when you’re visually impaired. After my studies I was looking for work, meeting up with friends occasionally and going to the gym now and again however I still felt bored, frustrated and down and felt like I wasn’t being productive and felt like everything was repetitive and invariable. As a result I gave up on looking for things to do in the area after trying for so long.

That was until another visually impaired friend of mine came across an App called Run Together. In partnership with England Athletics and promoted by British Blind Sport it is designed to help Blind and partially sighted people find a guide runner who will help them run and navigate routes. This is not a service in Wales though which is such a shame however despite this our guide runner Mary Rees will come to run with us once every couple weeks and make the long journey to come pick us up. First meeting her late last year I had no idea how much I was going to enjoy running and how much I was going to progress. It started off running around a football field with a tether and getting used to it, then within a couple months doing my first 5K park run.

I then realised after that first park run that I had found what I had being looking for. Thanks to Mary’s help and support she got me networking with other runners in my area. I then started running with a man called Tony Parvin and a woman called Carla Green for park runs. I wanted to develop, progress and challenge myself so after a few park runs I started entering local 10K races with Carla being my guide for the majority of them. I was so happy to of found what gave me drive and motivation and was significantly improving my mental health as well. After a few months of running and racing I joined the North Wales Road Runners club which Carla is a member of. Despite being visually impaired the club is so friendly and inclusive that I felt I fitted right in straight away and I had no anxiety or concerns.

Now nearly a year on I train regularly with Tony and Carla and occasionally Mary and I am still entering races and pushing myself to go harder and faster with each one. I also have my first half marathon beginning of October, which I am buzzing for. I can't say thank you enough either for everyone who has ran with me either over the months as without their generosity and support I would not of being able to accomplish any of this. I would really recommend any blind/partially sighted person to actively participate in sport or leisure activity. The physical and mental benefits are so valuable and important to having a happy, healthy life and it will help you challenge yourself, network



with people, create friendships, integrate into clubs and events and so much more. Whether it’s running, cycling, swimming, gym classes or join a sport team, just take the leap and it could change your life. Thank you for reading my story.

*Dan Owen*

## Letter to the Editor.

If you would like to share your story or experiences with our readers, please contact megan@wcb-ccd.org.uk or call 02920 473954.

## Contact us.

**Email** megan@wcb-ccd.org.uk
**Telephone** 029 2047 3954
**Facebook** facebook.com/StormWCB
**Twitter** twitter.com/StormWCB
**Website** www.stormwcb.org.uk