

THE OCULAR
IMMUNOLOGY
AND UVEITIS
FOUNDATION

Ocular Immunology and Uveitis Foundation

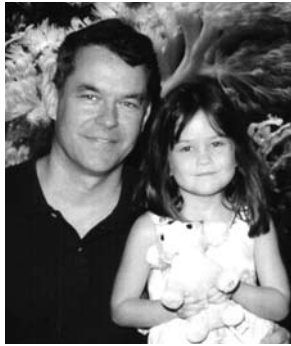
Massachusetts Eye Research and Surgery Institute

C. Stephen Foster, M.D., F.A.C.S., F.A.C.R.

Clinical Professor of Ophthalmology Harvard Medical School



Fall/Winter 2007-08



Steve and Gabrielle at the New England Aquarium

An OIUF Pathfinder story: Steve & Gabrielle Gabrys

On her second birthday, in March 2004, our daughter Gabrielle was put under general anesthesia and underwent an MRI on her horribly swollen knee. She was soon thereafter officially diagnosed with Juvenile Rheumatoid Arthritis (JRA), which is now known as Juvenile Idiopathic Arthritis (JIA). We were devastated and overwhelmed by the symptoms, doctors' appointments, lab tests,

referrals, diagnosis, medications, physical therapy, and all the normal worries of parents with a chronically ill child. In hindsight, in Gabrielle's case, this was nothing compared to her upcoming battles with her JIA-related uveitis.

During a standard slit lamp exam when Gabrielle was three and one half years old, our pediatric ophthalmologist observed white blood cells and keratic precipitates in both her eyes. Gabrielle was diagnosed with iritis, an inflammation of the irises which are part of the uveal tract. These were indications that the JIA, an autoimmune disease, was now also attacking healthy tissue in her baby blue eyes. We were floored by the news and put our trust in the hands of the ophthalmologist. After all, books mentioned that the JIA-related uveitis was possibly blinding but treatable. Four months later, after multiple unsuccessful steroid drop tapers, few answers, and diminishing hope, we started looking for additional help. The best information on the Internet kept showing up at a website www.uveitis.org. A friend also told us that Dr. Stephen Foster is "the best." After bottles and bottles of steroid drops, and another unsuccessful steroid taper where the cells in Gabrielle's eyes returned with a vengeance, my wife requested a referral to see Dr. Foster, got an appointment at MERSI, and booked a flight to Boston.

My wife (Daphne) and Gabrielle visited MERSI in February 2006. Daphne immediately observed Dr. Foster's experience, compassion, and great passion for eradicating uveitis. She returned home with information, multiple treatment options within the stepladder approach and, more importantly, hope. We could finally take some control in this devastating disease. Over the next month that hope was eroded as local coordination became difficult through disagreement and resistance. Even the requested referral to see Dr. Foster was denied by the insurance company. Undeterred, in April 2006, Gabrielle and I flew to Boston for an appointment with Dr. Foster as well as to attend the OIUF's Pediatric Uveitis Conference. I met Dr. Foster for the first time and agreed with Daphne's perceptions and

opinions. I also met many other children with JIA-related and idiopathic uveitis. They were an inspiration to me and their parents were a wealth of information.

Due to insurance company rejections of all our specialists' visits, I spent several months researching the disease, its treatments, and research studies. The more I learned, the more I was appalled by Gabrielle's treatment for the six months prior to Dr. Foster attempting to get her on the right path. That research information, plus anecdotal evidence from dozens of parents around the country made us sure we were at the right place. I wrote a lengthy, well-documented appeal's letter, attached a strongly worded letter from Dr. Foster himself, and convinced our insurance company to cover all office visits to MERSI. Although we eventually found a new local-area uveitis specialist, we continue to travel to Boston periodically (3000 miles round trip) to ensure Dr. Foster is "driving the bus" on Gabrielle's care.

I encourage all parents to get involved in the online support group, and attend meetings and conferences as best they can. Gabrielle's eyes are currently doing very well thanks to an early diagnosis, a delayed but relatively early first visit to MERSI, and the experience and guidance of Dr. Foster and his treatment program. She is currently on a successful immunomodulatory treatment (IMT) program, has 20/20 vision in both eyes, no active inflammation off all steroids, and has no cataracts, glaucoma, or other permanent damage to the eyes.

