Welcome... to the first edition of the Children’s Glaucoma Foundation newsletter, Progress for Sight. We hope that this newsletter will keep you, our supporters, informed of the work being done to improve the care and treatment of children with glaucoma of all ages. This newsletter will keep readers up to date on research we support, offer informative articles about pediatric ophthalmology and glaucoma, and provide personal stories from patients of Dr. David S. Walton and Dr. Helen H. Yeung whose lives have been affected positively by work supported by the Children’s Glaucoma Foundation.

For twenty years, we have worked alongside families and friends of patients with childhood glaucoma to increase awareness of this disease. We have provided educational assistance to parents and physicians to be alert to the signs and symptoms of childhood glaucoma. Most importantly, we have been able to provide direct support for medical care to assist affected families.

Thank you for supporting the Children’s Glaucoma Foundation to achieve our goals...

Progress for Sight!
Words from Our President

The Children's Glaucoma Foundation was founded twenty years ago and has actively supported significant programs to improve the care of children with childhood glaucoma. Basic university-based research, awareness activities to enable early recognition of glaucoma, post-fellowship physician education, support for physicians in less well-developed countries, and direct payment for medical care here in Boston are now being supported. Cutting edge equipment for my office has been purchased to advance the care of adolescents requiring continued care following successful early surgery or those with late-onset of childhood glaucoma. All of this expenditure has been possible because of the incredible work of parents and their friends who have held and supported Gala events, and to the many families and dedicated organizations that have also supported the Children’s Glaucoma Foundation with their very generous gifts.

We want to begin to more actively describe the work, accomplishments, and goals of the CGF. To accomplish this, we are initiating a CGF newsletter, which will be sent out at least annually. In addition to being informative, I am hopeful that this will stimulate questions to be addressed in future editions and suggestions for us to improve all that we do. I also look forward to continued input of experiences of families of children with glaucoma to be shared with other families. I am confident this will be both helpful and often inspirational.

In addition to continued support for the work described, we have initiated research to definitively solve the devastating complication of glaucoma following infantile cataract surgery, which now occurs in 30-40% of infants who undergo cataract removal. The mechanism of the glaucoma seems clear, and the research work will focus on preventive therapy to prevent this unacceptable complication. Congenital cataracts occur in about 1 in 2500 children. This complication is a major cause of childhood blindness worldwide and is a leading cause of blindness in children under five years of age.

I am very grateful for the tremendous support that the Children’s Glaucoma Foundation has received and am both humbled and motivated by the trust that has been bestowed. We have the responsibility to make the future brighter for future generations of children affected with glaucoma. You have made this goal possible, and I look forward to sharing future work to help make this a reality.

Respectfully,

David S. Walton, MD
Welcome Dr. Yeung!

Dr. Walton is pleased to welcome Helen H. Yeung, MD, who has joined his office for care of pediatric patients.

Dr. Yeung is a fellowship-trained pediatric ophthalmologist and pediatrician. She specializes in pediatric eye disease including, strabismus, and the medical and surgical management of glaucoma and pediatric cataracts.

After graduating from Tufts University School of Medicine, Dr. Yeung completed her Pediatric residency at Massachusetts General Hospital and her Ophthalmology residency at New York Eye and Ear Infirmary of Mount Sinai. She then completed a Pediatric Ophthalmology and Strabismus fellowship at Children’s National Health System in Washington, DC followed by a fellowship in Glaucoma at the Yale School of Medicine in New Haven, CT.

CGF News / Events

SAVE THE DATE

November 14, 2020

◊ The Children’s Glaucoma Foundation has begun the planning of our next Visionary Gala!

