Irish Times Tue, Sep 15, 2015

## My health experience: I can see only about 10 inches ahead

**Rebecca** Kelly is 24 and has a genetic condition, with 3-5 per cent vision in both eyes



Rebecca Kelly studied music at NUI Maynooth and performs and sings with her family.

Photograph: Cyril Byrne

In conversation with Cian Traynor

I was born with a form of macular degeneration called cone dystrophy, which means the light cells at the back of the eyes die off one by one. This is a slow process that stabilises by the time you reach adulthood, so you normally don't lose all of your sight. It's also a genetic condition: my dad has it, his dad had it, and my brother and one of my sisters have it too.

I have 3-5 per cent vision in both eyes. My peripheral vision is relatively good but it's the central vision that's a problem. It's hard to quantify

distances but I can see someone only if they're about 10 inches in front of me.

I can't look at people straight in the eye because their face just isn't clear enough, so sometimes they have to get used to me looking at them sideways.

If there are people walking about 20 feet away, I can see only their outline. There are no details. I'm partially colourblind as well, which can make some things even harder to distinguish.

Having family members who know what you're going through has been a huge help, obviously. We've always been told to just do the best you can, and music has always been central to that. We've all done musical theatre and Irish dancing from an early age and today we perform group harmonies as the Kelly Family Vocal Ensemble.

Earlier this year, I appeared as a contestant on the *Voice of Ireland*. A lot goes on before you see one little bit on telly: I had four or five auditions before actually being on the show. As much as I love singing, I've been a bit of a nervous person in the past and I was conscious of just how big a platform the show would be.

## Flash of light

It was a "blind audition", so the judges can't see you and you can't see how they're reacting. But the lights were so bright, I couldn't really see anything anyway.

The intensity of it turned everything white. I thought I saw a flash of light and some sort of movement but I wasn't 100 per cent sure.

Kian Egan had turned around, sending me through to the next stage, but I had to ask what had happened because I didn't know. I thought the crowd was cheering just to be nice.

It was a big shock, and an unbelievable experience, but I felt like I learned a lot and gained the kind of things that I really wanted to take from it.

Performing songs I wouldn't normally choose for myself showed me that I can do a lot of different styles of music. It also proved that I can stand up on my own in front of a live audience, with celebrity judges, and be confident while the cameras are pointed at me. My father has been a music teacher and choral director for decades, so he's a big inspiration. The way he arranges all his music on a megatablet, which is like a bigger version of an iPad, is amazing.

I studied music at NUI Maynooth, and after getting my degree I went on to do a diploma in professional musicianship at BIMM Dublin. College proved to be a revelation compared with school, which could be challenging as so much work is written on the board. I went from using an Opti Verso digital magnifier – a big, bulky arm that had to be set up for every class and kept breaking all the time – to using an iPad to take pictures, zoom right in and store everything I need on one handy-tocarry device.

But during my second year at Maynooth, my light sensitivity started to get worse unexpectedly. That's not normal. There was a lot to deal with, which pulled me back a bit, so I had to work extra-hard to keep up. Thankfully, the people there were wonderfully supportive and my sight isn't as severe as it was then.

I've had to start using a guide stick to get around at times, but I don't let that hold me back. I've been able to do things such as water-skiing, rock climbing and canoeing through a brilliant group called Vision Sports Ireland, which organises sports for the blind and all streams of visually impaired people.

They take you through everything step by step so you know exactly what's happening at any given moment. It can be a bit scary, but if you really want to do it you have to face your fears and find out what you're capable of.

## **Community choir**

People might be surprised by how many things you can get involved in if you have issues with sight, whether it's yoga, swimming or weekly walking groups. In September, my father and I are starting up a community choir in Dublin for blind and visually impaired people. It's all about learning the harmonies for songs you love to sing and enjoying them in a new light.

Music can be a great confidence builder. As a family, it has allowed us to push boundaries and, personally speaking, I've always been about trying new things until I get them. There's no point in just letting the world go by.