Gabrielle would also like to personally thank Dr. Foster for helping "the cells in my eyes" and hopes to repay him someday when she is a "superhero" or "sea animal doctor." She would also like to know when she can stop the Friday night shots (less than two years now, Sweetie; less than two years and counting!)

[Steve Gabrys is a member of the Pathfinders program which helps others with uveitis, or in his case to help other parents whose children have uveitis.]

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Calendar of Events

November 29, 2007

Support Group

Adjuncts to therapy for Ocular Inflammatory disease
George Mandler, Licensed Nutritionist and
Acupuncturist

January 10, 2008

Support Group

Uveitis Updates: Outcomes of Intraocular Lenses
in Children with JRA & More!
Karina Quinones, MD

March 6, 2008

Support Group

Research in Uveitis

April 2, 2008

Third Annual Through Their Eyes: Art Auction

June 7, 2008

Support Group

Pediatric Uveitis Conference

June 19, 2008

Support Group

Anniversary Meeting
C. Stephen Foster, MD

September 27, 2008

“Walk for Vision”

October 4, 2008

First Annual Birdshot Retinopathy Conference

October 25, 2008

Third Annual Physician Education Conference:
“New Paradigms in the Treatment of Anterior
Segment Disease”

THE OCULAR
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FOUNDATION

Our Mission

The Ocular Immunology and Uveitis Foundation is a 501c(3), national non-profit, tax-exempt organization. Our mission is to find cures for ocular inflammatory diseases, to erase the worldwide deficit of properly trained ocular immunologists, and to provide education and emotional support for those patients afflicted with ocular inflammatory disease.

Ways to Give

The end of the year is often a time to review financial matters and charitable commitments. To help meet your philanthropic goals, OIUF accepts gifts of many types, including appreciated securities, bequests, real estate, qualified retirement and life income gifts. Any charitable gift made prior to December 31st may reduce 2007 income and estate taxes. For more information please contact Alison Justus at (617) 494-1431 x112 or oiuf@uveitis.org

***Please use the enclosed envelope
for your donation***

**We are looking for fine art
and antiques for the 2008 art
auction. If you are an artist or
know someone who would like
to donate, please contact OIUF.**

Letter from our President and Founder

It has been 6 months since my last report to you, and things have changed considerably for the Ocular Immunology Uveitis Foundation (OIUF) and Massachusetts Eye Research and Surgery Institute (MERSI). Over those past six months, thanks in large measure to the generosity of the patients of MERSI and to the support and generosity of friends of the Foundation. All of these people countable individually and collectively, saw that they have an opportunity to play an active part in making the discoveries that form the basis for the cures of tomorrow. The funding of the research at the Foundation made possible by the generosity of all of these philanthropic souls has already changed the lives of many, and will continue, year after year, to give the gifts of sight to those who otherwise would be blind.



C. Stephen Foster, M.D.

The demand for our services has increased more rapidly than any of us anticipated; and there's a consequence, we have added medical and support staff, and have invested in an additional surgical facility and the new technology. Dr David Hinkle, as most of you know, is an Eye MD, ophthalmologist, ocular immunologist, who now forms part of the faculty and is one of the physicians seeing patients at MERSI and conducting research at the Foundation. The increasing number of patients wishing to be cared for at MERSI, combined with the increasing requests for our services outside of Massachusetts, has resulted in the necessity of interviewing other physicians who are interested in joining the faculty at MERSI and at the Foundation. Increasing numbers of medical students and visiting eye care specialists are requesting fellowship and sabbatical opportunities for learning at MERSI and I am increasingly requested to lecture within other departments in the Harvard Medical School system, (for example, immunology and neurology and gastroenterology), and to be visiting professor nationally and internationally. This carries with it the potential for increasing burdens on MERSI and OIUF staff if I'm absent from Cambridge excessively, and therefore I have enlisted the help of my wife, Frances, and of the practice administrator, Mr. Scott Evans, to help keep this matter under tight control and yet attempt to avoid insult to those extended invitations that must be declined.

