THE OCULAR Immunology And Uveitis Foundation

Ocular Immunology and Uveitis Foundation

Massachusetts Eye Research and Surgery Institution MERSI

C. Stephen Foster, M.D., F.A.C.S., F.A.C.R. Clinical Professor of Ophthalmology Harvard Medical School



Winter 2010/2011

Patients Glve Back to OIUF in Strides and Drives

"Uvee-what?" was a common question we received from merchants as we sought sponsors for our first local fundraiser to benefit the Ocular Immunology and Uveitis Foundation (OIUF).

<u>Olivia's Story</u>



From Left to Right: Steve, Luke, Olivia and Kim Eafano

was deteriorating. She was experiencing severe weight swings. She was constantly nauseous. She developed uncontrolled glaucoma. The prognosis we were given was devastating. Olivia would probably lose her vision. She was also struggling at school and at least one teacher suggested she begin learning to use Braille. Luckily, our pediatric ophthalmologist took the time to research Olivia's disease. Recognizing that his own expertise was limited, he referred us to Dr. Foster.

were damaging her in

other ways. Olivia's vision

Like many who have sought treatment with Dr. Foster, after our first visit, our lives and our outlook completely changed. For the very first time, we were not only surrounded by professionals who knew what uveitis was, we were surrounded by professionals who had battled it and won. We also found solace with and became involved in the support group. We developed a partnership between Dr. Foster and our local doctors and found a treatment option that was effective in controlling our daughter's inflammation. Lauren's Story

My name is Lauren Jacobs-Lazer and I am a 30 year old medical social worker living in New Jersey. I have had uveitis for over 15 years now, and continue to stay positive regarding my situation. As is



From Left to Right: Bruce & Ilene Jacobs, Lauren Jacobs-Lazer & Adam Lazer

typical in many chronic cases of uveitis, I have had many bouts with inflammation, causing me to be in what seemed like a circus of eye drops, steroids, and chemotherapeutic agents. I have had two cataract surgeries, and several procedures for retinal detachments. Thankfully, the vision in my left eye continues to be close to 20/20!

I am ever so grateful to the Ocular Immunology and Uveitis Foundation (OIUF) for helping me through some difficult times. While I receive the majority of my medical care in New York and New Jersey, OIUF has served a great purpose in my life. In fact, I am now being followed by David Chu, a uveitis specialist trained by Dr. Foster! Dr. Chu, an ophthalmologist at the Institute of Ophthalmology and Visual Science at the University of Medicine and Dentistry of New Jersey (UMDNJ), has really made my life with uveitis easier. He is calm and caring, and has me on a regimen that has been very successful. Dr. Chu was integral in spreading the word about the Walk for Vision NJ.

For the last several years I have been working closely with the OIUF to raise awareness of uveitis in the tri-state area and to raise funds for further research of the disease. New Jersey has now been home to three Walk for Visions! We have had participants from throughout New Jersey, Pennsylvania, and New York. The 3rd Walk for Vision in October 2010 had 175 participants. Over 120 other donations poured in from around the country, and the total donated to the OIUF was \$28,000 this year. We surpassed our goal in both monies and participants! A dozen of the walkers have uveitis and brought family members and friends to the Walk. We were all able to meet each other and share stories. What a wonderful way to feel supported!



Cut along the dotted line and retain for reference.

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Calendar of Events

February, 1, 2011

Support Group Natural Strategies for Tackling Inflammation Rajiv, Shah, MD 6:30-8:30pm

April 12, 2011

Support Group Let's Talk About It 1:00-2:00pm

April 15-17th , 2011

Uveitis Fellows Forum

June 12, 2011

Suppport Group Research Updates C. Stephen Foster, MD 6:30-8:30pm

August, 21 2010 (Tentative Date)

Walk for Vision Boston, MA

September 10, 2011

2011 Summit on Posterior Segment Therapy

October 14, 2011

6th Annual Through Their Eyes Art Auction The Liberty Hotel, Boston, MA

October 16, 2011

Walk for Vision Verona,New Jersey

THE OCULAR IMMUNOLOGY AND UVEITIS 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 2010 may reduce 2010 income and estate taxes.

For information on becoming a member of "The Foster Society" and to receive OIUF's planned giving guide please contact Alison Justus at (617) 494-1431 x112 or e-mail oiuf@uveitis.org

Please use the enclosed envelope for your donation

Looking for a way to honor a loved one this holiday season?:

Log on to: <u>http://www.firstgiving.com/uveitis</u> and create a fundraising web page in his or her honor.

