Jay Jay French’s Pinkburst Project
Donates Over $110,000 to OIUF

“When I embarked on the Pinkburst Project three and one-half years ago on behalf of my daughter Samantha and her struggle with uveitis, I did it at first to raise much needed money for research and a cure. I didn’t realize where that journey would take me.” says Jay Jay French, founder and lead guitarist of Twisted Sister.

Samantha’s struggle goes all the way back to 2001. She has been on five different cycles of immunosuppressive therapy over the last 10 years. This past year, Samantha was put on Humira, one of the newer drugs, that is injected every two weeks by a doctor just above the hip. So far, she has reacted very well to this and her eyes are ‘clear’ of any inflammation. Thanks to early detection and proper treatment, Samantha stands a good chance of maintaining her normal sight for the rest of her life.

“The Pinkburst Project” is a collection of custom Gibson, Fender, Gretsch, Epiphone, Paul Reed Smith, Roukangas and Martin guitars and custom Fender, Marshall, Vox, Mesa, Orange, Hartke and Diamond amplifiers built to raise awareness and fund ongoing research, education and support for The Ocular Immunology and Uveitis Foundation.

Jay Jay commissioned the custom shops of the world’s top electric guitar makers to replicate the color and style of his pink sunburst Gibson Les Paul. To anyone even remotely involved with this industry, this dream would seem completely unrealistic as all these companies are highly competitive and many have even sued each other over the slightest attempt at copying anything that the other was doing. “It really meant that I was asking Fender, Paul Reed Smith, Epiphone, Gretsch, and Martin to put aside their differences for something for the greater good,” says Jay Jay.

It took three years, many conversations, multiple dinners and hundreds of miles logged. In the end, most of the leading guitar luthiers in the world each created custom models specifically for The Pinkburst Project: Gibson, Fender, Gretsch, Epiphone, Paul Reed Smith, Roukangas and Martin.

Getting the amplifier companies involved was an entirely different story. The material that covers each amp is called tolex, and the covering of each amp company is unique to that company.

Through several contacts and years, Jay Jay was finally able to connect to the president of Kayline Industries, the maker of most of the tolex that you see covering most every amplifier. The president, Harley Hoffman, was “one of the nicest people you could ever talk to.”

Hoffman personally contacted Fender, Marshall, Vox, Mesa, Orange, Hartke and Diamond on behalf of the Project. He had made a small amount of tolex for a project for Marshall that did not develop. It was magenta in color and Hoffman thought it would be perfect for the Pinkburst Project. Turns out, there was just enough to cover the amp collection. Because no guitar and amp collection is complete without the accessories, TKL made custom guitar cases, Red Monkey made custom Straps, and IN Tune made custom picks.

Continued on page 4
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.

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

Walkers and Spirit Walkers:

Log on to http://www.firstgiving.com/uveitis and create your own fundraising web page

Start making strides NOW in Ocular Inflammatory Disease research!
Letter from Our President

As Jay Jay French (father of 17 year old uveitis patient Samantha French and lead guitarist of "Twisted Sister"), states in the cover story, in speaking about his fundraising and awareness effort for OIUF, the "Pinkbust Project", "I have come to realize that the combination of hard work focus, and the incredible help from so many people have created a social network of families who are fighting this disease and no longer feel like nobody in the world cares. People DO care."

Thanks to individuals like Jay Jay and other patients and family members, researchers, physicians and advocates, the last 6 months have been defined by tremendous progress and accomplishments in our research, education and support efforts.

Our research continues to focus on state of the art therapies for anterior and posterior segment diseases. Recent developments in systemic and local injectable immunosuppressive intraocular therapy represents progress in the treatment of patients with ocular inflammatory disease. Our clinical fellows continue to contribute to our research efforts and most of them were afforded the opportunity to present their work at the Association for Research in Vision and Ophthalmology (ARVO) annual meeting. Several were able to give case presentations at the (FOIS) Foster Immunology Society dinner which was a great success as interest in networking among those with a shared experience and the number of OIUF fellows trained at MERSI increases year after year. In an effort to promote a sense of “family” and camaraderie among young ophthalmologists who have chosen to sub-specialize in the field of Ocular Immunology and Uveitis (pictured below), in April OIUF hosted the second annual Uveitis Fellows Forum.

