Throughout 2014, we have seen many people take the initiative in helping make a difference for the Ocular Immunology and Uveitis Foundation. These individuals have used their talent and expertise in many different ways. We are so grateful for their continued time and dedication to our mission and we hope their work will inspire others to help the Foundation grow and help us find a cure for ocular inflammatory disease.

Andrea Patisteas

Andrea’s daughter Mia has been a patient of Dr. Foster’s since 2010, and therefore a beneficiary of the Ocular Immunology and Uveitis Foundations’ work. Mia’s family has always been a family that enjoys getting involved when they have a cause to back and to them, it just seemed logical to give back to OIUF. Andrea decided that a golf tournament was a great way to get people together to have fun and to donate at the same time. She states “We believe if everyone who benefits from the work of OIUF, raised just a little, a lot would be raised. I always think that one of the dollars that I raise will be the dollar used to fund the research that finds a cure, that is a driver for me (no pun intended.). The other reason I choose to support OIUF comes from a quote Mia sent me from Margaret Mead, “Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed it is the only thing that ever has.”

This year’s golf tournament raised $127,000! We hope the readers of this publication will consider joining us in our tournament next year on September 16, 2015 at The Golf Club of Cape Cod and Ballymeade Country Club to help us double that amount.

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed it is the only thing that ever has.”

- Margaret Mead

Andrea Patisteas & her daughter Mia
Jay Jay French
Cindy Moore
Saletta Hindemath and her daughter Rosanna
Daniel J. Quirk
Calendar of Events

January 13, 2015
Support Group – Let’s Talk About It
MERSI – 1pm – 2pm

March 3, 2015
Research Updates from Fellows
6:30pm

April 28, 2015
Support Group – Let’s Talk About It
MERSI – 1pm – 2pm

August 23, 2015
Boston Walk for Vision

September 16, 2015
2nd Annual OIUF Golf Tournament

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.

How You Can Make A Visible Difference
Your gifts and donations help the work of the Ocular Immunology and Uveitis Foundation in achieving our mission.

To help meet your philanthropic goals, OIUF accepts gifts of many types, including appreciated securities, bequests, real estate, qualified retirement and life income gifts.

Planning a wedding? In Lieu of favors, consider a donation to OIUF!
For more information please contact Alison Justus at (617) 494-1431 x112 or email oiuf@uveitis.org
Please use the enclosed envelope for your donation

Looking for a way to honor a loved one this holiday season?
Contact Alison Justus at ajustus@mersi.com to create your own online fundraising page in his or her honor.
Letter from Our President

What an incredible summer and fall it has been for the Foundation! While reflecting on the past months, I am truly amazed on the outpouring of support we have seen from so many friends and patients. As you will see in this newsletter, our weeks were packed with events across the country dedicated to our mission.

On Friday, July 25th, I had the honor and privilege of appearing onstage with Twisted Sister as part of Fox and Friends’ Summer Concert Series at Fox Studios in New York City. Jay Jay French, the lead Guitarist and Founder of the band, whose daughter has uveitis, has been instrumental in raising funds and awareness for uveitis. Twisted Sister also held a second benefit concert for OIUF at the Best Buy Theater on Broadway in New York City on September 5th, which OIUF staff and I attended.

We had beautiful weather for both Walks for Vision in Boston and New Jersey. Our annual Auction Benefit, held in November, continues to be a success. On September 13th, we held our annual physician education conference: “Preventable Blindness Hot Topics Crash Course.” As I sat in the audience that day, it was a proud moment to watch, as three of my former Fellows made up the Faculty of experts in the field.

In October, I traveled to Chicago for the Annual Academy of Ophthalmology Meeting, where I co-chaired the Uveitis Subspecialty Day. Dr. Stephen Anesi, a former Fellow of mine and current Staff Physician at MERSI, was also a guest lecturer. In addition to those annual events mentioned above, this year is particularly meaningful because of the growing number of “Faces of Philanthropy.” These stories, which you will read about, are just a few examples of people going above and beyond to help our dream of a cure for ocular inflammatory disease become a reality.

The Board of Directors is growing, as we welcomed Catherine Powers of State Street Global Advisors and Pamela King, an Independent Consultant of rare diseases. We are very excited to have their expertise and experience on-hand.

