

# Believe

we can



Treatment now in sight!



BEYOND BATTEN DISEASE  
FOUNDATION



One day you think you are taking your child to get a pair of glasses and instead you come home with this:

Batten disease. A rare and fatal neurodegenerative condition affecting children for which there are no treatments or cure.

THE DOCTORS SAID **Be Strong...**

Your child will suffer from seizures and vision loss.

THE DOCTORS SAID **Be Brave...**

Expect cognitive decline resulting in mental and physical incapacity.

THE DOCTORS SAID **Be Prepared...**

There are no treatments. There is no cure.





No one ever said...

Believe





## ON THE COVER:

Mary Morgan Brumley, Claire Tickle, Gwen Geisler, Wren Brumley and Charlotte Mahmoud at Family Night held in August 2015.  
Photo by Bill Geisler.

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BEYOND BATTEN DISEASE  
FOUNDATION

### FOUNDERS

Charlotte and Craig Benson

### BOARD OF DIRECTORS

Craig Benson  
Chairman

Sabrina Brown

Caroline Goodner

Jeff Hunt

Will Murphy

Scott Young, DDS

### STAFF

Mary Beth Kiser  
President and CEO

Danielle M. Kerkovich, PhD  
Principal Scientist

Brittany Thomas  
Communications Manager

Carolyn Donovan  
Development Manager  
of the Will Herndon Fund

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### BE A FOLLOWER



Facebook - [www.facebook.com/beyondbatten](http://www.facebook.com/beyondbatten)  
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LinkedIn- [www.linkedin.com/company/beyond-batten-disease-foundation](http://www.linkedin.com/company/beyond-batten-disease-foundation)





## DEAR FRIENDS,

Believe. Believe Beyond. Beyond Batten. These are the words that inspired our community to rally around the Bensons when they received Christiane's devastating diagnosis over eight years ago. These words were also the drivers that resulted in the formation of Beyond Batten Disease Foundation. Additionally, these ideas are integrated into our research strategy and have resulted in our global reach, connecting us with hundreds of partners all over the world representing many different diseases.

Theodore Roosevelt said, "Believe you can and you are halfway there." That definitely rings true for Beyond Batten Disease Foundation. The unwavering support of our friends and communities, outreach to new donors, combined with strong scientific leadership and a sound plan, sprinkled with a lot of hope and courage, will be the formula that gets us the rest of the way to our goal.

The following pages of our 2015-2016 annual report highlight the results of what can be accomplished when you believe. They also include the fundraising activities of The Will Herndon Fund and their supporters who believe in HOPE. Missy and Wayne Herndon are vital partners in our collaboration strategy and success. We are announcing an exciting medical breakthrough and introducing you to The Be Project, our 24 month \$6 million campaign to fund a treatment and beat Batten now! We also have news and information and lots of photos specific to the last 12 months. We want to thank you and recognize your efforts. Your support is impacting the landscape for Batten disease and beyond; now and in the future.

*"We are announcing an exciting medical breakthrough and introducing you to The Be Project, our 24 month \$6 million campaign to fund the treatment and beat Batten now."*

As Charlotte mentions in The Mother's Story on page 28, we are staring at a short window of time to make a meaningful difference for the kids suffering from Batten disease today. Please join us and help make the treatment a reality for these families. We are asking you to believe that we can. Please embrace The Be Project movement by being a donor or a fundraiser. Get involved and Be the Hope or Be the Change. Together we can leave a legacy that lives on for kids and families affected by Batten and many other diseases.

We are so grateful for your support!

With gratitude,

A handwritten signature in dark ink that reads "Mary Beth Kiser". The script is fluid and cursive.

Mary Beth Kiser  
President and CEO



# MISSION

Beyond Batten Disease Foundation was established to eradicate juvenile Batten disease by raising awareness and funds to accelerate research for a treatment or cure.

Charlotte and Craig Benson established Beyond Batten Disease Foundation in 2008 after their then 5-year-old daughter, Christiane, was diagnosed with juvenile Batten disease. With hundreds of families affected by Batten disease and supporters who share their hope and resolve, they are working tirelessly to create a brighter future for Christiane and all children with Batten disease.



Following the diagnosis of their son, Will, in 2009, Missy and Wayne Herndon joined Beyond Batten Disease Foundation to create the Will Herndon Fund for Research (HOPE). With The Woodlands community, they are determined to find a treatment or a cure for Will and the many children affected by Batten disease.