Fundraising events such as the “Pinkburst Project” (Cover story) and the “Flashmob for Vision” (on page six) continue to be initiated by patients and their family members who are committed to raising the needed funds and awareness to diminish the devastating and far reaching effects of ocular inflammatory disease. I am grateful to my past fellow Rene Cervantes who has taken on the challenge of organizing an OIUF Chapter in San Diego to provide patients in Southern California with ocular inflammatory disease needed education and support.

As the nation’s leading organization dedicated to ocular inflammation and ocular immunology, our work has had a profound impact finding causes and cures for blinding ocular inflammatory diseases, producing the ocular immunologists of the future who will populate departments of ophthalmology around the world, thereby providing better education for ophthalmology residents in the subjects of ocular immunology and inflammation, fostering continuing medical education programs for general ophthalmologists through our training program and our physician education conferences; and benefiting your lives through in house and online support and patient educational conferences. I ask you to read through the pages of this newsletter and learn more about the individuals who have made these developments and achievements possible.

C. Stephen Foster, MD
The collection was auctioned for sale through Skinner Auctioneers Fine Musical Instruments Department on Sunday, May 1, 2011 in Boston, MA.

In conjunction with the auction, Twisted Sister held a benefit concert on April 29, 2011 at the Best Buy Theatre in NYC in Times Square. Dr. Foster joined Jay Jay and Samantha on stage to express his gratitude to both of them and the other members of Twisted Sister. $110,000 (from the concert & the auction) has been donated to the Ocular Immunology and Uveitis Foundation. Jay Jay stated “the money raised of course is much needed but the media exposure and the realization that getting out the story could actually save people's sight was something that I didn't think about. Now I have come to realize that the combination of hard work, focus and the incredible help from so many people have created a social network of families who are fighting this disease and no longer feel like nobody in the world cares. People DO care...” Families from all over the country, who have struggled for years with uveitis, wrote to Jay Jay, sharing their uveitis stories and thanking him for his commitment to the cause.

Prior to the concert, OIUF along with Sara Kim and Annette and Anthony Roscigno hosted a concert cocktail “Pre-Party” for friends of the Foundation at the Chelsea Stratus Club who traveled to New York from Boston and beyond to rock out in support of the Pinkburst Project.

“The passion of Jay Jay French and of Twisted Sister in helping the Foundation in this matter is stunning, and our gratitude to them for this cannot be overstated.” said Dr. Foster. In addition, OIUF thanks Sara Kim and Annette Roscigno for hosting the concert pre-party, Quirk Automobile for hosting the Auction pre-party on April 30th at Skinner Auction House and sends a special thank you to Marie Keep from Skinner Auctioneers for her part in making the Pinkburst Project a success.
Jay Jay shares a few words at the auction about the importance of the Pinkburst Project.

Samantha thanks everyone for their support.

Dr. Foster says a few words at Auction pre-party.

Donors phone in their bids for one of a kind Pinkburst guitars.

Jay Jay and OIUF board member Richard Rovner.

Samantha, Sharon Gitelle, Dr. Foster and Jay Jay.

Jay Jay shares a few words at the auction about the importance of the Pinkburst Project.
One day in June 2010, my ten-year-old daughter, Ally, came to me with an irritated right eye. On our way to the pediatrician’s office to check it out, she told me that she couldn’t read the clock on the dashboard from the backseat of our car. Upon examination, the doctor said it could either be a chemical infection, or allergies. The doctor wanted to treat her for allergies for a few days and see if it got better. “But she can’t see!” I argued. As we went back and forth, Ally called the doctor over and said, “Look, one of my pupils is bigger than the other.” At that moment, they rushed us to the office of ophthalmology, where we got a diagnosis. Ally had uveitis.