◊ The Gala will take place on November 14, 2020 at the Seaport Hotel in Boston

◊ Please save the date so we can look forward to having you with us to make this another great night for the future of Childhood Glaucoma

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After graduating from Tufts University School of Medicine, Dr. Yeung completed her Pediatric residency at Massachusetts General Hospital and her Ophthalmology residency at New York Eye and Ear Infirmary of Mount Sinai. She then completed a Pediatric Ophthalmology and Strabismus fellowship at Children’s National Health System in Washington, DC followed by a fellowship in Glaucoma at the Yale School of Medicine in New Haven, CT.
Dr. Lauderdale, along with his lab at the University of Georgia, has been working on a treatment for Aniridia Related Keratopathy with the support of the CGF for the past 12 years. Aniridia is a genetic disease that affects the eye and brain. A significant complication associated with the eye is the failure of corneal cells to repair themselves after injury or damage. This causes cloudiness of the cornea and other complications of the eye that can contribute to severe vision loss. Existing treatments include surgical intervention such as tissue transplant or prosthetic implantation. These treatments are expensive, painful, and not well suited for children. Current tissue transplant procedures for the treatment of aniridia run a high risk of complication due to donor tissue rejection. What if we could find a way to use the patients’ cells for the transplant, eliminating the risk of rejection completely? Dr. Lauderdale and his lab aim to develop a more non-invasive treatment of the cornea that can be used to treat anyone.

From 2017 to 2018, Dr. Lauderdale and his lab were able to generate cell lines from individuals with aniridia successfully. They used skin cells from the patient and then reverted them to a new cell type that has the potential to become a corneal cell. These iPSCs (induced pluripotent stem cells) can produce a variety of cells that can help repair the eye. This includes limbal stem cells that are used to repair and form the cornea. It also potentially includes cells that can make retina and trabecular meshwork cells. This allows an unlimited source of cells from the patient to be used for transplant.

The lab is currently exploring how to make these iPSCs into limbal stem cells. Dr. Lauderdale has gained partial success in using these limbal cells to functionally repair the cornea in rabbits with limbal stem cell deficiencies. This is very exciting because it shows that it can be done! Progress is promising but is still an active area of investigation.

Another exciting development in the past couple of years is the use of genome engineering technology CRISPR-cas to correct the mutation in the DNA of cells obtained from patients with aniridia. This is the first time that a mutation has been repaired in iPSCs from someone with aniridia!

Perhaps the most exciting part of these promising advances funded by the Children’s Glaucoma Foundation is the discovery that cells can be reintroduced to the eye using a contact lens. This has the potential to be an easy, non-invasive way of treating the cornea in people of all ages affected by aniridia and other corneal disorders.

Continued on Next Page …
Research Update

Continued ...

For this coming year, Dr. Lauderdale and his team plan to focus on utilizing cells from 2-3 known individuals with varying aniridic mutations. Using the CRISPR-cas technique, they will test to see if the mutations can be repaired and if the repaired cells can then be used to rebuild the cornea in a test model. If successful, these repaired cells have the potential to be used for clinical trials to resurface the corneal surface of affected children and restore their visual loss caused by the development of cloudy corneas.

Recent addition to the Children’s Glaucoma Foundation team, Hanna Prendeville, had the opportunity to travel down to the University of Georgia in February to observe the progress of this research firsthand.

“I was welcomed into the lab by Dr. Lauderdale and his lab assistants and students eagerly and warmly. It was amazing to see and hear about the scientific methods behind this research directly from the source. Dr. Lauderdale seemed excited to share his progress of the research and was enthusiastic about its goals for the future.”

– Hanna Prendeville
I have been a patient of Dr. Walton’s for almost my entire life. When I was eight weeks old, Dr. Walton diagnosed me with aniridia, and from that point onward, my life was set in motion upon a path of forever renewing hope. The health of my eyes has always been of great importance to me. It was when I developed a corneal erosion (the displacement of cells on the outermost surface of the eye) and lost a portion of my vision that I became more aware of the impact my treatment, as well as my understanding of it, could have on those in a similar situation.

I didn’t, however, come to this conclusion on my own. Dr. Walton has always been there to offer his intelligence and care. My visits to Dr. Walton’s were full of him reminding me that in staying on top of my treatment plan, I was helping to improve our understanding of different approaches towards the treatment of corneal erosions. Not only that, but he would tell me that he was proud of me for all the hard work I was putting in to keep my eyes healthy. Do you know how nice that feels—to be told by someone whom you, your entire family and a worldwide community of people look up to that they are proud of you? Well, it warms your heart, and makes you cry happy tears just writing about it.