Beyond Batten Disease Foundation is proud to welcome the Hugs for Hudson Fund. Amy and Eddie Phillips, Hudson's parents, say "partnering with BBDF has given us a chance to seek out the greatest opportunities available for helping Hudson and every other child that suffers from this devastating disease."





## GLOBAL RESEARCH STRATEGY

When the Bensons received Christiane's diagnosis in 2008, the research landscape was a desolate place, devoid of any real hope on the horizon. They established Beyond Batten Disease Foundation with the help of their community who believed that together they could make a difference. The landscape has changed dramatically over the last eight years as a direct result of that community and strong scientific leadership.



A comprehensive, sound research strategy has guided the efforts of the foundation from the beginning. Hiring a full-time principal scientist, Danielle Kerkovich, PhD, and incorporating the best practices of highly successful medical research organizations were two important keys to the strategy.

We knew that we could not do it alone. By providing affected families, their foundations, and communities with a menu of timely and scientifically vetted projects to choose from, we are advancing Batten research together. Other rare and common neurological disease groups have found our programs interesting and informative and have added their support. This has created a continuous intellectual and financial feedback loop.

Our research strategy brings together all stakeholders, including affected families, like-minded foundations, and other neurodegenerative disease groups.

Since inception  
**BBDF HAS SPENT**

# 84%

According to The American Institute of Philanthropy most highly efficient charities spend 75% or more on programs

## HOW DO WE HAVE AN IMPACT BEYOND BATTEN DISEASE?

Beyond Batten is not just a good name for a foundation, it's actually what we do. BBDF's strategy has been successful by partnering and receiving co-funding from Batten and other neurodegenerative disease groups. While developing treatments for Batten, BBDF funded discoveries have been able to inform and accelerate progress in other neurodegenerative conditions such as Parkinson's and Alzheimer's, additional rare diseases and more common illnesses. To date we have partnered and collaborated with over 100 other organizations to advance our mission. We are having a global effect by extending our reach to other disease groups. Together we have been able to invest over \$16 million in research over the last 8 years.

BBDF has matched every donation

# \$ DOLLAR FOR DOLLAR

by leveraging partnerships and co-funding resulting in **\$16 million in Research** over the last 8 years

# MEDICAL BREAKTHROUGH

TREATMENT NOW IN SIGHT!

- These efforts have resulted in a treatment which slows disease progression in Batten models.
- This treatment needs to go through an expensive validation and development process in order to enter a clinical trial.
- To complete this project and prepare for clinical trial success we need to raise

## \$6 million within 24 months.

There are three primary components to this project: identifying treatments, preparing for clinical trials and advancing research towards a cure.

This medical breakthrough is an exciting new treatment developed over the last 6 years. While not a cure, this treatment has proven to delay symptoms and extend life in Batten disease models, like mice and cell cultures. Because treatments must go through expensive validation, dose-determination, and safety procedures prior to entering into a clinical trial, our work is not done. We must continue to fund researchers at the Jan and Dan Duncan Neurological Research Institute

in Houston where the original discovery was made, together with Evotec, our contract research partner in Germany (see pg. 33 for more details). The goal of these teams is to prepare a rich and informative data package to present to the FDA in order to get permission to enter clinical trials.

While researchers are hard at work, we need to prepare for clinical trial success by creating patient registries. We must also be able to measure progress during the trial with biomarkers which objectively measure the response to therapeutic intervention. Biomarkers will allow us to determine whether or not its dose is effective and safe. Support

for these measurements is critical to our success. Clinical trial approval isn't our only goal. We want to make sure proven treatments become widely available and are covered by health insurance.

In addition, there is also ongoing research for a cure. There is exciting new technology emerging, like gene therapy, exon skipping and stem cell therapy. All are currently being explored in the laboratory; many with support from BBDF. We are working diligently to buy time for affected children and their families and will not stop until we have a cure for this devastating disease.

## WHY \$6 MILLION WITHIN 24 MONTHS? Here's the math:



100% of your Be Project donation will go directly to funding this effort.

### FUND THE TREATMENT

Validate initial academic work to pharmaceutical standards while determining optimal dosing, efficacy and safety information	\$3,000,000
Support critical science at Texas Children's Hospital to inform and complete validation studies	\$1,300,000

### PREPARE FOR CLINICAL TRIAL SUCCESS

Support development of an international patient registry	\$400,000
Further critical biomarker studies	\$300,000
FDA regulatory consultation and clinical trial preparation	\$200,000

### CONTINUE TO SUPPORT RESEARCH FOR A CURE

Continue to support other rapidly evolving technology in stem cells, gene therapy, and gene skipping	\$500,000
Provide scientists with important Batten specific research tools	\$300,000



Introducing the



Fund the treatment & beat Batten now

# WHAT IS THE BE PROJECT?

The Be Project is a 24 month campaign to raise \$6 million. In order to reach our goal, we have broadened the scope of our campaign to maximize our fundraising efforts to include multiple ways to be involved. Join the movement and get involved with the Be Project.



