> "My biggest goal was still having the perception that I could do anything. Whether I actually could or not didn't matter. I still wanted to have the perception that I could."

# Jessica

**Born March 1986 | Tucson, AZ**
Living with LHON

With all her belongings packed carefully into boxes in her parent's garage in Phoenix, Arizona, the day was fast approaching for Jessica to close on her house. At age 27, she was newly employed with her first "real job" out of college. She always dreamed of buying her own home and had finally found one she could afford. But just as she was finalizing the paperwork, a problem arose. Her vision had changed; she couldn't see out of her left eye. "I was just praying it wouldn't go to my other eye," recounts Jessica. Symptoms did not let up, however, and within a few months the vision in her right eye started to blur as well. Jessica called her mortgage broker to convey the troubling news. "Listen," she said hesitantly. "I can't go through with this. I'm losing my vision." Jessica had to back out of buying the house, and began the reverse process of unpacking all of her boxes and moving back in with her parents.

**“‘Hi my name is Jessica. I have a brand new job and I think I’m losing my vision. Can you help me?’”**

Within six months, Jessica went from being a fully sighted, fully functional, independent young woman, to becoming severely visually impaired: unable to recognize faces, stairs, or written words. “How will you cook without chopping your fingers off?” her mother had exclaimed. Jessica spent the next year-and-a-half living with her parents where she re-learned how to cook, clean, communicate, and traverse the world with a blind cane.

During childhood, her younger brother had lost partial vision at the age of eight. “Back then all it meant was that his homework was blown up really big and he sat close to the TV. We would go to doctor after doctor, but no one knew about LHON at that time.” LHON, or Leber's hereditary optic neuropathy, is a mitochondrial inherited degeneration of retinal ganglion cells (RGCs) and their axons that leads to a loss of central vision. Jessica’s aunt also went completely blind at age 62. Jessica noticed this pattern in her family, but when she first lost vision in her left eye she refused to believe there was a hereditary connection.

“Hi my name is Jessica. I have a brand new job and I think I’m losing my vision,” Jessica spoke into the phone. “Can you help me?” On the receiving line was Lissa, a woman Jessica found through her initial searches online. Lissa administered a Facebook page for the LHON blind and visually impaired community, a role she took on after her own son was diagnosed with LHON. After a quick message response to Jessica, Lissa became an invaluable friend and mentor. “Lissa was there for me immediately. She told me everything I needed to know and

what I needed to do and learn at that time." Through Lissa's Facebook page as well as Arizona Services for the Blind, Jessica found excellent resources for training and support. Jessica's searches online also uncovered many glaring stigmas associated with blind and visually impaired people. "There is so much depressing stuff about blindness, like the stereotype that blind people always look disheveled; that they just roll out of bed with sunglasses on." Wearing an immaculately ironed silk dress, high heels, and expertly applied makeup, Jessica clearly defies any existing stereotypes.

This took no small amount of effort. "My first major hurdle was still looking put together; like I hadn't missed a step." Although Jessica cannot recognize faces, she converses loquaciously while looking you straight in the eye. "I tell people that I see *underwater*. My world is really blurry—I have no central vision. I can't see your face, but I know that you are there."

With such stark loss of vision, Jessica could no longer drive, making commuting the next challenge in her desire to be an independent woman with her own career. "I knew it was no longer safe [to drive] when the halos were so big around the lights that I didn't know if they were green or red. That's when I knew I should be off the road." When Jessica sold her car, it marked a significant turning point in her independence. "Everyone with LHON remembers the last time they drove a car."

Despite transitioning to paratransit, Jessica never lost her drive to remain a fervent young professional woman. One day, while catching the Sun Van (Arizona's paratransit), the driver exclaimed to her, "What? I thought you can't see—what are you doing wearing heels like that?" To which Jessica replied, "My legs aren't broken!" The exchange inspired Jessica to start her own blog, appropriately titled *Blind Girls Can Rock Heels*, where she describes her experience living with LHON and deconstructing the barriers associated with visual impairment. "My biggest goal was maintaining the perception that I could do anything. Whether I actually could or not didn't matter. I still wanted to have the perception that I could."

When Jessica first lost vision, it was imperative to her that she keep her new job. But how? It was something she could not do alone. While keeping up the impression of a fully sighted, fully functioning Sales and Marketing Coordinator, every evening after hours, her mother, father and best friend would sneak into her tiny office to help play catch-up. From about 8-11:30 p.m. they worked—her best friend was the typist, her mother would file and her father would organize. "Then we all went home, and I came into the office the next morning saying, 'Oh that was so easy!'" For months, unbeknownst to the company, Jessica's family and best friend helped her with the basic tasks she hadn't yet mastered since losing her vision that were needed in order for Jessica to keep up her employment. She kept the coffee brewing for her secret helpers as she slowly learned how to efficiently multitask without dependency on her eyes to guide her. "We spent hours catching up, and no one knew." Jessica proved capable of learning to do her job without vision and although she required some extra assistance, she began to grow her nascent career in marketing and public relations. Years later she would land a job at the University of Arizona in the Clinical Trials Department, moving from Phoenix to Tucson—her "happiest place on Earth."