The ophthalmologist told me I had waited too long. Scar tissue had already formed. We would have to keep the eye dilated for weeks and use steroid drops around-the-clock. We saw many doctors and specialists. We treated the uveitis religiously, but it wouldn’t go away. No one could give us a prognosis and our ophthalmologist told us that there was nothing else he could do. He thought that the underlying cause of Ally’s uveitis must be juvenile rheumatoid arthritis and we would have to see a rheumatologist who could treat Ally for arthritis. The only problem was, Ally didn’t have arthritis. She had no symptoms in her joints at all.

At this point I was feeling lost and hopeless as a parent. I didn’t know how to help my daughter. Then, one day, while spending time with friends at a local yacht club, one of the members walked up to my daughter and said, “You have uveitis!” How did she know that? The woman came to me and said, “Her eye is dilated just like my husband’s. I recognized it right away. You need to see Dr. Foster!” That same week, I learned that a friend of mine from work was also seeing Dr. Foster for uveitis. In fact, the more research I did, the more I realized that all uveitis roads lead to Dr. Foster! Finally, it was clear that if anyone could help us, it was Dr. Foster.

When I met Dr. Foster, I told him our story, adding, “If my daughter isn’t responding to drops, then this inflammation must be coming from somewhere else. I don’t understand why we keep treating the eye, instead of treating whatever is causing the inflammation!” He smiled, nodding his head, and said, “That is the basis of everything we do here. We can treat her systemically for uveitis, and we would be happy to take her on as a patient.” With tears in my eyes, I thanked Dr. Foster, and hope was restored.

As anyone with uveitis knows, treatment for uveitis is not a quick fix and Dr. Foster’s “Step ladder” approach to treatment can take a long time. As I watched Ally go through several trials of medications in an effort to find something that would work for her, I wondered what I could do as a parent to help my daughter remain positive and teach her how to deal with adversity. I wondered how I could raise awareness for other parents to see the signs of uveitis in their own children. I wondered how I could show my gratitude for having a place to turn to in the face of my daughter’s illness. The answer soon became clear: Flashmob for Vision!

A flashmob is a seemingly spontaneous gathering of a large number of people who perform a specific act, then quickly disperse. Videos of flashmobs can be found all over the internet, particularly on Youtube. Flashmobs are currently used for several purposes including political statements, advertisements, or simply for shock-value. I decided to create a philanthropic flashmob that would raise funds for the Ocular Immunology and Uveitis Foundation. The surprise public gathering would raise awareness about uveitis, while funds raised would benefit OIUF.

Since Ally and I are both dancers, I wanted to create a dance for our flashmob and use Ally as the focal point. Using my Facebook account and an online fundraising web source called Crowdrise, I
The Stephen and Frances Foster Lecture at Duke Eye Center

Following in the same philanthropic spirit and steadfast dedication of those who gave life to the Ocular Immunology and Uveitis Foundation, Dr. Foster and Frances wanted to give back to an institution that has inspired their life’s work.

Dr. Foster received a Bachelor of Science degree in Chemistry from Duke University with Distinction and Phi Beta in 1965, and received his Doctor of Medicine degree from Duke University Medical Center in 1969, being elected to Alpha Omega Alpha.

As part of their 20-year mission to increase education and awareness of ocular inflammatory disease, they established The Stephen and Frances Foster Lecture Fund in 2010 at Duke’s Department of Ophthalmology.

“If one surveys the number of training programs, one is struck by the absence of a dedicated ocular immunology faculty. There are only 11 faculty in all of 120 training programs.” This fund allows the Department of Ophthalmology to invite featured speakers annually to deliver the Stephen and Frances Foster lecture dedicated to the subject of ocular inflammatory diseases.

