PROFILE

Sharon Tracey

LIVING WITH STARGARDT DISEASE

"Visual impairment can be seen as a barrier to a full life, but it doesn't have to be."

Sharon Tracey was 18 yrs when she was diagnosed with Stargardt disease. She wore glasses throughout her school years but could never see the blackboard clearly; she just assumed everyone had blurred vision. It wasn't until she began having problems navigating that she visited her GP and insisted they refer her to a specialist.

Sharon was told that her eyesight would deteriorate and there was nothing they could do for her. At the time Sharon was still grieving her grandmother, who raised her, and it felt like her world had collapsed around her. She was in a dark place. Today, Sharon's love for life is palpable, and contagious. "I made a decision a long time ago to think about my disability as a challenge to overcome, not a barrier. That mental shift changed my life."

Sharon trained as a blind telephonist in Sligo and secured work experience with the Midland Health Board Tullamore. Since then her career has taken her to Guinness in Dublin, the Department of Education in Athlone and eventually back to Tullamore to the Department of Education and Skills where Sharon is an Executive Officer.

And that's just the day job. "I love learning and meeting new people and have qualifications in Equality Studies, Counselling skills, Life Coaching, Reflexology, Access Consciousness, Integrated Energy Therapy and Reiki." explains Sharon.

"I also give motivational talks on the subject of disability. I'm a strong believer in everyone acknowledging their abilities and accepting their limitations and asking for help. We're all human, we all need support – whether you have a disability or not. Visual impairment can be seen as a barrier to a full life, but it doesn't have to be."

Sharon is also a media ambassador for the charity Fighting Blindness and regularly speaks to radio stations and newspapers about the importance of research and support.

RARE DISEASE

About Stargardt Disease

Stargardt disease is the most common form of inherited juvenile macular degeneration, usually first identified in childhood or adolescence. It is a genetic condition that affects the central region of the retina, known as the macula. Light sensitive cells, called photoreceptors, are found here and are responsible for fine, detailed central and colour vision. In Stargardt disease, these crucial photoreceptors degenerate over time and people with this condition experience a gradual decline in their central vision. Side (peripheral) vision is usually preserved.

Stargardt disease has a prevalence estimated between one in 8,000 and one in 10,000 people. The carrier rate has been quoted as high as 1 in 20 to 1 in 50 people.

As of yet, there are no approved therapies or treatments, but retinal research is entering an exciting era where safe and effective interventions are realistic goals.

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