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Community and Other Ordinary Miracles

Mara Faulkner

My dad had an eye disease called retinitis pigmentosa, as do four of my sisters, two nephews, a grandmother and an uncle, numerous cousins, and I. The progress of RP is gradual, unpredictable, and inexorable. There are several kinds, each caused by a different genetic mutation, all leading to the death of the cells that receive light and translate it into colors, shapes, and perspective. Most forms of RP share some physical manifestations: night blindness (as one of my sisters says, at night we're all as blind as a horse's butt) and the gradual narrowing of the visual field until you see a world of dimming colors through two tunnels or soda straws. Though my father was legally blind all my life and almost totally blind when he died, at age 70, blindness was our family secret—the word we didn't say out loud. Until I was 45, I thought I'd lucked out; then an alert doctor saw the telltale pigment encroaching around the edges of my retinas. But not until I began to write my book *Going Blind* did I begin to search for ways to deal with many kinds of blindness, but especially the gradual kind that affects my family—ways that had to be better than our secretiveness and denial.

That's one part of the story. The other part is that I've been a member of a Benedictine monastic community for more than forty years. My Christian faith and the radical choice to live in community have shaped my approach, convincing me that blindness and many other disabilities could be much less disastrous than they often are. You might say I'm looking for miracles.

Retinitis pigmentosa came with my ancestors from Ireland in the steerage compartment of an emigrant ship. My great-grandmother Elizabeth (Bessie) Kelly somehow survived the Great Hunger of the 1840s and, around 1855, came to America with her family, eventually marrying and settling in western Minnesota. She passed RP on to her daughter, Julia Maloney Faulkner, who passed it on to my dad, Dennis Faulkner. In our family, the genes that cause the disease ride on the X chromosome. My father couldn't pass this disease on to sons; but each daughter had a 50-50 chance of having it, and we're all carriers. My dad had one son and six daughters—bad luck for us, the Irish might say. Because RP is progressive but unpredictable, most people who have it live in a twilight zone between sight and blindness, without the simple, devastating clarity of people who are blind from birth or who are blinded suddenly by an accident.

I think I understand what Bessie Kelly felt as she left her green island, with its soft rains and lark songs, to come to the harshness of western Minnesota. I'm on an emigrant ship, too, and I can feel it tossing under me. One part of me is back in the sun-drenched, seeing world. My central vision is still pretty good. I can see leaves just beginning to turn red on our maple tree and the subtle shifts of emotion on my students' faces. I can read normal-size print and was even able to renew my driver's license, though I don't drive at night or in freeway traffic. Most of the time I stand with the see-ers; I still find in myself some attitudes, bred in me by my family and our culture, that make me as blind to blindness as many of the sharp-eyed people around me.

But in the twenty-five years since I discovered I, too, have RP, I've learned something about the fog-shrouded country ahead of me. Like the emigrant Irish, people who've already made the crossing from sight to blindness send messages back to those of us who are just setting out. To find some of those messages, I researched my own family, starting with the letters my dad wrote to my mom during their long courtship. I've had conversations with my family, moving out from this center in ever widening circles to understand both the facts and the feelings that define blindness.

Research gives essential knowledge. Over the years I've gained another kind, based on experience. My visual world is gradually narrowing, as pigment edges in on all sides of my retinas. People and objects to