On Wednesday March 22, 2011, Dr. Foster gave the first Stephen and Frances Foster lecture, titled “Ocular Immunology and Uveitis Foundation: Past, Present, and Future” at Duke University.

Flashmob for Vision

Continued from page 6

reached out to about 500 friends, asking them to donate, dance, or both. We held rehearsals for several weeks at an athletic club where I work part-time. The result of our effort was overwhelming. On March 26th, 2011, Flashmob for Vision took place at Market-Place Center in Faneuil Hall, Boston with over 100 dancers!

Donations, which are still trickling in, are now just shy of $12,000. Treatment for Ally is at times disheartening. We have recently begun infusions of Remicade to control her uveitis. But I do believe that through this struggle, my daughter has learned a valuable lesson. We will all face adversity in our lifetime. Yet, we have a choice about how we handle it. Ally now knows that by raising awareness, helping others, and enlisting community support for those in need, we can always find strength and hope. And if we forget for a minute, Flashmob for Vision is on Youtube to remind us, just a click away.
2011 ARVO Ocular Immunology and Uveitis Foundation Travel Grant Recipient, Rui Zhang

Without the OIUF Travel Grant, Case Western Reserve medical student Rui Zhang would be unable to attend and present her research at the Association for Research in Vision and Ophthalmology (ARVO) National Meeting in Fort Lauderdale, FL. Ms. Zhang greatly enjoyed the chance to present her research to fellow colleagues. Zhang states, “I made many connections with various people doing similar research as I, and actually got the chance to meet a collaborator on my research whom I have not met previously. In addition, I met ophthalmology residents from various programs and made great connections and received great tips in applying for residency.”

Rui thanks the Ocular Immunology and Uveitis Foundation for making this important opportunity possible!

2011 ARVO Stephen and Frances B. Foster Foundation Travel Grant Recipient Wen Allen Tseng

Wen Allen Tseng, PhD candidate at Harvard University, is currently working at Schepens Eye Research Institute on a project relating to innate immunity in age-related macular degeneration. “Receiving the C. Stephen and Frances B. Foster Foundation Travel Grant this year was a wonderful honor, and it helped my laboratory send me to my first ARVO Annual Meeting. Not only was I able to learn a tremendous amount of cutting-edge information from posters and presentations, but I also received a great deal of important feedback and suggestions from fellow researchers in the field that will help me advance my project. I also made new connections with other researchers, opening the door to possible collaboration in the future.”
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.

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.
## KIDS CORNER

### QUESTIONS ABOUT UVEITIS

<table>
<thead>
<tr>
<th>Kids Ask:</th>
<th>Dr. Foster Answers:</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does “uveitis” stand for? What is uveitis?</td>
<td>Inflammation inside the eye.</td>
</tr>
<tr>
<td>Is uveitis a bad eye disease for kids?</td>
<td>If by “bad” you mean is uveitis a serious health problem, the answer is yes.</td>
</tr>
<tr>
<td>Can uveitis be treated?</td>
<td>Yes. We know a lot about how to help kids that have uveitis.</td>
</tr>
<tr>
<td>What causes uveitis?</td>
<td>About 50 different things can cause uveitis in kids.</td>
</tr>
<tr>
<td>What do I tell my 6th grade friends when they ask me what uveitis is?</td>
<td>That it is inflammation inside the eye, like having inflammation from a burn, but inside the eye.</td>
</tr>
<tr>
<td>Is uveitis contagious? Can other kids “catch” uveitis from me?</td>
<td>No.</td>
</tr>
<tr>
<td>How can I help my sister with uveitis?</td>
<td>Let her talk to you about it. You don’t need to “do” or “say” anything. Just listen.</td>
</tr>
<tr>
<td>What are some of the various reasons for getting uveitis? If you have uveitis, are you considered an ill or sick person with a disease?</td>
<td>Yes, uveitis is an illness. Infection, trauma, and autoimmune illness are the most frequent reasons that uveitis develops in children.</td>
</tr>
<tr>
<td>Why can’t you see uveitis; is it only a eye disease, or can you develop it some other way?</td>
<td>Doctors can “see” your uveitis with a special microscope called a slit lamp. Go to <a href="http://www.uveitis.org/kids/EYE-brary/article1.htm">http://www.uveitis.org/kids/EYE-brary/article1.htm</a> to read more about the slit lamp.</td>
</tr>
<tr>
<td>Are you scared that other kids might come to be blind from uveitis?</td>
<td>No, not scared. But, concerned, which is why I do what I do.</td>
</tr>
<tr>
<td>Does everyone with uveitis have JRA?</td>
<td>No.</td>
</tr>
<tr>
<td>Does someone with uveitis have to have eye surgery?</td>
<td>Sometimes, but not usually.</td>
</tr>
</tbody>
</table>