Letter from Our President



C. Stephen Foster, M.D.

Dear Friends,

In the cover story, two patients and their families share their experiences in giving back to OIUF by organizing fundraisers in their respective communities to make a difference in their lives and for others who are battling potentially blinding ocular inflammatory diseases. Kim Eafano (mother of patient who organized golf tournament) writes "like the OIUF, planning a fundraiser put us in control and gave us the strength to continue the fight." It is this same passion and philanthropic spirit that has led to the growth of OIUF. Physically, the Foundation will be expanding its space in early 2011 at 5 Cambridge Center on the eighth floor. The development of more office space will allow OIUF to be even more

successful in conducting groundbreaking research and powerful support and educational efforts.

Over the past six months, our current clinical research initiatives have focused on finding novel therapies to treat active cases of uveitis. We are also testing new treatments to help keep quiescent cases of uveitis under control while chemotherapy is discontinued. OIUF's research continues to be defined by the joint efforts of past and present fellows interested in a range of matters that are essential to the Foundation's mission with topics varying from Pemphigoid to Birdshot Retinochoroidopathy to Behcet's Disease to Scleritis.

In addition to participating in OIUF's Symposium on Childhood Uveitis on August 7th and our 5th Annual Physician Education Conference on September 25th (on page 4), this year's group of fellows will play an important role in the second annual Uveitis Fellows Forum being held at MERSI from April 15th-17th in 2011. OIUF will be hosting the directors and fellows from all of the uveitis training programs in the USA to discuss topics of importance to fellows who are planning careers in the subspecialty of uveitis.

In October, I chaired the uveitis subspecialty day course with Dr. Quan Nguyen from Johns Hopkins University, at the annual AAO meeting in Chicago. The event was a huge success with enrollment and attendance surpassing past numbers. I am honored to be the President-Elect of the American Uveitis Society's Board of Directors. I am also pleased to welcome OIUF's newest board members: longtime supporter Shaun Levesque, head of US Institutional Sales, Schroders Investments, Thomas Paulson, Vice President of Investments at Merrill Lynch; and Peter Netland, MD who has recently been appointed as Chairman of the Ophthalmology Department at the University of Virginia's School of Medicine. All three members bring valuable experience and enthusiasm to the board of directors.



New Board member Dr. Peter Netland lectures at OIUF's 5th Annual Physician Education Conference

In this newsletter, you will read about the significant growth and multitude of fundraising efforts and awareness of our mission around the country. It is with this great initiative and determination that inspired the birth of OIUF five years ago. And because of you, and the growing circle of support for our mission, individuals living with ocular inflammatory disease can celebrate with OIUF a bright future.

With much gratitude,

Fish

C. Stephen Foster, MD

Walk for Vision 2010



Walk for Vision reached greater distances in 2010, raising over \$73,000 with the addition of the new OIUF Connecticut Chapter's walk in Hartford. Thanks to all the individuals that participated in Boston, New Jersey, and Connecticut for helping us raise awareness and significant funds for ocular inflammatory disease research. Special thanks to Lux BioSciences and Quirk Auto Dealers for sponsoring the 2010 Walk.

Walk for Vision Boston

On Saturday, October 9, 2010, Walkers enjoyed a brunch and talk by Dr. Foster at the Royal Sonesta Hotel in Cambridge before setting out on a beautiful 5k walk around the Charles River to raise over \$37,000. A special thank you to top Boston fundraiser Stacey Gold!

Walk for Vision New Jersey

On Sunday October 17th, Lauren Jacobs Lazer held in Verona Park in Verona New Jersey. "We had 175 walkers at the 5k event, 60 more people than last year!", she said. The event raised \$18,000 and her parents have made a \$10,000 match, bringing the grand total to \$28,000.

Walk for Vision Connecticut

On Saturday, August 21, 2010, the new Connecticut chapter of OIUF held the first Connecticut Walk for Vision in Bushnell Park in Hartford. The walk raised 8k thanks to board member and chair of the Connecticut chapter Greg Hughes, who also sponsored a reception and lunch for walkers at Black -Eyed Sally's. Also, a big heartfelt thank you to Connecticut Chapter Support Group leaders Jessica Borden and Jennifer Wall for their help in making the walk a success.



