Mariza's Empowerment Guide

How 28 Years with Cone-Rod Dystrophy and Retina South Africa Gave Me Back My Power

My name is Mariza Jurgens. I was diagnosed with an inherited retinal condition in 1996 and joined Retina South Africa in 1998.

The biggest gift membership gave me was information and empowerment. Retina South Africa has always believed that a patient becomes truly powerful the moment they understand their condition deeply.

Over the years I've learned that many of us, myself included, end up knowing our condition so well that we sometimes sit in the doctor's room knowing more than the clinician. Because we track every new development, every research paper, every treatment option. When you have reliable information at your fingertips, you stop feeling helpless.

The support I've received from fellow members and from Retina South Africa itself has been extraordinary. They helped me find the genetic cause of my condition after three different genetic tests, two of them inconclusive. I also received three different clinical diagnoses over the years. The Retina team explained how difficult it is to diagnose retinal conditions, especially when the retina is already badly damaged.

Knowing exactly what I have brought me real peace of mind; especially when I was expecting and worrying whether my children would inherit the condition. Those questions feel very personal and sometimes lonely, but Retina South Africa guided me through the inheritance patterns and referred me for proper genetic counselling.

What I love most is that Retina South Africa never tries to keep people dependent. Yes, we live with visual impairment. Yes, we have the right to reasonable accommodations at work and in life. But we refuse to let blindness define us. We are whole people; we can still play sport, work, study, and achieve everything we're capable of.

My five Retina-Ready lessons I wish every newly diagnosed person knew:

1. Keep asking until you get a clear diagnosis – even if it takes multiple tests.
2. Understand your exact genetic type; it matters for your family's future.
3. Information removes fear; the more you know, the more in control you feel.
4. Connect with others who truly understand; you are not alone.
5. Your condition is part of you, but it does not own you.

If you're reading this, know that there is support, there is knowledge, and there is hope. Retina South Africa has walked beside me for nearly thirty years, and they are ready to walk beside you too.