Yet, despite these wonderful events, one of the most exciting days came when I was notified that my 1,000th research article had been published. Let me emphasize, this is not about my work. This day was celebrated by the entire Foundation. It is the Fellows who are here late into the night, working on research. Dr. Anesi continues to conduct research here at OIUF as a staff physician. Every single article published is because of the team of people involved, from physician, lab technician, research coordinators, staff, Fellows, and most importantly, supporters like yourselves. Our research needs funding in order to continue. Because of you, we were able to achieve this incredible milestone. On behalf of all the patients who will benefit because of your generosity, I extend my utmost gratitude.

With sincerest best wishes for a Healthy and Happy New year,

C. Stephen Foster, MD

Dr. Foster with current Clinical Fellows
Connection Between Skin Disorders and Ocular Disease

C. Stephen Foster, M.D.

Most individuals do not realize the extraordinary connection between skin and eye, much less the fact that many skin diseases have concomitant ocular manifestations. These may range from the relatively trivial, nuisance consequences of acne rosacea, with its associated chronic eye lid and conjunctival inflammation, to the profoundly vision threatening ocular consequences of ichthyosis, pemphigoid, Stevens Johnson Syndrome, and, even in some cases, allergic diseases like eczema. Patients with inflammatory eye disease (as opposed to cataract or macula degeneration or glaucoma) would be well advised to alert their ophthalmologist to the fact that they have a skin disorder, if they have one. By being alerted to the existence of a dermatologic condition, the ophthalmologist may very well discover that the patient's inflammatory eye problem is, in fact, closely related to the dermatologic problem, and this may well guide therapy to a more systemic approach, rather than through the simple expedient of local topical drop therapy.

The Fellowship Experience

Swetha Dhanireddy

I realized my interest for ophthalmology early in my life. It was during my third year of medical school when I decided I wanted to pursue a career that offered a combination of patient continuity and surgical procedures. When I initially heard about Dr. C. Stephen Foster, his institution, and the Ocular immunology Uveitis and Foundation, I immediately knew I had to take to advantage of this unique setting. I was searching for an opportunity to further expand my medical knowledge and to build on my communicational and analytical skills to unravel complicated and life threatening diseases. The opportunities through OIUF were filled with priceless experiences. I was able to build palpable relationships with patients, learn the significance of the persistent search for the “why” behind ocular pathologies through unique lectures by in-house speakers and guest speakers. Thanks to OIUF, I was provided with day-to-day learning tools through bimonthly lab meetings and weekly formal lectures and was fortunate enough to travel locally and across the country for poster presentation conferences. However, the biggest lesson gained through my time as a Fellow at OIUF was to remember, as a physician, to always keep my mind open to the possibility that the eye, rather than being an isolated organ, could be the primary focus of an underlying systemic disorder. Ocular immunology and uveitis originates from the ability to treat patients in a comprehensive manner and not solely their eyes. This Fellowship solidified this ideal in me and I look forward to helping more patients with ocular inflammatory disease in my future career.

Spotlight on New Board Member

Pamela King

OIUF is happy to announce Pamela King has joined the Board of Directors. Ms. King spent the majority of her career utilizing her entrepreneurial skills helping build start-up Biotech companies. The last 8 years have been focused solely on Rare Diseases, working as a consultant side by side with Industry, Foundations and Researchers. Through her consulting group, she provides strategic guidance to companies and patient organizations that help strengthen their advocacy, expand their programs, and achieve organizational growth. Ms. King became involved with OIUF after seeking treatment for her own uveitis, under the care of Dr. C. Stephen Foster. Working with other patient foundations US and Internationally, she understands the importance of driving research, education, awareness and peer support. Her broad background has allowed her to help foundations enhance their funding strategies, programs and opportunities for increased research funding. She resides in Rhode Island with her husband and two dogs.
Walk for Vision 2014

Walk for Vision Boston

August 24, 2014 was a perfect summer day in Boston for our Annual Walk for Vision. This year, OIUF switched venues and our program was held at the Hyatt Regency Cambridge on Memorial Drive. After brunch at the hotel and a talk by Dr. Foster, we all set out for the 5k walk around the Charles River.

Walk for Vision New Jersey/New York

The Walk for Vision New Jersey/New York was held on another beautiful day, Sunday, October 12, 2014 at the Verona Park Boathouse in Verona, NJ. Alison Justus, OIUF’s Director of Development and Dr. Foster and his wife Frances, made the journey from Boston for the event. A special thank you to Lauren Jacobs-Lazer, David, Chu, MD, Sylvia Stern, Susan Brady, and Eileen and Milton Fong for organizing the Walk. For the fourth consecutive year, Lauren’s parents have generously matched the first $10,000 raised for the New Jersey/New York Walk and we are so grateful for their continued support!