Lauren's Story

Continued from Page 1

I also have to thank our local Walk for Vision NJ sponsors: including Verona Pizza, The Bagel Box, The Alternative Press, Karen's Kandies, J.C. Reiss Opticians, Call Us Clowns, and Dave Bataille web design. Without support from these sponsors, the walk participants, and donors, we wouldn't have been able to have such a successful event! We are slowly building a network of patients and families in the tri-state area with uveitis and it has helped all of us in our journey. We share information on physicians and the disease process, and look forward to seeing each other annually at the Walk for Vision New Jersey!



The Walk for Vision NJ has been so rewarding for me it is hard to find the words to describe it. It is an unbelievable sight to see almost 200 people donning their Walk for Vision t-shirts spreading the word about uveitis and supporting one another. Each year the Walk for Vision NJ has grown exponentially. The monies raised and participants increase each year as the word spreads and people with uveitis come out with their families and friends. Many individuals with uveitis feel that they don't have a support network, or know others with the disease. The Walk brings together these people and shows them that they are not alone in their uveitis journey. It is also a way for people with uveitis to explain to their friends what the condition is all about. We feel loved and supported in many ways on the day of the Walk, and the fundraising and walking are wonderful ways to use our energy!

Thank you to all who have supported people with uveitis. We appreciate your spirit, kindness, and generosity!

2010 Conferences Highlight OIUF's Groundbreaking Educational and Support Group Initiatives.

This year, the Ocular Immunology and Uveitis Foundation held two conferences highlighting the Foundation's steadfast commitment to educating physicians and families of patients about ocular Inflammatory diseases.

On August 7th, 2010 the Ocular Immunology and Uveitis Foundation held a symposium on Childhood Uveitis for ophthalmologists, rheumatologists, pediatricians, and parents at the Marriott in Cambridge, MA. Presenters, along with Dr. Foster included rheumatologist from Massachusetts General Hospital, Dr. Patrick Whelan, as well as former fellows of Dr. Foster, Dr. David Chu from New Jersey Medical and Dental Center and Dr. Michael Sampson from New York Eye and Ear Infirmary. They spoke on topics from epidemiology to pathophysiology to treatment to improving outcomes. Additionally, clinical social worker Janis Arnold gave an informative talk on coping titled "A Family Affair."

A satellite meeting was held at MERSI comprised of support group activities for children with uveitis. The activity was organized by Stefanie Sordillo-Ryan, MA, an art therapist from Massachusetts General Hospital. Young patients and their siblings created journals and the "Eye of Wisdom," which now can be seen in the Kid's Korner at MERSI. They also enjoyed music with music therapist Lorrie Kubicek, Mt-Bc of the Massachusetts General Hospital and gave a choral presentation of the day's activities to the parents and physicians in attendance.

We also hosted the 5th Annual Physician Education Conference: "The 2010 Summit on Anterior Segment Therapy," on September 25th at the Tang Center of MIT in Cambridge, MA. Physicians from the greater Boston area and beyond participated in lectures from world-renowned ophthalmologists during this eight hour meeting. Topics included cataract surgery, glaucoma, cornea, refractive surgery, oculoplastics and uveitis.





(ABOVE) 2010 Physician Education Conference faculty (From left:) Peter Netland, MD; Thomas John, MD; Samir Melki, MD; Claus Dohlman; Dr. Foster; Olga Ceron, MD; Kenneth Kenyon, MD; Ioannis Glavas, MD Missing from photo, David Hinkle, MD, and in photo on above right: Robert Ritch, MD

(ON THE RIGHT) Childhood Uveitis Symposium faculty (From left:): Michael Samson, MD; Howard Tessler, MD; Nida Sen, MD; Egla Rabinovich, MD; David Chu, MD; Dr. Foster; David Hinkle, MD; and Patrick Whelan, MD







Research Highlights

Abbott –Adalimumab

2 multi-center international placebo controlled trials, sponsored by Abbott have recently started enrollment of patients. Both trials are designed to investigate the efficacy and safety of the human anti-TNF monoclonal antibody adalimumab in adult subjects in the treatment of noninfectious intermediate-, posterior-, or pan-uveitis. One trial is enrolling patients with controlled uveitis; the other trial is enrolling patients with active uveitis.

Allergan AKC Trial

A multi-center study, in which the purpose is to determine the efficacy and safety of cyclosporine ophthalmic solution in patients with atopic keratoconjunctivitis (AKC), a bilateral, inflammatory external ocular disease. Whereas the current treatment for AKC focuses on controlling the symptoms of the disease, this study will investigate whether a medication like cyclosporine, a potent immunosuppressant, will not only treat the symptoms, but stop the disease progression altogether. The study enrollment at MERSI is complete.

