MARK LASSER

Mark Lasser lives in Denver, CO with his wife and two small dogs. He has worked in the film and television business, as a tech sales person, as a consultant with Pricewaterhouse Coopers, as a forensic accountant, and as a lecturer at the University of Colorado. Mark Lasser was 47 years old when he woke up one morning to find he suddenly couldn't see out of one eye. Within a matter of days, he experienced a similar loss of vision in his other eye, leaving him 95% blind.

He has a BA in Public Policy from Duke University, an MBA and an MS in Accounting from the University of Colorado. He has been published in several magazines and newspapers including a column in the Denver Post. In addition to being blind, he loves to travel, read, see movies, attend live sports events and play poker.
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MARK'S DIAGNOSIS & HISTORY

Mark's condition called Non-Arteritic Anterior Ischemic Optic Neuropathy (NAION), refers to loss of blood flow to the optic nerve (which is the cable that connects the eye to the brain). This condition typically causes sudden vision loss in one eye, without any pain. In many cases, the patient notices significant loss of vision in one eye immediately upon waking up in the morning. The visual loss typically remains fairly stable, without getting markedly better or worse once it has occurred.

Mark had the rare experience of developing NAION in both eyes, which caused him to lose most of his ability to see and all of his ability to read, write, and drive over the period of only a week. He sees going blind as a hassle and inconvenience, not as a life ruining event or massive reduction in quality of life. In the last year, he's learned Braille and uses several assisted technologies, such as screen readers, to make his life more independent. Use of these technologies and devices brought him back into the world and enables him to lead a reasonably normal, independent life.

LAURA GEE

Laura Gee was diagnosed with Type 1 Diabetes when she was 7 years old. She realized while very young that she wanted to pay it forward and give something back to the research and development that saved her life. Laura decided she wanted to work in research and help others. Growing up with diabetes gave her a foundation that allowed her to see the importance of fitness, health, and nutrition. She watched her life evolve from a life where diabetes controlled her to a life where she was able to control and fine-tune her diabetes with the advancements in technology; names an insulin pump with continuous glucose monitor. When her husband Rob was diagnosed with Type 1 Diabetes at age 29, Laura was grateful that he would also benefit from the same advancements that were now making her life manageable too. In Laura's lifetime, she has seen drastic and positive changes with diabetic care and technology. Today, Laura and Rob use these advancements to live without bounds.

Laura worked for 13 years in research including roles in animal care, the laboratory, management and training. In 2013, Laura retired and began coaching others full time using social media platforms, email, phone, and webinar services to help them achieve their health and wellness goals through support. She has met many fellow diabetics and has developed lasting friendships. In today's connected world, no one stands alone. Laura is also a professional speaker, empowering, motivating and challenging people through her heartfelt message.

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LAURA'S DIAGNOSIS & HISTORY

Each of these conditions have been aided by research and medicine & I'm eternally grateful!!

- Diagnosed at age 7 (August 15, 1986) with Type 1 Diabetes.
- My husband Rob, was also diagnosed with Type 1 Diabetes in 2007 - yes, we're soulmates!
- I have lost the majority of my family to cancer. Those diagnosed within the last 7 years are cancer survivors (this includes my mom and sister) due to the continuing evolution of medicine and research.
- Positive for BRCA gene mutation, putting me at a significant (nearly 90%) risk of developing cancer in my lifetime. Underwent bilateral prophylactic mastectomy in 2010 to help reduce lifetime cancer risk. Also, took the advice of medical practitioners to lead an active and healthy lifestyle to further reduce risk. My sister and mother are also positive for the same mutation; both have been diagnosed with cancer.
- Diagnosed with Polycystic Ovarian Syndrome and Hypothalamic dysfunction in 2014. Currently receiving medical care and continuing to incorporate a healthy, active lifestyle to manage body weight and hormone balance.

- Diagnosed with full-blown Osteoporosis in 2014. Currently receiving medical care to strengthen bones while continuing to incorporate quality nutrition and activity to improve bone health.
- Even though I have all of these health concerns (including several food intolerances) I feel absolutely fantastic and I am the picture of health. Each condition is manageable due to research and medicine.