On the matter of travel, two important meetings are of particular note because of the exposure of MERSI and the Foundation to the international community. The first was the meeting of the International Ocular Inflammation Society held in Paris in September of this year. The MERSI and OIUF team played a very significant role in that meeting, and, further, the Foster Ocular Immunology Society (FOIS) was listed permanently as one of the co-sponsoring participant societies. The second important trip during the past six months was that earlier this month to New Orleans to the annual meeting of the American Academy of Ophthalmology. I have lectured and taught at that meeting for the past 30 years, and was honored to receive the life achievement award from the academy this year, again getting significant exposure to our Foundation at this, the world's largest and most important clinical meeting in ophthalmology.

RESEARCH

I will be very brief in this segment, since we have an entire section further on in this newsletter devoted to the various research studies being conducted at MERSI through the aegis of the Ocular Immunology and Uveitis Foundation. Suffice it to say, it is almost unheard of for a group in the private sector, i.e., not within the confines of a university department of ophthalmology, to be as productive in the research arena as the MERSI and OIUF team is. We have government and private industry grants to support projects, and, as emphasized in the opening paragraph of this report, the spectacular power of our patient supporters who generously make an investment in the work that we do that touches people lives today makes an enormous difference in what we are able to accomplish. As I survey the universe of ophthalmology in general and of ocular inflammatory disease in particular, I am struck by the vastness of the chasm that exists between the care provided at MERSI and that provided elsewhere. Not only have few centers moved past the 1950s with corticosteroid therapy alone for treating ocular inflammatory disease, but I know of no other center which has within its walls an infusion suite for the employment of the very new, biologic response modifiers in the quest to prevent blindness while at the same time avoiding the inescapable, life-altering consequences of chronic corticosteroid therapy.

EDUCATION

Education for medical students, visiting residents, post doctoral fellows, practicing ophthalmologists, nurse practitioners, physician assistants, and ophthalmic technicians' remains at the heart of the mission of MERSI and the Foundation. Every patient who comes to MERSI is made to understand that he or she will, in one way or another, contribute to the education of the next generation of eye care professionals, if he or she chooses to engage in our services. I slowly realized, many years ago, that this is simply something that I must do; this is simply something that I cannot help but do. It is "in me". It is a phenomenon, it seems to me, similar to that described by the famous American novelist, William Faulkner, many years ago when someone asked him about what it was that drove him to write. Faulkner's answer was something to the effect that he simply could not help it; he had to do it. It was something inside him that would not let him rest until he got it out. This is so for me to, when it comes to teaching ophthalmology and ocular immunology, and will be as long as I live. And it doesn't stop at teaching fellows

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Making a Visible difference...volu



Guest of honor: Lawrence A. Yannuzzi, M.D.



Guests of honor Robert Nussenblatt, M.D., M.P.H., Dr. Foster, Jay S. Duker, M.D., Steve Charles, M.D., Donald D'Amico, M.D. and Henry J. Kaplan, M.D.



Guest of honor: Lloyd Paul Aiello, M.D., Ph.D.

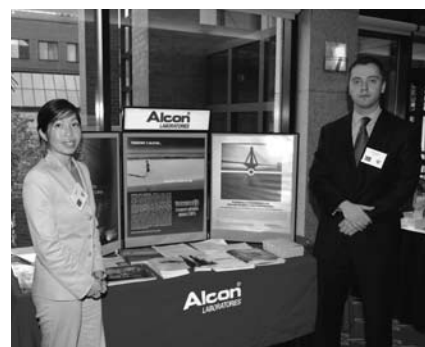


Second Annual Physician Education Conference: "What's New in Posterior Segment Disorders"

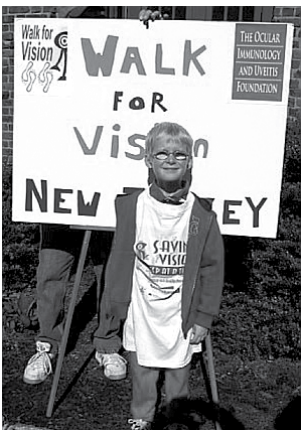
On Saturday October 20, 2007, the second Annual Physician Education conference was held at the Marriott Hotel in Cambridge, MA. Over one hundred physicians from New England, New York, Canada and beyond participated in this one day long event to earn 8.5 CME (Continuing Medical Education) credits and gain important knowledge from key opinion leaders (including Dr. Foster and MERSI staff physician Dr. David Hinkle) for a comprehensive review of the latest treatments and techniques for posterior segment disorders including macular degeneration, diabetic retinopathy, uveitis, macular edema and retinal vasculitis. Following the conference a number of participants joined Dr. Foster for a tour of MERSI's state of the art facility and to experience the wines of Michel Chapoutier. The Ocular Immunology and Uveits Foundation would like to thank Lux Biosciences and Northeast Interior Systems, Case Systems, Creative Laminates for sponsoring the Wine Tasting.