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**SAVE THE DATES – WALK for VISION 2011**

*For more information and to create your online fundraising page, visit www.firstgiving.com/uveitis*

**Sunday, August 21, 2011**

**Walk for Vision Cambridge!**

Join us for a 5k walk around the Charles River in Cambridge, MA.

The event will kick off with a talk by Dr. Foster and brunch at the Royal Sonesta Hotel.

Registration is @ 10:30am and the walk begins at 12 Noon.

To register, visit our website at www.uveitis.org or email Frances Foster at ffoster@mersi.com or call the Foundation at 617-797-8660.

**Saturday, September 17, 2011**

**Walk for Vision Connecticut!**

Join us for a 1.1 mile walk in West Hartford, Connecticut.

Registration will be @ 9:30am at 50 South Main Street (West Hartford Town Hall).

The walk will be held from 10-11am.

For more information, contact Cindy Moore at cindy191@hotmail.com

**Sunday, October 16, 2011**

**Walk for Vision New Jersey!**

Join us in Verona Park in Verona, New Jersey.

Registration 10:15am, walk @ 11:00am at the Verona Park Boathouse, Verona, NJ.

For more information contact Lauren Jacobs - Lazar at (973) 476-0002 or walkforvisionnj.com
2007-2008 OIUF Fellowship Update

After completing his Fellowship training in 2008, Rene Cerventes returned to his home town of Tijuana, Mexico, where he joined the CODET Vision institute as the head of the Retina, Vitreous and Ocular trauma department. He was subsequently appointed as the head of the Retina, Vitreous, and Ocular trauma department of the CODET Foundation for blindness prevention, a nonprofit organization that provides healthcare to a vulnerable, uninsured population that can’t afford to pay for proper care. He has also founded a clinical immunology lab to service patients with ocular inflammatory disorders and diabetes. He has most recently created the Retina and Vitreous Fellowship and currently has one Fellow. He is an active member of the Foster Ocular Immunology Society and most recently initiated the creation of a San Diego OIUF Chapter. On March 26, 2011, Rene met with patient and San Diego resident Patricia Bartlett, her husband Bruce Bartlett, Board members Scott Evans and Dr. Peter Netland to discuss the development of the Chapter, which will concentrate on education and support services for individuals living in the San Diego area struggling with ocular inflammatory disease.

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.

Benefactor

Patricia & Bruce Bartlett
Dr. C. Stephen & Frances Foster

Patron Level

Alcon
Allergan Foundation
Marc & Rosa Catalano
Fred & Donna Seigel

Sustaining Level

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EyeGate Pharma
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Genentech
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Daniel & Carmel Sauherhaft
Dr. Michael Schmaltz
Laurie Shiff
Gene & Barbara Smith
Vitaly Sorkin
Wallace Stimpson
William Terrell
James William III
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.

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

Monogroph 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.*

**Order Publicaitons directly from OIUF at www.uveits.org.**

**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.

**Watch for the Childhood Uveitis Monograph coming out soon developed from our Pediatric Uveitis Conference in 2010.**