



The Vision of Children Foundation funds cutting edge research to find cures for millions of children born with incurable vision disorders and offers programs to help families and children with such vision ailments.

Introduction

Imagine hearing the news that your child has a disease for which there is no cure, no treatment and no hope because very few scientists are researching the condition. Historically, that is what doctors told parents whose children were born with genetic vision disorders. Today the message is one of hope.

Sam and Vivian Hardage founded The Vision of Children Foundation in 1991 after their son, Chase, was born with a rare, debilitating disease called Ocular Albinism type 1. The Hardages were determined to encourage scientific research to find a cure for the congenital condition affecting their infant son. Knowing how devastating the diagnosis of an incurable vision disorder can be in your child, the Hardages also wanted to provide support to families who faced similar challenges.

The Vision of Children Foundation is now the foremost organization in the world supporting research for Ocular Albinism and related genetic vision disorders.

Program #1: Research

The Vision of Children Foundation focuses on genetic eye disorders (in which faulty genetic material is passed by the mother or father to the newborn). Studies on such inherited eye diseases have traditionally been under-represented and under-funded. The health community at large and most other research funds focus on decreasing the incidence of blindness caused by malnutrition, diseases and premature birth.

Millions of children around the world have uncorrectable vision disorders that severely impair their vision and have a devastating impact on their quality of life and ability to function "normally" within society. According to the Cleveland Clinic, inherited eye diseases account for more than 60 percent of cases of blindness among infants. Children who have vision disorders often endure many challenges, such as bullying from peers, as well as discomfort due to the special accommodations that call attention to their disabilities.

The Foundation's primary goal is to eradicate Ocular Albinism. To that end, the Foundation is working with researchers at leading institutions around the world, including the UCLA Stein Eye Institute and the San Raffaele Scientific Institute in Italy. These researchers have conducted revolutionary work that has broad implications for vision science. Among their many breakthroughs, they have isolated genetic mutations for eye diseases and developed DNA diagnostic tests.

These research results have led to collaborative efforts that will expedite the discovery of cures for a variety of other genetic vision disorders, including Oculocutaneous Albinism and retinal degenerations. Knowledge about genetic vision disorders has increased significantly since the Foundation was founded 25 years ago. Now, gene therapy and stem cell therapies, which seemed but a distant dream when the Foundation was founded, are becoming a reality. UCLA scientists funded by The Vision of Children Foundation are exploring how to best use byproducts of patients' own stem cells to replace defective DNA.

Program #2: World Symposiums

The Vision of Children Foundation hosts regular scientific symposiums that bring together an elite group of the world's top vision researchers to share and collaborate on their ongoing work before it is published.

The Symposiums were launched in 2000 with a special invitation to researchers who had been working independently to further the field of knowledge regarding genetic vision disorders. The goal was to bring this select group of scientists together to collaborate and share their discoveries to expedite the translation of their research into treatments for children born with such vision disorders. The steadfast requirement for participating in the Symposium was that all researchers be willing to present their "unfinished" work to the other scientists. At the time, this was a novel concept. Typically, researchers work independently and only share their findings after publishing their peer-reviewed, highly scrutinized and ultimately validated research results.

Since these Symposiums started, there has been a remarkable improvement in the culture regarding the willingness of researchers to share and collaborate to accelerate the pace of discovery. In 2016, we hosted our 9th World Symposium, "Where Vision Meets Reality," in San Diego, at which 19 leading vision and genetic eye researchers met to share and collaborate on their latest, unpublished research efforts involving genetic vision disorders.

Program #3: Family Support Network

The Vision of Children Foundation works to improve the lives of visually impaired individuals and their families by providing educational support and services.

Families of the visually impaired often feel isolated and confused, and need support to face day-to-day life. We believe communication between families, educators, healthcare professionals, and researchers who care for these children is critical, and we work to facilitate this process. The World Symposiums support this mission. Family members and individuals with genetic vision disorders are invited to attend the symposiums and participate in the scientific sessions, as well

as a special presentation focused on the impact of current research. In addition, other professionals, such as low-vision specialists and optometrists, are invited to attend the Symposium.

The Foundation also provides information and support via direct regular communications, social media and an informative Web site to support a worldwide network of families impacted by genetic vision disorders. Joining the Family Network enables parents and grandparents to contact other families who face similar challenges in their geographic region to offer support, and share experiences and local resources and programs.

Program #4: Vision Heroes Program

The Vision of Children Foundation's Vision Heroes program, and accompanying videos and blog posts, honors young people who have overcome their vision challenges and are living extraordinary lives. Many of these children have been told that they can't do what others can do, and they have used this as motivation to prove them wrong. They include a young artist who paints despite her blindness, a teen musician and a blind golf champion. Such compelling human-interest stories are powerful methods of engaging the public. The videos and blog posts are important elements in our effort to increase awareness of the Foundation, genetic vision disorders, and the challenges facing children with vision disorders.

Program #5: Project Vision Aid

The Vision of Children Foundation strives to enable thousands of children to have a clear image of the world around them. We provide information and tools available to ease the daily challenges that the visually impaired face. Under the Project Vision Aid umbrella, the Foundation donates tools, such as handheld video magnifiers and iPads, to children who are visually challenged. For children with low vision, the world can take on a whole new view when they use this technology.