This year's conference would not have been possible without the generosity of our Diamond Supporters, Alcon and Allergan Pharmaceuticals as well as all of our supporters; ISTA, Bausch & Lomb, Inspire, LuxBiosciences, Merrimack, EYEGATE Pharma, NextGen, IOP Inc., Carl Zeiss Meditec, Risk Transfer Alliance, Ophthalmic Instrument Company, Ophthalmic Imaging Systems and Sirion Therapeutics.

Pictures courtesy of Eric Antoniou Photography



Volunteer your skills...plan an event...

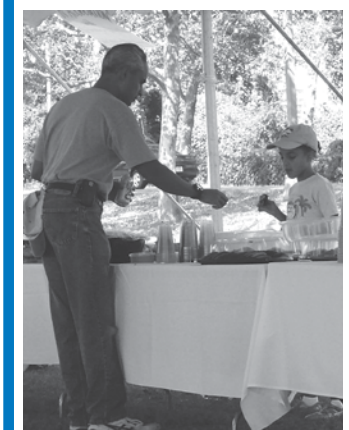


2007 "Walk For Vision"

The "Walk for Vision" sponsored by Bausch and Lomb, Lux Biosciences and Merrimack Pharmaceuticals was the most successful to date raising a total of \$50K! This year's fundraiser was made up of OIUF's annual walk in Massachusetts, two events in New Jersey, and many dedicated spirit walkers and fundraisers from around the country.

On Saturday, October 6th, 2007, the Ocular Immunology and Uveitis Foundation welcomed over 100 walkers (pictured above) to the Sonesta Hotel in Cambridge, Massachusetts for its annual 5k "Walk for Vision" around the Charles River. Walkers enjoyed unseasonably warm weather, an in-door barbeque and a talk by Dr. Foster on "Preferred Practice Patterns." On the same day (pictured on the right), Lux Biosciences held a successful event in Jersey City Liberty State Park. Pictured on the left, on Sunday, October 14, 2007, uveitis patient Lauren Jacobs organized the First Annual "Walk for Vision" in Verona Park, New Jersey. Sixty walkers joined Lauren for a 5k walk and to help spread awareness about Uveitis in her community.

The Ocular Immunology and Uveitis Foundation would like to thank all of our sponsors, walkers and volunteers for their successful fundraising efforts for the Foundation's groundbreaking research.



Research Highlights

Allergan Posurdex Steroid Implant Study

This study tests different doses of the Posurdex steroid implant, which is given by injection in the office (minor procedure, performed at MERSI) in patients with uveitis. The advantages: the pellet dissolves as it releases its medication. This is a large international study, with over 80 participating sites across the world, including the USA, Australia, the UK, South Africa. We will be enrolling more patients in this trial.

MUST Study

This study is the Multi-center Uveitis Steroid Treatment amallicutor study, funded by the National Institute of Health. It is the first clinical trial for uveitis that has been sponsored by the NIH. The goal is to compare standard medical therapy (immunosuppressive pills taken by mouth) for uveitis with a recently approved steroid implant placed inside the eye (surgery), to see which therapy results in better control of uveitis, which therapy patients prefer, and which has fewer side effects. The steroid implant is the Retisert®, which was approved by the FDA in 2005. Dr. Foster was part of the original study that led to its approval, and some of our patients have had this treatment, with excellent results.