Novartis AIN457

A proof-of-concept study sponsored by Novartis, in which the purpose of the study is to determine the safety of AIN457 in patients with uveitis and to investigate whether an antibody like AIN457, which neutralizes the cytokine IL-17A, will safely reduce the intraocular inflammation associated with noninfectious uveitis

Novartis AIN457 Quiescent Uveitis Studies

This is a multi-center, international, placebo controlled study sponsored by Novartis to determine the ability of the medication to maintain quiescence in patients whose disease is controlled, when compared with placebo or standard of care immunosuppressive therapy. The study medication for this trial is identical to that of the Novartis AIN457 trial with the only difference being the delivery method. The preliminary proof of concept trial studying the AIN457 antibody yielded promising data and has resulted in new studies which target specific ocular inflammatory diseases. This study is open to enrollment at MERSI and we are actively seeking participants.

Alcon Research Durezol Study

A multi-center study to assess the efficacy and safety of Durezol compared to Pred Forte in patients with active endogenous anterior uveitis. The goal of the trial is to determine if Durezol given four times a day is as effective as Pred Forte given eight times a day when treating active anterior uveitis. This study is open to enrolment at MERSI and we are actively seeking participants.

Johnson & Johnson, Glaucoma Study

The goal of any treatment for glaucoma or ocular hypertension is reduction of IOP through the use of ocular hypotensive medications. Data from several recent research studies suggest that patients may receive a therapeutic effect from fewer doses of medication. Johnson & Johnson is conducting a new multicenter study of the safety and intraocular pressure (IOP) lowering effect of daily lumigan (bimatoprost ophthalmic solution) 0.03% in patients with elevated intraocular pressure, when treatment is administered once every other day, or every third day as compared with the typical once daily dosing regimen. This study is now open to enrolment and we are currently seeking patients with open angle glaucoma or ocular hypertension.

SITE Study

The study is 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 was 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 data were complete as of July 2009. Conclusion: most commonly used immunosuppressive drugs do not increase overall or cancer mortality.

Lux Biosciences

Lux Biosciences have engineered a new immunomodulatory agent (LX211) which is chemically and mechanistically similar to cyclosporine A. These phase 3 clinical trials intend to evaluate the efficacy of this new drug for treating non-infectious uveitis of various etiologies. The preliminary results are very exciting and we look forward to the completion of a second trial and to FDA approval.

MUST

The Multicenter Uveitis Steroid Treatment (MUST) study across the USA is funded by the National Institutes of Health. 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.

Uveitis Support Group

The Uveitis/OID Support Group is a patient education and mutual support resource founded in 1996 by Dr. Foster, Frances Foster, MS, NP, John Hurley, LICSW, and patients of Dr. Foster. Our mission is to educate patients, their family members and friends, and the medical community about ocular inflammatory disease and to facilitate the exchange of information, emotional support, and mutual aid between members. We are also deeply committed to raising funds to support research related to the causes and effective treatment of uveitis/OID.

Please take advantage of all our free services in this upcoming year: support group meetings; online support groups for kids and adults; the website with a support group page for adults, parents, and children; parent/teacher guide; and Uveitis Guide. Our support group runs on generous contributions to the support group under the Foundation from our members, their family and friends.

We have six support group meetings a year. The meetings are committed to support, not criticism, and no medical advice is given unless the person has a medical degree to do so. All meetings are based at the Massachusetts Eye Research and Surgery Institution (MERSI) in Cambridge, Massachusetts. The time of each meeting varies to try to meet the needs of our members with some occurring in the day and others in the evening. Please see the event calendar for the next upcoming meeting.

Can't attend a meeting? Get support online!

In addition to the onsite meetings, the Uveitis/OID Support Group has an online support group and informational website for adults, parents, and kids. For more information, point your web browser to www.uveitis.org and click on the Support Group links for a list of these wonderful and informative resources.



Or if you just want to ask a question of an expert, go to our "Ask Dr. Foster" page.

Boston Walk for Vision: Supporting Uveitis/OID Research

We have exciting news to announce regarding our Boston walk. In 2011 we will be transitioning the Walk from the Fall to the Spring. Stay tuned for date information! The event will be held as usual at the Sonesta Hotel along the banks of the Charles River in Cambridge and the 5k walk itself is around the beautiful Charles River. The walk event will include a brunch and featured talk by Dr Foster. To register visit our website at www. uveitis.org or email Frances Foster at ffoster@mersi.com or call 617-494-1431 x112. You can also be a spirit walker and do a sponsored walk in your home location on the same or other day.