Blessed in having the incredible support of my family and Dr. Walton, I was given another gift. Dr. Walton had been in contact with Dr. Lauderdale, and together initiated a research project at the University of Georgia based upon aniridic cornea cells. With funds from the Children’s Glaucoma Foundation, this research was able to take off, and as it continued, I was able to hear more and more about what was being learned from it. I became so invested in this research that my mom, Dr. Walton and I flew down to Georgia together to really experience it for ourselves, and I ended up learning a great deal about genetics. Continued donations to the Children’s Glaucoma Foundation have allowed this research to continue, and I am so very grateful for that. This research allowed my interest in biology to grow to fruition, inspiring me to pursue biology in college.

Last year I went back down to Georgia to learn more about the progress this research has made, and I can tell you that such exciting things are in the making. So, now here I am: a biology major at Providence College, getting ready to donate some of her cells to Dr. Lauderdale’s research. Throughout my life the Children’s Glaucoma Foundation and those involved have taught me that each one of us matters. Our cells, our feelings, our lives—they all matter.

Things can get really hard. You can get a corneal erosion, be in pain, feel down and reduce the opinion of yourself to just a mass of matter. But let me tell you: everything you are going through, whether good or bad, and everything you are have meaning. Under the care of the Children’s Glaucoma Foundation you are never alone; it is a family of people who make the future so very bright.

– Eliza Barmakian
New Research Initiative

The Children’s Glaucoma Foundation is pleased to announce the support of a new research project at Tufts University School of Medicine headed by Rajendra Kumar-Singh, PhD, Professor of Developmental, Molecular, and Chemical Biology. The research will focus on Infantile Aphakic Glaucoma, to determine the mechanisms which cause this disease, and preventative treatments.

I have been working on the development of therapies for blindness during my entire career. As a graduate student at the University of Dublin, Trinity College; in Ireland, I experienced one of the most exciting times in the field of genetics. We were, for the first time, able to identify the genes involved in blindness. After my graduate studies, I secured a postdoctoral fellowship at the University of Michigan in the nascent field of gene therapy. I have been able to leverage those two experiences to develop the first gene therapy for the dry form of age-related macular degeneration (AMD)- a disease that causes blindness in the elderly. This gene therapy is currently in two phase I human clinical trials.

In the Spring of 2019, I met with Dr. David Walton through a mutual colleague. I recall that on that fateful day, I was in awe of the passion Dr. Walton conveyed in caring for his patients with childhood glaucoma and how anxious he was to develop a treatment for them. Those interactions led to the initiation of our joint studies.

Childhood glaucoma is a common complication following cataract surgery. After surgery, cells lining the lens can initiate processes that culminate in the blockage of drains used for drainage of fluid in the front chamber of the eye. With blocked drains, the pressure in the eye builds up, causing sensitive cells in the back of the eye to die. These cells would normally send electrical signals to the brain to generate sight, and hence their loss leads to blindness.

We plan to use the approach of gene therapy to prevent the clogging of the drains of the eye. The concept of gene therapy is amazingly simple. We will manufacture a virus in the laboratory that contains the gene that makes a product analogous to ‘Drano.’ More specifically, we will use a virus called Adeno-Associated Virus (AAV). AAVs do not cause any diseases and are very safe. The AAV containing the ‘Drano’ gene will be delivered to the front of the eye where it will get into the cells of the cornea. Those cells will act as factories for the production of ‘Drano’ that will consequently make its way to the clogged drains and result in their clearing. We believe that not only will we be able to unblock the drains, but also prevent them from future clogging. The delivery of the virus will only need to be performed once to provide a lifetime of protection.

With support from The Children’s Glaucoma Foundation, we have already made the virus and demonstrated that it gets into cells and produces the ‘Drano.’ Our next step is to confirm that the drains can be cleared by the virus and consequently reduce pressure in the eye. We anticipate achieving this goal and additional goals by the Summer of 2020. Assuming success, we will then begin the lengthy process of moving the gene therapy from the laboratory to the clinic. That part of the study will take two to three years.

The support of the benefactors of The Children’s Glaucoma Foundation is key to our future success. This is not going to be accomplished by just a few people. It will be all of you reading today, along with a large team that will achieve these goals. It is going to be an exciting journey, and the destination is going to be worthy. I look forward to taking this journey with all of you.

– Rajendra Kumar-Singh, PhD
In January, the Corsino Family organized a fundraiser for Glaucoma Awareness Month to benefit the Children’s Glaucoma Foundation.