Merrimack Pharmaceuticals Alpha Fetoprotein Study

This clinical study investigates a novel product, alpha fetoprotein (AFP), a hormone that is present in the blood of pregnant women. It has long been noted that uveitis and other autoimmune diseases improve during the later stages of pregnancy, when the levels of this

hormone also rise. The inference is that this hormone favorably affects the immune system, and pre-clinical studies have supported this idea. This study will test whether it is effective for sarcoidosis-associated uveitis and birdshot retinochoroidopathy. This will be an interesting new addition to the current therapy for uveitis, since the material is a natural product and not chemotherapy, with less side effects and less need for monitoring. Merrimack Pharmaceuticals cloned the gene for AFP, placed the gene into a herd of Irish goats, and harvest AFP from the goats' milk and then purifying AFP to medication form.

Lux Biosciences Uveitis Studies

Similar to the Merrimack study, these studies evaluate a novel synthetic compound – an immunosuppressive molecule that acts like cyclosporine, but at a fraction of the dose, and without the traditional side effects associated with cyclosporine. Due to his experience in treating uveitis patients with this medication, Dr. Foster was invited to speak at the Investigator's Conference for this study, which was attended by the 80+ US (and international) sites that were selected. In his own words, he is "tremendously excited" about this product, which is also the first uveitis medication to be tested in a randomized, controlled, masked clinical trial.

There are actually 3 sub-studies testing the molecule, one for intermediate or posterior uveitis, one for quiet/stable uveitis (in remission), and the third for anterior uveitis. We have patients now participating in these studies.

SITE Study

This study is also a multi center study (5 sites) across the USA, funded by the National Institutes of Health (NIH) . It is a chart review study, not a clinical trial. The goal is to determine whether the long term use of Systemic Immunosuppressive Therapy for Eye diseases leads to a higher risk of malignancy or death. Current data (published earlier by Dr. Foster) indicate that it does not. The SITE study will definitely answer this question, which people have been asking since the introduction of such therapy in the late 1970s by Dr. Foster. The idea is to 'pool' together all the patients from 5 centers across the Unites States, and to then analyze all of them together. The reason for taking such a large number of patients is to allow us to detect even a small increase in the development of cancer. Since Dr. Foster has the largest number of patients (compared to the other 4 centers), the NIH has provided not one, but two full time research fellows to take on this huge project. All the other centers only have 1 research fellow.

Lux Biosciences Corneal Transplant Studies

These studies have not started yet, but we are expecting them to be up and running soon. They involve the same novel drug that the Lux uveitis studies are testing, except here, instead of controlling uveitis, the goal will be to prolong the survival of corneal transplants. Most transplant patients have to take some sort of immuno-modulatory medication, so the reasoning is to see if this one is more effective than the standard ones or not.

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Carol Canner with Dr. Foster at
OIUF's 2006 Art Auction Benefit

SPOTLIGHT ON CAROL CANNER

OIUF BOARD MEMBER

Carol Canner, designer & sculptor begins her second year as an OIUF Board Member with great enthusiasm for the year ahead. Carol believes strongly in the work of the Foundation and as part of the Board's strategic planning committee, she has been instrumental in developing both the mission and long term vision. "There is such an overwhelming need for an increase in knowledge about uveitis and other ocular inflammatory disease, especially in research, education and support services for patients who are going untreated, or not being treated properly for their disease," says Canner.

Canner is no stranger to ocular inflammatory disease as she's been seeing Dr. Foster for Birdshot Choroidopathy since 2001. "Dr Foster has always been wonderfully responsive to my eye care. I was always fascinated

with his writing, teaching and managing all these difficult cases and particularly his research, so I began to support his research." Canner is on the planning committee for OIUF'S Art Auction, where she donates the mirrors she designs. Carol produces mirrors in collaboration with her husband Carl at their firm Carvers Guild in West Groton, Massachusetts. Her work has been recognized by the American Society of Furniture Designers and has received numerous other awards for her work. As an Artist, says Canner, "I can't imagine anything worse than going blind....When I was originally diagnosed with this disease, Dr Foster was the fifth ophthalmologist to see me and the only physician able to diagnose and properly treat my condition." Canner believes the work of the Foundation will change this by training future ophthalmologists in this chronically underserved field. "This critical education, states Canner, "will save vision and save lives by addressing the worldwide physician shortage."