You can also form your own walk as was done in New Jersey and Connecticut. The New Jersey walk will be held this coming year on October 15th, 2011 in Verona, New Jersey. The Connecticut walk takes place in Hartford.

GET INVOLVED!!!

Are you interested in working with The Ocular Immunology and Uveitis Foundation as a team to help us a reach the goals of the organization?

We are currently looking for dedicated and skilled individuals to work with our Board of Directors by serving on several working committees, including event planning, public relations, strategic planning and development.

Would you like to help organize a chapter in your area? Please contact the Foundation at (617) 494-1431 ext. 112 or at OIUF@uveitis.org.

Uveitis Support Group

Ocular Lymphoma and Uveitis

C. Stephen Foster, M.D.

Primary ocular lymphoma, an infrequent neoplasm, typically represents a diagnostic challenge masquerading as uveitis or vitritis. Ocular symptoms precede central nervous system involvement and symptoms in approximately 80% of patients. More than 150 cases of ocular lymphoma have been reported in the ophthalmic literature, and most of these cases where initially misdiagnosed as idiopathic uveitis or vitritis. Ocular lymphoma "vitritis" can even respond to steroid therapy, since the majority of cells present in the vitreous of patients with this malignancy are in fact not malignant cells but rather are "reactive" lymphocytes, sensitive to steroid therapy. Additional features contributing to the diagnostic difficulties of this disorder include the fact that, since so few of the cells present in the vitreous are frankly neoplastic, cytologic examination of vitreous biopsy specimens in the earlier stages of the disease often discloses little to no atypicality in the lymphocytes present in the specimen. Additionally, since CNS involvement lags ocular manifestations, cytologic analysis of cerebral spinal fluid, neurologic examinations, and imaging studies (including magnetic resonance imaging) are frequently normal.

Undiagnosed and untreated, the disorder typically progresses from unilateral to bilateral "vitritis", and then to central nervous system involvement. The mortality rate from the latter is extraordinarily high.

We wondered if the cytologic features of vitreous biopsy specimens from patients who were ultimately proven to have ocular lymphoma might be predictive of subsequent development of central nervous system lymphoma. The purpose of this report is to describe our review of 35 such specimens reviewed independently, in a masked manner, by two ocular pathologists.

We reviewed 35 cytology specimens harvested from the vitreous of 27 patients evaluated in the Cogan Eye Pathology Laboratory over a five-year period. The cytologic features of the specimens were reviewed by two ocular pathologists (Frederick A. Jakobiec and Thaddeus P. Dryja) in a masked manner. A negative specimen for lymphoma cells was indicated by the absence of any cells with malignant features in the specimen. A "suspect" diagnosis included those specimens for which sufficient atypicality existed that the pathologists were significantly concerned that early features of malignancy were present. A positive specimen met the cytologic criteria for frank malignant changes in the cells.

All of the vitreous specimens were obtained through standard preparation of a three port pars plana vitrectomy procedure. Before instituting infusion, however one cc of "neat," undiluted vitreous was aspirated into a three cc syringe with an attached 20 gauge needle. If such aspiration were impossible, the syringe was attached, via stopcock, to the vitrectomy cutter hand piece, and a "dry" vitrectomy performed so that one cc of specimen could be obtained into the syringe. The infusion was then begun, total vitrectomy performed, and both the one cc "neat" specimen and the diluted specimen in the vitrector cassette were immediately delivered to the cytopathology laboratory. The specimens were processed in 10% neutral buffered formalin in a dilution of one part 10% formalin to one part specimen, with fixation proceeding for approximately twelve hours. A 0.5 cc fixed specimen was then pipetted into the cytospin chamber and spun at 1000 rpm for five minutes, concentrating the cells in the specimen onto a glass slide. Air drying, staining with hemotoxin and eosin, and microscopy for pathology analysis were then conducted. Spinal tap cerebrospinal fluid cytology and MRI scanning of the brain were also performed in these patients.

The cytopathic results disclosed 16 cases which were unequivocally negative, four instances where the specimen was unequivocally positive, and three specimens which were highly suspicious but not diagnostic of malignancy, and specimens from an additional three patients resulting in an indeterminate reading, necessitating repeat vitreal biopsy. There was a 100% concordance between cytology results read independently by the two ocular pathologists over a five-year period of accession of the patient specimens. Negative specimens contained lymphocytes and some plasma cells and an occasional histiocyte, without evidence of mitotic figures, prominent nucleoli or irregular nuclear outline, features which were routinely present with the exception of mitotic figures in those specimens read as definitely positive.