**BE A DONOR** make a financial commitment to the campaign or pledge an annual, quarterly or monthly gift. Visit [www.beyondbatten.org](http://www.beyondbatten.org) to donate or pledge.



**BE THE CHANGE** is our kids fundraising initiative created to engage children in philanthropy. Take a jar and work with your kids or a group of kids to create fundraising opportunities to utilize their own networks: school clubs, sports teams, neighborhood friends, church groups, and community service groups. Contact Courtney Houston at [courtneyhouston@me.com](mailto:courtneyhouston@me.com) to learn more.



**BE GRANTED** is our committee of volunteers who research and apply for grant funding. They are raising lead and major gifts from foundation funders. Connect us with foundations you know. Contact Amber Meinzer at [aameinzer@gmail.com](mailto:aameinzer@gmail.com) with any ideas you may have.



**BE THE HOPE** is intended to engage bible studies and prayer groups. We are expanding our campaign through prayer. We are praying for the children and families affected by Batten disease and praying for God's discernment and guidance for the efforts of BBDF. To learn more about our prayer requests and how you can help, contact Kristin Cowden at [kristin@kris-10.com](mailto:kristin@kris-10.com).



**BE AN AMAZON** is an initiative to connect your Amazon account to BBDF. We will receive a percentage of every purchase you make. Simply visit [smile.amazon.com](http://smile.amazon.com) and select Beyond Batten Disease Foundation. You will still enjoy the same one click shopping and all the usual perks. Contact Allison Small at [ams@allisonsmall.com](mailto:ams@allisonsmall.com) for easy sign up instructions. We have instruction cards available to add to your Christmas cards for an easy way to enlist the help of friends.



**BE A HERO** is our social media campaign to promote the Be Project. Raise funds and spread awareness virally with our video clips created for this purpose. Follow BBDF on social media and like and share everything we push out. Post your own Be Project activities and tag BBDF. For more information, contact Jill and Carlton Wade [jillianwade@mac.com](mailto:jillianwade@mac.com).

## Who will you Be?





# BE PROJECT LEADERSHIP TEAM

In February 2016 BBDF gathered a group of invested supporters to create the Be Project Leadership Team. This group of volunteers worked tirelessly over several brainstorming sessions to develop and plan the Be Project campaign. From design feedback to idea sharing to networking, the Leadership Team has guided the development and execution of this critical campaign.

**Charlotte Benson**  
**Sabrina Brown**  
**Kristin Cowden**  
**Ashley Crider**  
**Darby Denison**

**Susanne Denison**  
**Lynn Fowler**  
**Caroline Goodner**  
**Diane Humphreys**  
**Jeff Hunt**

**Jackie Price**  
**Lance Thompson**  
**Dan Sharplin**  
**Susan Wittliff**  
**Sarah Zeigler**



Darby Denison, Kristin Cowden, Susanne Denison



Jeff Hunt and Dan Sharplin

The foundation was created and funded over 8 years ago with gifts from events hosted by the Bensons' friends in the communities where they had lived and worked. These original donors are recognized as the BBDF Founders Circle. With the help of our Leadership Team, and our biggest fans in multiple cities, the foundation unveiled the Be Project at a series of Be First events. These gatherings were designed to update the Founders Circle on the impact of their initial investment, announce the treatment and launch The Be Project. The events were kicked off with a special preview party for the BBDF Development Board and Austin launch, hosted by the Leadership Team. Donors at each of those events will be recognized as Be First Donors. Their contributions are critical for creating momentum for our fundraising efforts.

If you would like to become a Be First Donor, send in the enclosed donation card or donate online by December 31, 2016. All Be First Donors will be listed on the website, in the 2016-2017 annual report and will also be recognized in our Be Project newsletter.