The Corsino’s 2-year-old son, Lucas, was diagnosed with congenital glaucoma at just five weeks of age. Since then, Lucas has had seven surgeries to regulate his eye pressure. With proper care and monitoring his eye pressure, he will be able to maintain his vision. Thanks to early detection and proper care, Lucas will be able to enjoy his sight as he grows up. Unfortunately, many children do not have the means for care to treat childhood glaucoma like Lucas. The Corsino Family believes everyone can help share the gift of sight, no matter how big or small of a part you play.

Thank you to the Corsino Family!

The Lambda Nu Chapter of Pi Kappa Alpha at Boston University hosted the 10th Annual Pike’s Dream Girl Fundraising event this past year.

Dream Girl is a traditional philanthropy event for the Pi Kappa Alpha Fraternity in which various student group representatives among the Boston University community compete in a talent show competition consisting of four different categories: Letters, Athletics, Talent, and Formal. The winner takes home a non-cash prize, along with the Dream Girl crown, sash, and the privilege of serving as Pike’s Dream Girl for the next year.

Pi Kappa Alpha raised $33,197 during Pike’s 10th for the Children’s Glaucoma Foundation.

Thank you to Pi Kappa Alpha for their continued support of the Children’s Glaucoma Foundation!
Fundraising

We want to give a big shout out to Christopher Cuttler. Chris is a high school senior from Syracuse, NY, and has been actively fundraising for the Children’s Glaucoma Foundation for many years. He recently held a bake sale fundraiser at his church and raised over $657. The highlight of the bake sale was a raffle for an enormous cookie tray full of almost 4lbs of Italian cookies Chris’ grandmother made. Members of the church helped by baking extra cookies to sell, and they sold out of nearly everything very quickly.

Throughout the years since he was young, Chris has organized many other fundraisers to benefit the Children’s Glaucoma Foundation, including an annual “Bowl-a-Thon” and selling CGF bracelets. Chris was diagnosed with infantile glaucoma when he was four months old. He underwent three eye surgeries and continues to be monitored very routinely to make sure his pressures stay low and do not jeopardize his vision. Chris hopes that his contributions will one day help find a cure for childhood glaucoma and that he can help more people learn about this disease.

Thank you, Chris, for promoting awareness for childhood glaucoma & helping find a cure!

SHARE YOUR STORY WITH US!!!

Have a story or fundraising event that you would like us to share with the Children’s Glaucoma Foundation community? Send an email to hprendeville.cgf@gmail.com to be featured in our next newsletter.
Are you not ready for summer to be over?

We sure aren’t!

Keep the season alive with the Children’s Glaucoma Foundation Vineyard Vines Tote Bags!

These bags are still available at $85.00.

This one of a kind canvas tote bag has our CGF logo along with soft silk trimming, zip-top closure, water-resistant bottom, durable double navy straps, and four interior pockets with a light blue gingham pattern.

This tote is not only convenient for your future activities, but it is also an excellent way for you to show your support for the Children’s Glaucoma Foundation!

Call 617-227-3011 or email us at info@childrensglaucomafoundation.org if you are interested in purchasing a tote.

Remember when shopping from Amazon, to use AmazonSmile. It is the simple and automatic way for you to support the Children’s Glaucoma Foundation every time you shop, at no cost to you. When you shop at http://smile.amazon.com, you’ll find the same wide selection of products, low prices, and convenient shopping features as on Amazon.com, with the bonus that Amazon will donate 0.5% of the amount of eligible purchases to the Children’s Glaucoma Foundation!

**Steps to Register**

2. Sign in using your Amazon account username and password.
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To learn more and support the Children’s Glaucoma Foundation

- Visit our updated website to learn more about the history of our foundation and our past and future events:

  www.childrensglaucoma.org

- We would like to include you in our database for future mailings, emails, and events. Please send an email to hprenderville.cgf@gmail.com, including your name, address, phone number, and email address.

- Donations can be sent to:

  2 Longfellow Place, Suite 201 Boston, MA 02114

- Donations can also be made using PayPal on our website.

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Invite your friends and family to like our page as well to help spread awareness about Childhood Glaucoma.

Be sure to tag the Children’s Glaucoma Foundation any time you post about Childhood Glaucoma!