Hadley

Holding on to hope

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**Marc:** This is Hadley’s Insights and Sound Bites, where people facing vision loss share what has helped them cope and adjust.

**Ed McDaniel:** My name is Ed McDaniel. I live in the foothills of North Carolina.

I was diagnosed with retinitis pigmentosa when I was 28 years old. My older brother had already been diagnosed, so I knew it was a possibility that I would also have the eye condition. And in addition to RP, I also have hearing loss.

I was born with hearing loss. That really hasn't been so difficult for me. It was when I started losing my vision that that had a bigger impact on me, because I had normal vision at one point.

I was still searching for some hope. And one of the ways I was doing that was finding out more information about treatment research and whether that was ever going to be an option for me. And so, I came to this conference in Florida and during the day they had all these presentations about research and treatment and all of these different kinds of things. But in the evenings, they had the sessions where we could meet other people with RP. And that was really where I started to find some hope. It wasn't really in the research, which was the main topic of the conference, but it was in the evenings where I met other people and I met people who were all different ages, all different stages of vision loss.

And I was able to see that they were living very productive and full lives. So, I came away from that conference feeling a lot more hopeful, where I really had been struggling before that.

Thirty years later and there's still no treatment for RP. I'm glad there is research going on and I think there could at some point be some treatment, but if I had been focusing on that for the past 30 years, I wouldn't be where I am today by learning to live with my vision loss and not just putting all my hope into a cure for my vision loss.

**Marc**: You never know who might need to hear your story. If you’d like to share with us, just leave us a message on our Insights & Sound Bites voicemail. By calling, 847-512-4867. Or, you can use your smartphone or computer and email us a recording to podcast@HadleyHelps.org.