Thank you to our sponsors, supporters and walkers:
Quest Diagnostics, Quirk Auto Dealers, Horace A. Kimball Foundation
A huge thank you to walkers and supporters from across the country, who, from both walks, raised a combined total of $125,000!
Fox and Friends

On Friday, July 25th, 2014 Dr. Foster appeared on Fox and Friends in New York City with Twisted Sister to promote uveitis awareness!

Frances Foster is ready to rock!

Dr. Foster plays guitar backstage

Twisted Sister plays for the crowd and live audience

Preventable Blindness Hot Topics Crash Course

On Saturday, September 13, 2014, OIUF hosted the Preventable Blindness Hot Topics Crash Course at the Royal Sonesta Hotel in Cambridge, MA. This unique, half day conference was geared specifically towards avoiding vision loss from numerous ocular diseases, including ocular inflammatory diseases, by teaching awareness of timely presentation and recognition of such diseases when they present and the implementation of early steps in treatment or prompt referral to a specialist. The faculty was made up of renown ophthalmologists from across the country, three of whom were Dr. Foster’s previous Fellows.

Faculty, Left to Right: Former Fellow Rajiv Shah, MD; MERSI Staff Physician & Former Fellow Stephen Anesi, MD; Dr. Foster; OIUF Board Member Peter Netland, MD; OIUF Board Member and Former Fellow David Chu, MD

Physicians have the opportunity for Q&A

Physicians listen to faculty
The 9th Annual Auction Benefit: An Evening Dedicated to Making a Visible Difference, was held on Friday, November 7th at the Mandarin Oriental Hotel in Boston. Patients, families, and friends of OIUF gathered to celebrate a wonderful night and a cause close to the hearts of so many in attendance. A special thank you to Dr. Stephen and Darlene Anesi and Tom and Sue Paulson for co-chairing the event. Jay Jay French was our Master of Ceremonies and Marie Keep of Skinner Auctioneers and Appraisers, who has been with us since the very first auction, joined us for 9th night as our auctioneer. In addition to the Silent and Live Auction, and our “Heads and Tails” game introduced by Board Member Andrea Patisteas last year, we added a wine raffle as to the mix of activities for guests to enjoy. This year’s speaker, 16 year-old Olivia Eafano, has flown from Georgia to Boston since she was five years old to seek treatment from Dr. Foster since no properly trained ocular immunologists exist close to home.
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 A Guide to Ocular Inflammatory Disease. 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.

The Ocular Immunology and Uveitis Foundation reaches over 1800 fans on Facebook! Are you one of them? Visit the OIUF page at www.facebook.com/ocularimmunologyanduveitisfoundation and click the “Like” button at the top of the page to receive the latest updates about our activities and photos of our recent events, including the Walk for Vision and the annual Auction Benefit.

New Teen Support Group on Facebook! Kids 14 and older are welcome to join this private group for teens with ocular inflammatory disease. Email Ashley Floreen at afloreen@mersi.com to join!

OUIF is now on Twitter! Follow us at http://twitter.com/#!/uveitis1

The Kids Club is back! Check out our updated online support group for kids 13 and under. Email adult moderator Liz Irvin at eirvin@comcast.net for the protected password.

Resources:

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

1. Uveitis: The Adult Experience. Features 3 adults who all were diagnosed with uveitis in adulthood and 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: Colors 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.com or call 617-494-1431 ext 112
Jay Jay French

On Friday, September 5, 2014, Twisted Sister took the stage at the Best Buy Theater in New York City to raise funds for OIUF. This was the second benefit concert the rock band held for the Foundation, the first being in April, 2011. In addition to patients and OIUF staff members, many former Fellows were also in attendance; yet another example of the lasting friendships formed from the Fellowship experience. Jay Jay, whose daughter Samantha has uveitis, has become one of the Foundation’s leading supporters. He looks for every opportunity to shed light on our cause. This past July, when Twisted Sister performed on Fox and Friends Summer Concert Series, Jay Jay insisted Dr. Foster appear on stage with him to raise awareness for uveitis. The video of Dr. Foster and Twisted Sister on Fox and Friends is available on YouTube and our Facebook page. The September benefit concert raised $30,000 for OIUF! We cannot thank Jay Jay enough for helping us make a visible difference in the lives of so many people living with ocular inflammatory disease.