PAIGE NUES

Paige Nues dedicates her time to providing a safety net of accurate information, emotional support, and connections to empower the families, caregivers, and support teams of children with Rett syndrome at all stages of life.

Paige has served on the Board of Directors, as a Regional Representative, and is parent founder of Katie's Clinic for Rett Syndrome at UCSF Benioff Children's Hospital Oakland. She enjoyed a successful career in sales, marketing, and business development with Fortune 100 companies prior to her daughter Katie's diagnosis of Rett syndrome in 2003. She and her husband Jesse live in California and are the proud parents of three extraordinary girls.

About Katie

Please don't view Katie or our family as a burden to society, please view her syndrome as the burden. I would ask you to view managing her syndrome and her progressive symptoms as the opportunity, the dream, the possibility to relieve the burden of care, simplify the delivery of care, and give back some measure of the beautiful life that was unfolding before this random gene mutation stole her abilities from her.

She's in there, trapped, unable to tell us where it hurts, or if it hurts, but she's in there, and she will live this way for decades. As her parents, we're doing everything we can to make every day the best day possible for her. Doesn't every parent? But it's hard. She's complex, and frankly, the syndrome is 24/7 relentless. But I know it doesn't have to be as hard it is.

Short of the cure, I know that Industry has the technology and systems to help us coordinate her care across so many different specialists, from hospitals to private practice to therapy units to the pharmacy to the school system to home health to research institutes. Her specialist have and will continue to change over time. They go in and out of jobs. Our healthcare coverage changes with our every job change. Our pharmacy and formularies change with each of these changes. Her symptoms progress, and the tracking of her history throughout all of this often gets lost in translation, and it's getting increasingly hard for me as time goes on to be the "Keeper of All Things Important About Katie".

ABOUT RETTSYNDROME.ORG

Rettsyndrome.org, a 501(c)3 organization, is accelerating research for treatments and a cure for Rett syndrome. As the world's leading private funder of Rett research, we have funded more than $35 million in peer-reviewed research grants and programs to date.

www.rettsyndrome.org; 510.499.3858; 1.800.818.7388 (RETT)

She has aged in and out of early childhood, pediatric, and adolescent care and I don't even want to think about the transition to her adult care and case management. But I know that we have the ability to reduce office visits and home visits. Remote consults could resolve so many monthly and annual "standard" appointments just to obtain prescriptions refills and equipment checks, not to mention triaging or troubleshooting symptoms that crop up. Which, by the way, they never do Mon–Fri between 9am and 5pm, trust me!

I dream of devices that are small and unnoticeable, that have long battery lives and are waterproof, that can help me know when she is in or out of "normative" range for her syndrome and for who she is on the disorder's spectrum. Beyond fitness, I'm talking about worrying every minute about the stuff of life like: respiration, pulse, temperature, circulation, tremors, coughs, movement, sleep, seizures, digestion. These things happen normally for the most part, but because I know that they can be issues that might be undetectable by me until they've become a big problem, I worry. I worry all the time. There is so much that could help relieve these worries, that could keep us out of urgent care clinics, or in them for the right reasons!

We won't give up on her, and we ask that you don't either. This random mutation just happened. And it happens again and again every day to little girls all over the world. If we could just connect the technologies, information systems, devices and skills that exist in separate spheres together, I know that we could categorically improve not only her life, health and happiness, but our entire family's life. We could help her doctors deliver better care, reduce cost of care, and accelerate research by the sharing of her data. I consent a thousand times over!

I never touched on how this has decimated our personal financial or emotional reserves, that's another story for another day. I want the focus to be on Katie, and even more importantly, on the girls who live in rural or remote parts of the country or world, or who don't have parents that can chase down the information that we can, or are able to get to the offices and hospitals that we can.

Let's develop devices that could allow her some measure of independence and privacy, to sit alone and read a book, or watch a show, or enjoy a relaxing bubble bath without a constant attendant. At thirteen, I know she wants this, and she can't even have these small dignities that most of us take for granted.

Katie has Rett syndrome. We accept that. But we don't accept the disconnected, often ill-informed, bureaucratic, clunky way that we have to slog through systems to find the best care practices for her rare disorder. Rare doesn't have to mean obscure with today's technological advances and resources! Let's connect these dots and get her get back to living instead of just surviving.