

## **Eyes Wide Open: The Benefits of Living with Retinitis Pigmentosa**

written by Penny Castagnozzi

After a few years of banging into open cabinet doors, taking longer than most to grow accustomed to darker rooms, and going up on a few soft shoulders while driving at night, I was diagnosed with having retinitis pigmentosa. Told bluntly, the week before I turned thirty, that my failing eyesight would continue to worsen with age, getting older suddenly had new meaning. Knowing that this would affect not only me, but also the three small daughters who looked up to and depended on me, I was devastated. For a few hours.

What kept me from wallowing in despair for days and weeks to come? The day I learned of my future with RP was also the day I heard about one of my favorite comedienne, Gilda Radner, dying of ovarian cancer. I immediately compared my plight to hers. It was true, I would slowly lose the independence I'd always enjoyed, I had already lost the ability to drive at night and would soon lose daylight driving, my children would have to deal with a mom who would not be able to help coach them in soccer, and my husband would soon need to wear me on his arm like a permanent corsage to keep me from bumping my way around a crowded room like a pinball. In contrast, though, the other woman's journey of life was not merely hindered; it was ended. I still had life, I had love, I enjoyed sound, touch, smell, and taste - and I still had vision!

My sight's not perfect – I don't see well in the dark, can't read tiny print without magnification, and my peripheral vision is a thing of the past, but I can see what I need to see if I move my eyes or shed light on an object!

Speaking of shedding light on some dim matter, I'd like to offer a view of the lighter side of having RP, helping others see some of the benefits of having retinitis pigmentosa. If you've been blessed with RP, you may as well appreciate the perks while you wait for the cure that's just around the bend, thanks to compassionate people who have funded the research in cell transplants, gene therapy, retinal micro chips, etc.

### **Benefits of Living with Retinitis Pigmentosa:**

1. Just when you think you've eaten all your shrimp scampi, honest dinner mates point out one more shrimp hiding perilously on the rim of your plate! This can only be topped by finding one more forsaken chocolate chip cookie on the cookie sheet that's on deck, waiting to be washed!
2. You can go ahead and eat that extra cookie without a care. Although your family and friends unfortunately do not benefit from your loss of peripheral vision, it actually comes in handy when you're trying to avoid facing the few extra rolls that have grown accustomed to your midriff. Stand tall and proud before that full-length mirror in the bathroom and look at your face. Perfect! Not an extra pound to be seen!

3. Dogs love you. Truthfully it's only because they mistake the little bits of food you can't see to pick up off the floor as tokens of love and affection, but the reason is not important. What they don't know won't hurt them, and to me, it's a win-win situation.
4. Although the bad news is that you can no longer help out with the carpool, the good news is that you can no longer help out with the carpool! Yes, you'll miss the opportunity to spend a half hour each morning threatening to make the kids walk if they don't stop poking each other and making fake fart sounds in the back seat, but just maybe you'll be consoled a bit by that second cup of coffee you drink at the kitchen table with your feet up, enjoying the solitude of a house that's suddenly gone from chaotic to peaceful.
5. Ordinary vacation photographs turn into amusing "Where's Waldo" activities. I can't tell you the number of photographs I've taken where, focusing on a rugged boat tied to a dock, a majestic weeping willow in a field, or a child standing in a pumpkin patch, I'm surprised to later notice that there are strangers in all of my pictures! Sure enough, almost all of my gorgeous pictorial memories have corners that are adorned with tourists talking to each other, pointing to distant mountain ranges, pulling down creeping shorts, or squinting straight at me, probably wondering why some stalker is taking their picture!
6. You no longer are expected, or called upon, to kill spiders, ants, and flies. Your kids, who normally would shriek in horror for you to squash the little beasts, suddenly become experts at quick extermination, or at least covering the slow crawling bugs with cups until another grown-up comes home. Welcome home, Honey, we missed you!
7. People are generally more relaxed and at ease around people with RP. It's not that the vision impairment makes us any more personable, but we are eventually recognized as being much less critical about looks. Losing some hair? I didn't notice! Wrinkles? I don't see any! Afraid your bag doesn't match your shoes? What shoes? When we look at people, we zero in on the thoughtful eyes or engaging smiles, although not always at the same time. "Out of sight, out of mind" takes on new, appreciated meaning.
8. Clutter becomes a worry of the past. You don't need to spend lots of time and money buying expensive organizers and custom-made cabinets to store items you only use once a year. Just hide them where you won't see them – in the corners of each room. Presto! Problem solved!
9. People constantly give you credit solely because you haven't wandered off to sit in a cave somewhere to drown in self-pity, or because you haven't stormed off the playing field of life because you find it unfair. You suddenly become honorable! You're an inspiration to others! Clearly they haven't yet figured out that maybe the reason you haven't wandered out into a cave or stormed off the playing field is that you fear getting lost or having to find your way back!
10. Your days of being a loner are over. You'll never have to walk into a crowded room alone again, because people are glad to offer you their arms to guide you to where you need to go. This does not come without its perils, though, so keep your guard up. I have,

on more than one occasion, stood up after a lecture or concert and reached out for my husband's arm to leave the room, only to discover that the elbow I was hugging did not belong to the man I married! Just take a peek every so often as you dosey-doe from arm to arm, person to person, in the square-dance of life with RP!

Most importantly, and on a more serious note, one of the benefits of having RP is that you are forced to grow. Your other senses step it up a notch when one isn't quite cutting it. You learn how to jump hurdles that are placed in your way. (I mean this figuratively, of course. I think we all know that we wouldn't exactly be *jumping* over any hurdles people left in our way!) You find out how to let your guard down and let others help you. It finally occurs to you that you don't need to be omnipotent to be loved and cared for. You realize that you don't need to be perfect, and life doesn't need to be perfect to be enjoyable. What a relief that is! Every day can still be an event to remember; every moment, an opportunity for pleasure; every person, a gem to be appreciated.

The cure for RP will come soon, and I'll be celebrating with the rest who stand to regain their more complete sight, but until then, I'll be enjoying life, eyes wide open.

*Penny Castagnozzi and her sister, Nancy Telian, were diagnosed with retinitis pigmentosa over twenty years ago, but have refused to let that prevent them from achieving their goals of helping children and adults with reading disabilities. Co-founders and co-directors of Reading with TLC, and authors of Lively Letters and Sight Words You Can See, Penny and Nancy have been committed to using the sight that they do have to help others who may have perfect sight, but are unable to decode the words on a page. Nationally recognized speakers, Penny and Nancy are available for inspirational keynote addresses. For more information, call 781-331-7412, email [penny@readingwithTLC.com](mailto:penny@readingwithTLC.com), or visit [www.readingwithTLC.com](http://www.readingwithTLC.com).*