Cindy Moore

Cindy was diagnosed with Uveitis 7 years ago. She was fortunate enough to find Dr. Foster and during their initial appointment she remembers him saying “We will find a way to take care of this.” Those words were very important for Cindy, as she clung to them during the years it took to find the right treatment for her specific case. When asked why she decided to give back to OIUF, she states “When I saw the difference Dr. Foster and his team made for so many patients I wanted to give something back. Six years ago, when my husband and I got married, we decided that we would have a fundraiser wedding reception (guests made donations instead of giving us gifts) where we raised $3,500 that went to OIUF. We wanted to continue our support so in 2011 we organized a Walk for Vision in Connecticut where we had a great turn out. I am currently working for LEGO and donated LEGO bricks for the kids that are in treatment. There are so many of us that have benefited from the work that Dr. Foster has done through the Foundation. I know for me it changed my life and I will forever be grateful.”

Saletta Hindemath

Saletta and her daughter Rosanna have spent the past year collaborating with OIUF to establish a Chapter for OIUF in Canada. Rosanna, now a teenager, has been battling uveitis since she was a child. Their goal is to have a collaborative approach between physicians and patients. Additionally, they would like to educate patients about their eye condition and increase the resources available to patients in the community with ocular inflammatory disease which will help them after their diagnosis. Saletta would like to acknowledge OIUF for their support and all of their efforts in helping them advocate through their website and and helping them establish a Chapter in Canada.

Daniel J. Quirk

Daniel J. Quirk of Quirk Auto Dealers nominated OIUF for The Subaru Hometown “Share the Love” event. Anyone who purchases a Subaru from Quirk Subaru dealership from November, 2014-January, 2015 will have the opportunity to choose which charities will receive the donation from Subaru and OIUF is among them! Dan Quirk will also be matching each donation made to OUUF! This cause is close to Daniel J. Quirk, a former Board Member of the Foundation. His daughter, Bridget, has uveitis and has been under the care of Dr. Foster for many years. Although Bridget is now an adult, her family continues to give back to the Foundation responsible for treating their daughter and we are grateful for their continued support.
Research Highlights

Aciont:
The purpose of this study is to determine the safety, efficacy and tolerability of DSP-Visulex in patients with acute non-infectious anterior uveitis. The Visulex-passive system (Visulex-P) is a non-invasive drug delivery platform for treating sight threatening diseases. Aciont, Inc. is developing a non-preserved, solution formulation of dexamethasone sodium phosphate (DSP) to be used together with the Visulex™ ocular applicator called DSP-Visulex. The DSP-Visulex is administered topically onto the eye for 5 minutes per treatment with a planned treatment frequency of once per week. Male and female subjects, at least 18 years of age, who are diagnosed with acute non-infectious anterior uveitis in one or both eyes, may be eligible for this study. Subjects will be consecutively enrolled to either 8% or 15% DSP-Visulex and placebo eye drops or V-Visulex with prednisolone acetate 1% drops which will serve as a control. In addition, all groups will receive cyclopentolate eye drops. The study will last 28 days and will include 6 clinic visits. Study procedures include a standard ophthalmology examination, fluorescein/lissamine green staining, and other visual assessments.

Clearside Biomedical:
Since triamcinolone acetonide (TA) has previously demonstrated that it can be beneficial for the treatment of uveitis, Clearside Biomedical, Inc. has developed a proprietary formulation of triamcinolone acetonide injectable suspension (CLS-TA) along with a technique to deliver drugs directly to the choroid through a microinjection procedure. The primary objective of this study is to determine the safety and efficacy of CLS-TA in treating patients with macular edema following non-infectious uveitis. Patients who are at least 18 years of age with active macular edema and a history of non-infectious uveitis, including anterior, intermediate, posterior or panuveitis, currently in remission may be eligible for this study. Subjects will be randomized in a 1:1 ratio to receive a single injection of CLS-TA, 4 mg in a volume of 100 μL or CLS-TA, 0.8 mg in a volume of 100 μL. The study design includes 5 clinic visits over roughly two months. Study procedures include a standard ophthalmology exam, blood testing, vital signs, and other visual assessments.

