

VISION SCIENCE AND EYE

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The bridge from diagnosis to potential treatment: The crucial role clinicians play in success for blind individuals

Kristin Smedley

President & Co-Founder, Curing Retinal Blindness Foundation, USA

Overview: This dynamic session will provide concrete examples of how connecting blind individuals to resources creates a bridge from diagnosis to potential treatment, thereby enabling the individual to lead a successful life without sight.

Background: A diagnosis of blindness is devastating. Whether it is an adult that finds out they are losing their sight or a parent finding out their baby has no sight, it is a traumatic experience. Typically, clinicians say nothing more than “I’m sorry” to the patients and their caregivers. Parents’ dreams for their child are destroyed and they feel hopeless, which usually causes them to completely alter the way in which they parent that blind child. Adults that lose their sight often end up unemployed and depressed. In fact, 70% of blind adults are unemployed. Although the impact of blindness is affecting more and more people, most sighted people have no idea of what blind individuals are capable of and therefore a stigma of sadness and pity is misappropriated to the blind community. This stigma creates a vicious cycle of low expectations, under achievement and dependence for blind individuals.

Changing The Blindness/Visual Impairment Diagnosis Delivery: Kristin Smedley is raising two sons that are blind due to CRB1 LCA/RP. In the seventeen years she has been a parent of blind children she has connected with many successful blind adults to guide her in raising her expectations of her boys and getting all the resources they need to level the educational and social playing field of their peers. She connected with other families raising CRB1 LCA/RP children to share resources. Smedley leads the Curing Retinal Blindness Foundation, the only patient organization in the world for CRB1 LCA/RP. The CRBF is a leader in the rare eye disease community. The CRBF has created a resource toolkit for clinicians, educators, and caregivers to change the way a blindness/visual impairment diagnosis is delivered such that patients are empowered to lead a full life.

Results: Due to consistent exposure to blind role models and proper resources as well as maintaining high expectations for a full life, Smedley’s two blind sons have achieved success much greater than many blind children their age: baseball and swimming championships, elected student council executives, International Braille competition awards, gifted programs in regular public schools and more. In addition, the CRBF has forged collaboration in the rare eye disease community where multiple organizations are combining resources to affect many more patients, clinicians, researchers and caregivers for a positive impact worldwide.

Biography

Kristin Smedley, from Bucks County, Pennsylvania, is an award winning non-profit leader, TEDx speaker, and author - but she never planned on any of that. Kristin did plan to be a really great third grade teacher, however her personal path to greatness took an unexpected turn when two of her three children were diagnosed as blind. She had to learn the tools of blindness and build a team of experts that would help her navigate this path that she had not been trained for. Kristin’s two blind sons are now thriving as gifted high school and middle school students, elected student council officials, baseball championship winners, International Braille competition finalists, and social butterflies.

curingretinalblindness@gmail.com