Specimens which were highly suspicious but not diagnostic could eventually be analyzed, through repeat vitrectomy, not only with classic histiopathologic techniques, but also through assay of intravitreal IL-10 and IL-12 levels.

We believe that, while tedious and challenging, the following components are essential if one is to maximize the likelihood that malignancy will be detected in a patient with large cell lymphoma masquerading as uveitis:

- 1. A properly-collected vitreal specimen, undiluted, preferably without the need for cutting action from the vitrector, with specimen transported immediately for preparation and analysis by an expert cytopathologist.
- 2. Evaluation of the cytospin preparation by an expert cytopathologist who has access to monoclonal antibody staining strategies.
- 3. Availability of ELISA assays for both IL-10 and IL-12.
- 4. Availability of PCR analysis technology for IgH eye rearrangements.

Because the mortality rate is so extraordinarily high, historically, in patients with large cell lymphoma masquerading as uveitis, it is to be hoped that increasing awareness of the aforementioned features to analysis of vitreous biopsy specimens, and the increasing availability of ELISA studies for IL-10 and 12 will result in earlier diagnosis of patients with this disease, hopefully at a time, when the "cure rate" will be considerably higher than it currently is, with the relatively late diagnosis of most cases.

Uveitis Support Group



THE OCULAR IMMUNOLOGY AND UVEITIS FOUNDATION www.uveitis.org

Em's Excellent School Adventure: Math

It's 12 noon, 15 minutes left to 6th period math class. Mr. Butner, my eighth grade sequential one math teacher has been droning on for 83 minutes about quadratic equations. I look around the room and observe my fellow classmates staring off into space and doodling in their notebooks. Then I realize it's time for me to get out of class to do my 12:00 dose of Vexol. I guess that's what's called a bitter irony.

Discovering my disease was a fluke. When I was 8, my mom took me to the eye doctor because one of my eyes looked like I was having an allergic reaction. After examining my eyes, the doctor actually found iritis in my other eye. The redness and itchiness had nothing to do with my disease, although ultimately I was diagnosed in both eyes. It was like someone had sent us a sign that something was wrong. If it was wasn't for my mom and her "over-protectiveness" I would have begun to lose my vision. Thus started a long journey of doctors' offices and prednisone eyedrops and dilating drops and monthly visits (and more) to the eye doctor.

I've seen so many eye doctors with so many opinions on what should be done about my iritis/uveitis in the past few years. It's getting to the point where if I have to listen to my mom tell one more doctor my medical history, I'm going to become physically sick. Up until recently, I never felt that my disease was really impacting my life. So I had to do nine eye drops a day. I guess I got used to it. My mom and I would be driving home from an appointment after more cells were discovered and she would ask me, "Emily, how come you aren't affected by this?" I would say that all it meant was another drop every day. It didn't affect my daily life. But now I am fourteen, and my disease has definitely had an impact on my life. Last year when my eyes were being examined at a monthly appointment, my eye pressure had suddenly increased. I was given glaucoma drops, and everything has changed.

Now I'm on a drug to deal with this new problem because everything has changed. It's called methotrexate. Methotrexate. It's such a scary name for a drug that every ophthalmologist I've spoken to describes as a miracle drug. Why can't they name it something else? Like, oh maybe, "Trixie?" Then on Sundays at 10:00 a.m. after breakfast I could say to my mom, "I'm taking my Trixie now!" Or at least something a little more kid-friendly. After all, there are a lot of kids, including me, who are depending on this drug to keep their eyes "quiet."

To be perfectly honest, I'm not exactly sure how I feel about my disease. Some days I'm scared; some days I feel like going a little bit crazy and screaming and punching a pillow; some days I feel adrift and not totally connected to my situation. But on some rare days I feel strong and determined to beat this disease. I know I'll do whatever it takes.

Parent's Corner

Documentaries for sale:

Pricing: \$20.00 per DVD. Extra charge for international shipping applies.

1. Uveitis: The Adult Experience. Features 3 adults (2 females and a male) who all got uveitis in adulthood. It talks about their treatment, coping, and outcomes to care.

2. Growing Up with Uveitis: The Child's Experience. Features 3 females who have uveitis related to juvenile arthritis and their different experiences and treatments as well as outcomes related to their particular types of treatments.

Free guides:

A Guide to Ocular Inflammatory Disease (OID): Discusses different types of OID, causes, and treatment step ladder.

A Guide for Teachers and Parents: Gives an overview of uveitis, effects on vision, and tips to employ to help children adapt in school.