XOMA 133:
XOMA has been testing gevokizumab, a monoclonal antibody that binds strongly to interleukin-1B (IL-1B), a pro-inflammatory cytokine shown to be involved in non-infectious uveitis and other auto-inflammatory diseases. The objective of this study is to assess the efficacy and safety of gevokizumab in treating Behçet’s disease uveitis (BDU). Subjects with characteristics of Behçet’s disease consistent with International Study Group Criteria for Behçet’s disease who are at least 18 years of age and meet either of the following criteria may be eligible to enroll into this study: 1) Subjects who are currently experiencing an active ocular inflammatory episode and for whom in the opinion of the Investigator it is appropriate to receive systemic immunomodulatory treatment; or 2) Subjects whose ocular inflammation is currently controlled and for whom in the opinion of the Investigator it is appropriate
to receive an alternative systemic immunomodulatory treatment. The study is composed of two parts, an open-label and a double-masked treatment period, with a total duration of 9-12 months. The open-label period of the study will help determine the efficacy of gevokizumab, and the masked-treatment period of the study will compare the efficacy of gevokizumab to placebo. Study procedures include vital signs, blood testing, standard ophthalmic exams and other visual testing.

**Allergan:**
This study, sponsored by Allergan, aims to compare cyclosporine ophthalmic emulsion (COE) 0.1% to vehicle, in patients with atopic keratoconjunctivitis (AKC) that is inadequately controlled with conventional therapy. Cyclosporine specifically inhibits T lymphocytes, which are thought to play a role in chronic inflammation associated with AKC. At the baseline visit, qualified patients will be randomly allocated to either COE 0.1% or vehicle (1:1 ratio). Assigned study treatment will be administered by the patient as one drop in both eyes 4 times daily. At the week 26 visit, all patients enrolled in the COE 0.1% arm only will be randomly reallocated to either COE 0.1% or vehicle (2:1 ratio). The study will last approximately 60 weeks. Study procedures include standard eye exams, diary entries, surveys, corneal sodium fluorescein staining, and a schirmer tear test.

**Dompé:**
The primary objective of this study, sponsored by Dompé, is to evaluate the efficacy of 20 µg/ml of recombinant human nerve growth factor (rhNGF) eye drops solution (formulation containing anti-oxidant) in treating patients with stage 2 and 3 neurotrophic keratitis (NK). The study consists of an 8 week double-masked treatment period followed by a 4-12 week follow-up period. Eligible patients with stage 2 or 3 NK who are at least 18 years of age will be randomized 1:1 to the active treatment arm or vehicle control arm six times a day. Study procedures include a standard ophthalmology exam, vital signs, blood testing, corneal fluorescein staining and other visual tests.

**Sanofi:**
Sanofi has been testing sarilumab, a potent and specific inhibitor of IL-6, a pro-inflammatory cytokine shown to be elevated in the vitreous of patients with non-infectious uveitis. The goal of this study is to evaluate the efficacy and safety of sarilumab administered subcutaneously every 2 weeks in patients with non–infectious uveitis (NIU). Eligible patients who are at least 18 years of age with non-infectious intermediate-, posterior-, or pan-uveitis will be randomized 2:1 (sarilumab:placebo). At randomization, the patient has to be under treatment with prednisone as single therapy or in combination with methotrexate. The study includes 2 periods, a principal treatment period and an extension treatment period. Study procedures include, blood testing, vital signs, a standard ophthalmology exam and other visual tests.

**OIUF Research Reaches Global Scale**
OIDU receives weekly updates from ResearchGate regarding statistics surrounding the number of times our research has been viewed, cited, and downloaded. The results are astounding. It is not uncommon for our research to be viewed over 200 times in one week alone. We have shared the latest total numbers below. Thank you again for your continued support in allowing physicians and patients from across the world to access the novel discoveries conducted at OIUF each day.

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Hot off the Press – New Publication!

THE MONOGRAPH FROM THE 2ND INTERNATIONAL SYMPOSIUM ON BIRDSHOT RETINOCHOROIDOPATHY IS NOW AVAILABLE FOR PURCHASE!

This monograph is based on lectures delivered at symposium held in Boston on September 28, 2013. Please visit our online store at www.uveitis.org for more information!

Publications of Interest to Physicians and Patients for Sale


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.


Monograph from the Ocular Immunology and Uveitis Foundation’s Symposium on Childhood Uveitis held on August 7, 2010 in Cambridge, MA.

This monograph is based on the lectures delivered by the following experts in the field, Janis Arnold, David Chu, MD, David Hinkle, MD, C. Eglia Rabinovich, MD, MPH, C. Michael Samson, MD, MBA, H. Nida Sen, MD, MCHc, Howard H. Tessler, MD, Patrick Whelan, MD, PhD, and C. Stephen Foster, MD.

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