Aniridia Foundation International

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Help Us Make A Miracle!

Join us in supporting and participating in our mission to improve the lives of people living with Aniridia Syndrome

Take Our Hands, Walk with Us, Share Our Dreams, and Make a Miracle!

Help Us Make A Miracle!

We need you to become an active registered supporter of AFI and join us in participating in our mission. Together we can make a difference in many lives!

Find out ways you can help by visiting our website and fill out our supporter registration form under "Join Us."

Aniridia Foundation International (AFI) is a 501(c)3 nonprofit organization whose mission is to help people born with low vision or blindness due to a genetic defect causing Aniridia Syndrome. AFI helps children and adults who are affected and their families through research, educational resources, and community support. Through these initiatives, AFI is also working toward a cure for Aniridia Syndrome.

Aniridia Syndrome is a genetic disorder affecting the development and maintenance of the eyes and other parts of the body. For each person born with Aniridia Syndrome there is a 50 percent chance with each pregnancy of passing it to the next generation, called autosomal dominant inheritance. Therefore some families have multiple family members and multiple generations affected. This is one reason AFI continues to help with important research and work passionately towards a cure.

Because of the genetic component, the visual acuities among those with Aniridia Syndrome may vary according to the level of development of their eye structures like the optic nerve and retina. Most children and adults born with Aniridia Syndrome have visual acuities between low vision and legal blindness or worse. The majority have no iris development (the colored part of the eye) and have multiple challenging eye conditions which can cause further vision loss including: difficult-to-treat glaucoma,

corneal scarring, childhood cataracts, and retinal issues, that can appear anytime between birth through young adulthood. These conditions individually are common in the general population; however, it is uncommon to have many occur in one person.

Through AFI's help with research, the scientific community is now realizing that the genetics causing this syndrome affects more than the eyes. It also plays an important role in the development and maintenance of the pancreas, central nervous system, olfactory system, and parts of the brain. More research is needed in the areas of insulin resistance and diabetes, autism spectrum disorders, metabolism and endocrinology.

Mission: Research

Aniridia Foundation International helps research in two ways: funding scientists conducting Aniridia Syndrome research and through our own research program, The Aniridia Foundation International Medical Registry.

The AFI Medical Registry

The AFI Medical Registry securely collects medical data from people with Aniridia Syndrome. This de-identified data has been used by medical professionals and researchers for many peer-reviewed medical and scientific papers written over

the last decade. These new findings have led to a better understanding of Aniridia Syndrome. The goal of these and future studies is to work towards better treatments and therapies, eliminating the inheritance into future generations, and the cure of Aniridia Syndrome and the conditions associated with it.

Aniridia Foundation International works closely with researchers leading aniridia research and physicians with successful experience in aniridia care. AFI Medical Registry registrants are often invited first to participate in Aniridia Syndrome research studies (both paid and unpaid) and in clinical trials.

Some of the data collection can be done from home, some during the AFI "Make a Miracle" conferences, and some in clinic by the ophthalmologists experienced in Aniridia Syndrome.

Since we are learning new things so rapidly, the AFI Medical Registry is continually improving its ways of data collection. Some examples are: participating in the annually-updated medical survey, medical information sent by doctors at your request, taking photographs and sharing genetic testing results.

An additional benefit for AFI registered supporters participating in the AFI Medical Registry is funding for genetic testing. Obtaining personal genetic data is important to know to help determine if a person is a candidate for future therapies. For those who already had genetic testing, the results can also be submitted to the AFI Medical Registry. This important genetic data helps researchers learn more about the genotypic/phenotypic relationship (comparing the genetic sequence and the physical conditions present in a person with Aniridia Syndrome).

Mission: Educational Resources

The Aniridia Foundation International "Make a Miracle" conferences

Our most successful educational program, the "Make a Miracle" conferences, has been in existence since our beginning in 2002. These unique conferences bring together physicians, researchers, medical and research grad students, those affected and their families to learn the latest information about Aniridia Syndrome during several days of informational sessions. Also, professional sessions allow physicians and researchers to come together and brainstorm, increasing the bidirectional learning between research lab and clinic.

In addition to the sessions, there are special events where families can share their stories about living with Aniridia Syndrome with others who truly understand and address their social and support needs. Lasting friendships are made during these times of personal connection. While the parents are learning from the professionals, children and

Get your AFI Medical Registry file started today and become a part of a better understanding of the complexities of Aniridia Syndrome.

teens have a program all their own, including fun activities, age-appropriate sessions, and time to create friendships.