President's Letter

Cont'd from page 3

and students. We are committed to an annual meeting of continuing ophthalmic education for eye MDs, having just recently completed an extraordinary successful posterior segment conference, devoted to all disorders affecting the eye from the pupil back to the retina. I also taught in the Schepens biannual Cornea Conference, held at the Star Conference Center in Boston in October, and, as mentioned previously, at the American Academy of Ophthalmology meeting and at the IOIS meeting in Paris. Publishing and creating other educational materials is part of it all, and we have recently completed and will independently publish an atlas on ocular inflammatory disease, containing pictures to help other eye care specialists better identify the various features of eye tissues being affected by inflammation. This atlas will be displayed in the display case at MERSI soon.

FUTURE DIRECTIONS

The coming publication of the picture atlas of ocular inflammatory disease opened my eyes to a new technology which will make a number of additional publications possible. I have exploited a technology known as "Publishing on Demand", thereby obviating the need for a publisher and for the costs associated with both publishing maintain inventory. One of my textbooks, *The Sclera*, has been out of print for several years. I asked for, and received from the original publisher the copyright for the Work and I intend to bring this publication out once more to "Publishing on Demand". I also probably will produce a new work on "The Ocular Manifestations of the Connected Tissue Diseases" aimed predominately at primary doctors and rheumatologists.

A very impressively blinding disease, Stevens Johnson Syndrome, continues, unabated, despite 40 years of research on the matter that has resulted in patients who develop that problem surviving in greater numbers. But the ocular consequences are unchanged. My efforts, many years ago, to establish collaboration with physicians in Boston to beat back the frontiers of this matter during the acute phases failed. I have now established relationships with physicians at the Cornell School of Medicine in New York City, and it is with guarded optimism, I hope we can began the long journey of making inroads into this matter over the next decade.

It is these sorts of challenges, unmet needs that are neglected because "it's too difficult" to do the work leading to the discoveries that will prevent blindness that distinguishes our team from others, and which distinguish our supporters from others. Our growing nucleus of our donors see an opportunity to amplify their efforts by encouraging the hearts and minds of others to be like minded and to be philanthropic and to contribute, regularly, to our research efforts. Like a pebble thrown into a pond, the ripple effect of reaching out and soliciting the help of others, recruiting as if for an army of 10 million, produces an extraordinary amplification effect that will catapult us, I believe, into the future far ahead of what would have being possible had it to been for the ingenuity and efforts of these wonderful people. Just as they have, so can you set your sights on tomorrow with the goal of giving the gift of sight and helping the world to see.

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Weston, MA 02493
www.uveitis.org

Research Highlights

Cont'd from page 6

ACCEPTED FOR PUBLICATION

- Study of the safety and effectiveness of intraocular lens implant in children with a history of uveitis - accepted for publication in the Journal of Cataract and Refractive Surgery
- The use of systemic tacrolimus and cyclosporine in treating patients with atopic keratoconjunctivitis – accepted for publication in Cornea
- An analysis of the use of Zenapax in Birdshot Choroidopathy - accepted for publication in Archives of Ophthalmology
- A study of effectiveness of Immunomodulatory Therapy versus Pars Plana Vitrectomy in Uveitis - accepted for publication in the journal Retina
- Study reporting the use of serum IL-2 receptor levels in diagnosing uveitis - accepted for publication in the journal Acta Ophthalmologica
- A report of the novel presentation, successful diagnosis and treatment of intra-ocular lymphoma – accepted in the European Journal of Ophthalmology

SUBMITTED FOR PUBLICATION:

- Study of lipid medication for treating glaucoma associated with uveitis - submitted to the European Journal of Ophthalmology
- Study of the effectiveness of an anticancer medication, injected into the vitreous, for the treatment of diabetic retinopathy, retinal and subretinal neovascularization, and macula edema – submitted to the journal Ophthalmology
- Analysis of patients with juvenile idiopathic arthritis treated with mycophenolate –submitted to the British Journal of Ophthalmology
- Analysis of patients with sarcoidosis treated with mofetil –submitted to the journal Archives of Ophthalmology
- An analysis of patients with ‘durable remission’ after receiving Immunomodulatory Therapy(IMT) – submitted for publication to the Archives of Ophthalmology
- Analysis of patient outcome and treatment strategies for Acute Posterior Multifocal Placoid Pigment Epitheliopathy (APMPPE) - submitted for publication to the British Journal of Ophthalmology