

[Speaker 1] John is a 14-year-old high school student, who's living with the disease called Retinitis Pigmentosa or RP, which is a form of degenerate blindness. His vision has been and continues to deteriorate as he gets older. The following segment will provide outsiders perspective on blindness and allow us to take a look into the lives of a mother and son who despite their hardships have a refreshingly positive outlook on life.

Can you tell me a little bit about RP?

[Speaker 2] RP is a retinal disease that affects the rods and cones of the eye. It affects the retina and what happens is the rods and cones start to die off which does not allow for light to be received into the retina to bounce back to visualize and see things. Unfortunately there aren't any treatments or cures right now. There are some in the process that help repair these rods and cones and so when they die off, they die off and that's what ends up ultimately leading to a person's blindness. In Sean's case he has Retinitis Pigmentosa, he loses his peripheral vision and as he loses the peripheral it comes down into a tunnel and that's what primarily he'll see until that tunnel closes up and then there will be nothing left.

[Speaker 1] What were some of the signs that your son possessed that made you question his ability to see?

[Speaker 2] Well he was about, Sean was about um kindergarten 4 or 5 years old, and I started noticing him being a very clumsy child but then I wasn't sure if he was, if every kid was just as clumsy. I started noticing he was a bit more especially at night and it really hit around Halloween. We went trick-or-treating and I'll just, I'll never forget um you know how kids just run from house to house to house to house, there was a low hedge probably about a 2 foot hedge and all the kids ran and they leaped over this hedge they're like yeah we're going to the next house. Sean ran snap right into it and fell down and oh my gosh you what is wrong with him why can't he see these things but little did I know um that he truly could not see these things. So that December um an ophthalmologist sent us to um the Doheny Eye Institute at USC and they ran him through a battery of tests and lo and behold and about 5 years old discovered that his retinas were not operable they weren't reacting the way that a normal retina should have. Yeah so those were basically some of the things that uh that's usually the very first thing that people discover is night blindness. You start noticing that as you go out at night things are noticeably darker and you think its only you where um or everybody else is this way or you start questioning does everybody see this way? That's normally the first sign and clumsiness comes with it, running into doors, turning into tables that you just don't see. So as I said um as a little guy that's when we found out

[Speaker 1] Have you ever heard of degenerate blindness?

[Speaker 3] No. I've heard of people having accidents that cause them to go blind later in life, but never a disease that causes you to go blind over time. I mean in a

way I guess its better the people with this disease have a chance to see things for a portion of their lives but live day to day knowing when you could wake up tomorrow and not see anything that would be pretty hard to deal with.

[Speaker 1] How was having a son with RP affected your life um positively?

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