



Aniridia and WAGR Syndrome: A Guide for Patients and Their Families

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Our hope is to enlighten and encourage those affected by aniridia and WAGR Syndrome by providing patient support and medical information. There is information to inform parents, teachers, doctors, employers, and the public about aniridia and what it is like to live with it. Several renowned doctors contribute medical chapters. Personal experiences from individuals with aniridia and parents with children with aniridia provide encouragement. Contact information for Aniridia Foundation International (AFI) is included.

When a child is born without a complete iris, it is usually a symptom of a broader condition. Known as aniridia, this condition can also be a sign other parts of the eye are underdeveloped as well. Moreover, recent research shows that the gene involved can also affect the kidneys, pancreas and forebrain, so aniridia can coincide with a range of symptoms known as WAGR syndrome. Until recently, however, there was very little information available on aniridia and WAGR Syndrome. Even now, not all of the available information is current or correct, so that when a child is diagnosed with aniridia, the parents often find or are given information that is confusing and even frightening.

We created this book to help those families see that they are not alone, and there are a lot of answers and a great deal of hope. It contains information about aniridia and WAGR Syndrome for parents, other family members, friends, teachers, doctors, and employers. We have been very fortunate to have several renowned doctors contribute current and comprehensive medical information that will help to provide concrete answers to basic questions and demystify these conditions. The book has many personal stories from individuals and parents that will help to give a more complete picture of what it is like to live with aniridia and WAGR Syndrome and provide encouragement and comfort. It also contains information about where to go for more answers and support, including the Aniridia Foundation International (AFI), <http://www.aniridia.net>, a non-profit organization created by one of the authors, Jill Nerby.

We hope that you will read this book and join us in creating a better future for those with aniridia and WAGR Syndrome.

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Clarence Danner:

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