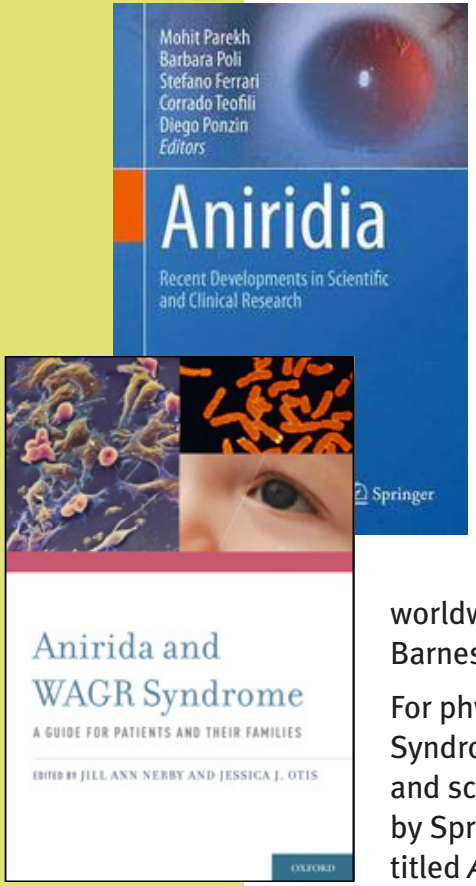
The conferences are also a time to participate in data collection for the AFI Medical Registry and new research studies. In appreciation for helping others and themselves through these data collections, some conferences offer the opportunity to be seen in the "See the Experts" clinic at no charge.

Other Educational Resources

Aniridia Foundation International shares the latest information with their registered supporters and donors through AFI's *Eye on Aniridia* news edition. These news editions contain information about research and medical advancements in Aniridia Syndrome, fundraising events and opportunities, as well as personal stories. Issues are sent to those with current contact information registered with AFI.

A wonderful book entitled *Aniridia and WAGR Syndrome: A Guide for Patients and Their Families* by Jill A. Nerby and Jessica J. Otis is highly recommended reading by many. This book has medical chapters written by AFI Medical and Scientific Board professionals in

Become a registered supporter of AFI to receive our informative and inspiring news editions.



a non-technical way for better understanding of the many facets of Aniridia Syndrome. Other chapters include information about resources and support for patients and their families, real-life stories of patient and family experiences, suggestive teaching for the low vision child, and Aniridia Foundation International's mission. This book can be ordered from the publisher, Oxford University Press, from our office, or worldwide from sites like Amazon or Barnes and Noble.

For physicians treating Aniridia Syndrome, there is a technical medical and scientific textbook published by Springer International Publishing titled *Aniridia: Recent Developments in Scientific and Clinical Research*. The book highlights topics such as: *"Current Research Dedicated To The Ocular Defects Of Aniridia," "The Latest Surgical Approaches"* and *"Special Attention To Pediatric Patients."*

Included are chapters authored by Jill Nerby, BS and some of AFI's Medical / Scientific Advisory Council professionals.

Mission: Lifelong Support

There is no better feeling than to be truly understood. Aniridia Foundation International provides support through peer and professional counseling with those living with Aniridia Syndrome and their family members.

Sharing with others and asking questions is an important aspect for those living with Aniridia Syndrome. Therefore, by request, AFI has created a private online forum to meet others with Aniridia Syndrome and their family members to share personal experiences, ask questions, read the latest informational articles and more. There will be topic chat times for children, teens and adults.

Stay connected to the community through these venues:

Our website at www.make-a-miracle.org, our Facebook page at Aniridia-Foundation-International, and our Twitter feed @AFIMakeAMiracle.

Get involved in Aniridia Foundation International and stay in touch with people who truly understand the Aniridia Syndrome journey.

Leading the Way

From the beginning in 2002, we have relied on a group of volunteers to run AFI so overhead is minimal and every donation is used for our mission. Funding needs for research, genetic testing, and hosting the "Make a Miracle" conferences continue to grow. These initiatives are very important in working towards better therapies, genetic breakthroughs and a cure for Aniridia Syndrome.

We can lead the way to help people living with Aniridia Syndrome; however, we cannot do it alone. We need you, the aniridia community, families and friends to show your loving support through becoming donors, hosting fundraisers, participating in data collections and sharing your skills as a volunteer for Aniridia Foundation International.

Join Aniridia Foundation International

We need you to become an active registered supporter of AFI and join us in participating in our mission. Together we can make a difference in many lives!

Find out ways you can help by visiting our website and fill out our registration form under "Join Us." Registrations must be renewed yearly to remain current.

Some of the AFI registered supporter benefits include:

The latest information about Aniridia Syndrome in our private online forum and *Eye on Aniridia* news edition.

Invitations to the AFI "Make A Miracle" Conferences.

Free genetic testing (when funds are available) and first notification of new research studies and clinical trials for those participating in the AFI Medical Registry.

A community of support for children, adults and their families living with Aniridia Syndrome.

Thanks to volunteers, nearly 100% of all donations to AFI go directly toward helping people living with Aniridia Syndrome, and all donations stay in the USA.

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