Bracelets: adult or child sizes: Color for adults are red, blue, and combo blue mixed with red. Child sizes are combo color only. Bracelets are \$2.50. Discount offered if bought in bulk.

If interested in our products, order online or email: ffoster@mersi.us or call 617-494-1431 ext 112

Olivia's Story

Continued from Page 1

Today, seven years and four surgeries later, Olivia still has uveitis, but her outlook is not as bleak. Her vision is nearly perfect with glasses. She experiences occasional flare-ups, but has enjoyed long periods of remission. Last year, she was awarded a certificate in fifth grade for achieving straight A's all year and is doing just as well this year in middle school. We have accepted the fact that Olivia is not going to 'outgrow this disease'; it's something she will need to manage her whole life. Fortunately, with Dr. Foster and the OIUF, she has the support structure she needs to manage it effectively.



Giving Back

Our family is extremely thankful to Dr. Foster and the OIUF for all they have done and as such, will help the foundation in any way we can. Although we typically participate in the Boston-based fundraisers, this year we decided to hold our own here in Atlanta. We held Golf for Vision, a unique family-style golf tournament, picnic, and raffle in our



neighborhood on November 20. The entry fee for our event was a donation to the OIUF. The very creative nine-hole golf course was built by our neighbors, yes, in their yards.

The work to pull together the event was enormous – building the course, creating all the documentation, soliciting/tracking sponsors, planning the picnic – and at times, we didn't think we would ever get it done. With some very long hours, several sleepless nights, and the help of wonderful friends, we did. The event was a huge success. We received sponsorships from more than 30 area merchants and raised over \$3500.

Why?

We are happy to raise money for OIUF because, at the very least, we know that every penny will help individuals like our daughter Olivia, who are battling inflammatory eye disease. Seeking sponsors for our fundraiser was not easy. Many did not know what uveitis was or why we were helping some foundation more than a thousand miles away. But, to us, it's personal. It's personal because the disease is part of our family and has been for seven years.





Chronic conditions like uveitis control your lives. Holding Golf for Vision put us, at least temporarily,

in control. Running the event, we were not just parents of a sick child; we were fundraisers helping other sick children. The relatives and friends who donated or came to our event were not just giving to some unknown national charity – they were helping us. Olivia was not just a child taking pills or eye drops to manage a disease she really didn't understand, she was surrounded by people who loved her and was raising money for a cure.

Our fundraiser was very successful because those attending had a great time and we exceeded our goal. Most importantly, however, our fundraiser like the OIUF, put us in control and gave us the strength to continue the fight.



2009 - 2010 OIUF Fellowship Update

Upon completion of his clinical fellowship at MERSI, Dr. Mark Dacey relocated to the Denver area, where he joined the medical staff at Margolis Vision and SkyRidge Hospital. He has founded the Rocky Mountain Ocular Immunology Center in Lone Tree, Colorado, to serve patients with ocular inflammatory conditions in Colorado and surrounding states. Dr. Dacey is involved with several active clinical research trials for the treatment of uveitis. He has also joined the ophthalmology faculties at the University of Colorado and Rocky Vista University to educate medical students and residents in uveitis and ophthalmology. Dr. Dacey is active in fundraising and lectures for the Colorado Arthritis Foundation for patients with JIA. In his spare time, Dr. Dacey and his wife Sarah have been enjoying hiking and skiing in the Rockies.

5th Annual Through Their Eyes Art Auction October 23, 2010 · Liberty Hotel Boston, MA

The Ocular Immunology and Uveitis Foundation would like to give a heartfelt thanks to Stephen and Ronney Traynor, Quirk Auto Dealerships, Phillips Van Heusen, Parrelli Optical and Roche Bros. for sponsoring the auction benefit and helping the Foundation raise over \$50,000, which will be used towards the Foundation's research and educational efforts. Over 100 friends and supporters joined Dr. Foster and the Ocular Immunology and Uveitis Foundation's board of directors where they bid on live and silent auction items which included vacation destinations and fine art created by well-known artists and patients living with ocular inflammatory disease.



