

Aniridia Foundation International is proud to announce the release of their first book:

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



Aniridia Foundation International

Book review

Aniridia and WAGR syndrome

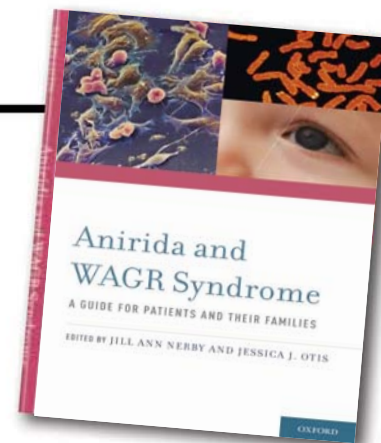
Bill Harvey commends the format of a new book on aniridia aimed at patients and their relatives and wonders if it might not be equally applied to more common eye conditions

Only once had to deal with a patient with aniridia many years ago. Apart from the obvious need to help with the extreme light sensitivity the young woman was struggling to cope with, it was also obvious that the condition was taking its toll on the patient's mental health. She was clearly very depressed and had little motivation and, quite frankly, I felt out of my depth at that early stage of my career. I was thankful that there was help available elsewhere in the form of counselling and rehabilitation. I recalled this recently when I came across a new book published by Oxford University Press.

Aniridia and WAGR Syndrome is written by the psychologist Jill Nerby and the author Jessica Otis. Both are themselves aniridic and both have sons who have inherited the condition. The authenticity of some of the writing

is clear throughout and reflects their own personal experiences with the condition. The book is an inspiring mix of the didactic, with several chapters co-written with medical specialists, and the personal and experiential, with chapters based upon testimonials from relatives and patients as well as advice on coping strategies and support.

The opening chapter offers an excellent description of the condition and, perhaps more importantly from a clinician's point of view, all the various systemic and associated conditions found with aniridia. This chapter would be useful to all those studying ocular disease. Setting the tone for the rest of the book, chapter 2 follows on from this very detailed medical perspective with a chapter called 'Inspirations'. Essentially this is a collection of 'stories from those who do not let anything keep them from



achieving their goals and who inspire us'. With many publications this could be verging on the patronising but with these authors and with the quality of writing I found the testimonials quite moving.

Further chapters include descriptions of treatments and management (including low vision) alongside further testimonials from relatives and parents, all littered with some excellent advice that patients themselves might find changed their lives. I wish I had been able to offer this book to that patient 20 years ago. I also would love to see similarly patient focused books, with just the right mix of clinical, social and personal, published on conditions such as retinitis pigmentosa and even macular degeneration. ●

(As seen in *Optician*, February 11, 2011)

Our book is available for purchase through the following sources:

Medical and universities bulk order:
Oxford University Press
www.oup.com

Individual orders:
Amazon.com (USA)
and other worldwide Amazon websites