As her vision changed, so did her hobbies and friends. Jessica began to meet other people within the LHON community and was especially inspired by a young man named Chaz, who despite his vision impairment, was an accomplished long distance runner. He challenged her to try running and she loved it. "I was never a sighted runner," she distinguishes, as it wasn't until after she went blind that she started. "I had no idea what blind running meant. It was the scariest

thing at first." To start, she connected with a few running guides who one by one took her out on simple trails. Her mother would meet each of them and wait in the car for their return, until they proved trustworthy. "When everyone asked what I was training for, I told them I was just a happy runner. I didn't have to use my cane, or use my vision, I just got out there and ran free. Whenever I'm running I have a huge smile on my face." What LHON had robbed of her sight, running returned of her freedom.

With a new outlook, Jessica started organizing Dinner in the Dark fundraisers, in which sighted participants share a three-course meal completely blindfolded. The first dinner she held in Phoenix was advertised all through word of mouth and welcomed 98 people in attendance. Her second year brought 143 participants, including congressmen and firefighters, and during her fourth year, she raised the most money yet. In total, Jessica has raised over $25,000 for the blind and visually impaired community.

Aside from raising funds, the dinners are an opportunity for Jessica to teach the broader public important lessons about the ways blindness and vision are perceived in society. "I wait for that hum of silence when everyone can't find their food," she says. "All of a sudden you hear the hum gets quieter, and that's the moment that I wait for. That's success, you know, the realness sets in." She provides space as well as a platform for the visually-impaired to teach their simple truths—to unmask their condition and foster mutual understanding between the two groups. "I wanted to do something to make a difference, to be able to help do my part. Raise awareness."

After sitting with Jessica outside of her office on the University of Arizona campus, we take a drive into the hills of Gates Pass. Opening up to a limitless vista of the Tucson mountains, we park and then guide Jessica along the dirt path and venture into desert hills. "It's so beautiful out here!" Jessica rejoices. When asked if she can see the plants and the colors, she responds, "I see the blue sky and I see the horizon and yeah, that's all I need." We take a picture with her smart phone; she then holds the phone an inch from her eyes, and while zooming in, alights at the beauty seen there.

As the sun sets over the mountains, Jessica tells us that she will wake up at 4:30 a.m. "to run a quick eight miles before work." She currently runs with guides five days a week and is training to run the Boston Marathon with the United States Association of Blind Athletes. It is remarkable to witness Jessica's strength, perseverance and positive attitude. After becoming severely visually impaired at age 27, Jessica excels in her professional life, lives on her own, runs marathons, and has become an inspiring keynote speaker. Jessica is especially enthusiastic about being a positive role model for younger people and is looking forward to making her keynote speech at ENVISION, a camp for blind and visually impaired children in Wichita this summer. "There's this perception that just because you can't see, you can't, can't, and can't." If one thing is for certain, Jessica can, does, and will. After receiving her diagnosis of LHON, she has taken off running.

# About

**Living in the Light™** is a patient advocacy initiative utilizing the potency of fine art photography, compelling personal narratives, and engaging filmmaking to educate the biotech and medical community about the realities of rare diseases and the unprecedented effect they have on families and daily life.

This distinct concentration grew out of an understanding that the rare disease community is comprised of many people and many voices. By shifting the focus from patient to person, Living in the Light presents the dignified and sincere perspectives of individuals and their families as they approach major life challenges. Our work is not simply to record, but to convey the deep resilience, unique wisdom, and profound beauty of people as their journeys unfold.

No matter who the patient is, it is the entire family that receives a diagnosis—everyone is affected in some way. We understand this, and our approach is poised to honor and accommodate the families we document. Since our founding in 2012, telling rare disease stories has been our sole focus. It is what we are most passionate about and what we do best. To date, we have interviewed and photographed more than 300 families, living with over 50 different rare conditions around the world.

We are driven by our mission of empowering families and individuals affected by rare diseases to be seen and heard as they relay their stories and advocate for their needs. In doing so, we help our partners form lasting relationships with these families, patient advocacy organizations, and other industry leaders who are dedicated to developing new therapies with the potential to treat a broad range of rare diseases.

To find out more, visit:
**www.FromPatientToPerson.com**

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