Dr Foster and wife, Frances enjoy the evening



Chris Collins, Sports Anchor/Reporter, Comcast Sportsnet, shares with audience why this cause is important to him



Sue Paulson shares her battle with uveitis and ocular lymphoma with husband Tom Paulson (new Board member) by her side



Jay Jay French (founder and guitarist of the hair metal band Twisted Sister), is joined by daughter Samantha and Marie Keep from Skinner Auctioneers & Appraisers, encourages audience to raise their bids on Twisted Sister Signed Epiphone Pink Burst Twisted Sister/Jay Jay French guitar



Board member Dan Quirk and wife Mary Jo take part in Auction bidding war



Board member Greg Hughes is joined by (From R:) Jennifer Hughes, her daughter Erin Fournier and mother, Jean Babinou

The Foster Society

In 2008 the Ocular Immunology and Uveitis Foundation created the Foster Society to honor the generosity and vision of those individuals, foundations and corporations who support the mission of the Ocular Immunology and Uveitis Foundation.

It is with much gratitude that we thank these donors for being part of our society this year.

Benefactor

Alcon Foundation Patricia & Bruce Bartlett Dr. C. Stephen & Frances Foster Greg & Jennifer Hughes

Sustaining Level

Bausch & Lomb Carol & Carl Canner Carole Clark EyeGate Pharma Richard Frisbie Genentech Sally & Frank Hanna Greg Hughes Inspire IOP, Inc. ISTA Pharmaceuticals Bruce & llene Jacobs JP Morgan Chase & Co. Shaun & Kate Levesque Lux Biosciences Amy Nolan Sue & Tom Paulson Richard & Rhonda Rovner Stephen & Ronney Traynor

Patron Level

Alcon Allergan Marc & Rosa Catalano

Audio Digest

Kenneth & Lori Clark

Richard & Priscilla

Cornetta

Karen Domitrz

Cynthia & Lawrence

Fields

Samuel & Nancy

Fleming

Daniel Galloway

Richard & Louise

Hersum

The Horace A. Kimball Foundation Fred & Donna Seigel Dan & Mary Jo Quirk

Members

Inspire Lewis Marsh The Massarelli Family Foundation Kenneth Moran Glenn & Sandra Miller Parrelli Optical Phillips Van Heusen Corporation OIS Richard & Catherine Powers Donna Robinson Roche Bros. Daniel & Carmel Sauherhaft Dr. Michael Schmaltz Gene & Barbara Smith Wallace Stimpson Herman & Judith Swartz William Terrell James William III THE OCULAR Immunology and Uveitis Foundation

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Research Highlights

Cont'd from page 6

ACCEPTED FOR PUBLICATION

- Mycophenolate mofetil as monotherapy in pediatric uveitis

 accepted to Eye
- Herpes Keratitis in a patient undergoing treatment with Mitomycin- C – accepted to Cornea
- Anterior segment optical coherence tomography accepted to Semin Ophthalmology
- Durezol (Difluprednate Ophthalmic Emulsion 0.05%) compared with Pred Forte 1% ophthalmic suspension in the treatment of endogenous anterior uveitis – accepted to Journal of Ocular Pharmacology
- Scleral Necrosis in a patient with congenital erythropoietic porphyrin – accepted to Cornea

SUBMITTED FOR PUBLICATION:

- Immunohistochemical differences between normal and chronically inflamed conjunctiva: diagnostic features – submitted to American Journal of Dermopathology
- PDS masquerading as acute anterior uveitis submitted to Ocular Immunology and Inflammation
- Systemic therapy with conventional and novel immunomodulatory agents for ocular inflammatory diseases – submitted to Ocular Immunology and Inflammation
- Ophthalmia Neonatorum submitted to Journal of Clinical and Experimental Ophthalmology

New Publications of Interest to Physicians and Patients for Sale:

Foster, C.S., Bhatt, P., Yilmaz, T. Cervantes, R., Mauro, J. <u>Atlas of Ocular Inflammatory Disease.</u> 2009. Cost \$198.00. The photographs were taken from the MERSI archives, and will provide a unique resource for ophthalmologists world-wide to view various types of lesions caused by ocular inflammation as a result of roughly 100 different disorders, enabling them to more readily recognize and diagnose these diverse disorders.

Foster, C.S., Amorese. L, Dacey, M, Rosenbaum, R, Birdshot Retinochoidopaty. 2010. Cost \$50.00.

Monogragh from the Ocular Immunology and Uveiits Foundation's International Symposium on Birdshot Retinochoroidopathy held on October 4, 2008 at the Broad Institute in Cambridge, MA.

This monograph is based on the lectures delivered by the following experts in the field, Janet Davis, MD, David Hinkle, MD, Phuc Lehoang, MD, PhD, Robert Nussenblatt, MD, Aniki Rothova, MD, and Dr. Foster. It includes comprehensive information about this condition, including etiology, tests and treatment done for patients.

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