Lance Thompson





Beth Durrett, Elaine and Britt Benton, Shannon Windham



Suzie Wright and Christy Werner



Charlotte and Craig Benson, Ashley Putman

## BE FIRST PARTIES

**Development Board Preview – August 31, 2016**

**Austin – September 8, 2016**

**Houston – September 20, 2016**

**Little Rock – October 25, 2016**

**Baton Rouge – November 9, 2016**

**New Orleans – November 10, 2016**

**Dallas – November 17, 2016**

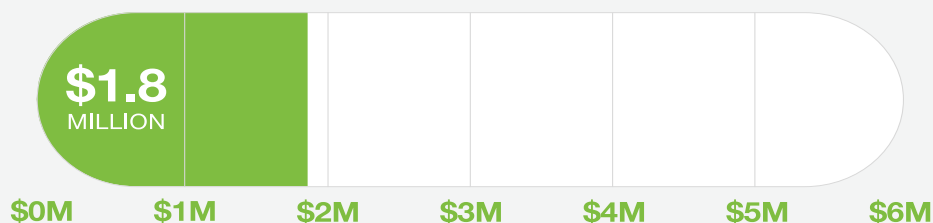


Greg Parham, Pam Hathaway, Dustin East and Mark Massey



Mike and Thresa Nasi

### Be First donations and pledges as of 11/14/2016







Cherie and Jim Flores



Craig and Charlotte Benson, Todd and Heidi Binet, Stephanie and Mark Hamilton

## Cherie and Jim Flores Matching Gift

Long time supporters of BBDF, Jim and Cherie Flores, announced a \$500,000 Matching Gift to launch The Be Project in December 2015. A past member of the BBDF Board of Directors, Cherie has been involved with the foundation since its inception. The Flores' first gift of \$2.5 million in 2008 was the single largest individual gift in Batten Disease history and helped launch juvenile Batten research at Texas Children's Hospital. The Flores' matching gift provides every donor with the chance to have his or her gift reach even further. We are so grateful for their continued support.

## BE FIRST DONORS

Our Be First donors are crucial to the success of the Be Project, which will provide children with a treatment option where one has never existed.

A Cure in the Nick of Time  
Erin & Richard Abraham  
Rachel & Lee Alcock  
Robert & Tish Anderson  
Shana & Brady Anderson  
Austin Community  
Foundation  
Aileen & Mike Aviles  
BBB Fishing Tournament - Neal  
Meinzer  
Charlotte & Craig Benson  
Elaine & Britt Benton  
Heidi & Todd Binet  
Lauren & Beau Blair  
Sharon & Calvin Brasseaux  
Beth & Neal Bronzo  
Sabrina & Jay Brown  
Mary Kay & Terrell Brown  
Bruce Butler  
Sidney & Larry Carter  
Carly & Clayton Christopher  
Christy & Brian Clark  
Tracy & Scott Cohagan  
Jimmy Field Campaign  
Dustin & Hunter East  
Kelly & Mark Field  
Bill Fletcher  
John R. & Judy W. Fletcher  
Family Foundation  
Julie & Scott Folse

Cherie & Jim Flores  
Lynn & Bill Fowler  
Melanie & Jeff Fox  
Pam & Keith Fullenweider  
Nan & Britt Galloway  
Paula & Tom Gandy  
Jay & Pam Gadberry  
GE Foundation  
Caroline & Sam Goodner  
Nancy Gordon  
Laura & Morris Gottesman  
Susie & Ira Green  
Andrea & Christopher  
Greiner  
Stacy & Dave Grundfest  
Kerry & Steve Hall  
Allison & Spencer Hayes  
Heartland Foundation  
Maury Herman & Cristina  
Wysocki  
Susan & Herrin  
Hickingbotham  
Hojel Schumacher  
Foundation  
Ann & Richard Hojel  
Margaret & Gilbert Hooder  
Diane Lee Humphreys  
Anne & Jeff Hunt  
Paul B. & Constance D. Hunter  
Charitable Foundation

Mimi & Joe Hurst, Jr.  
Brett Ironside - Little Rock  
Diagnostic Clinic  
Shannon & Kyle Janek  
Soozi Graf & Andy  
Kershner  
Albert Koehler  
Karen & Eric Loeffel  
Luke & Rachel Batten  
Foundation  
Lumos Pharma, Inc.  
Cindy Luu  
Renata Marsilla & Jeff  
Lipshutz  
Tatiana & Craig Massey  
Suzanne & Mark Massey  
Gary McDaniel  
Meinig Family Foundation  
Mary Helen & Mike Miller  
Elizabeth Miller  
Kelli & Chris Mize  
Sara & Bill Morgan  
Ginja & Matt Moseley  
Hardy Murchison  
Nicole & Will Murphy  
National Christian  
Foundation  
Kristen & John Nelson  
Susan & John Nicklos  
Wendy & Ray Parker

Randa Patrick  
Yasmine Michel & Steve  
Patterson  
Peter Perino  
Mary Therese & Ricardo  
Peruquia  
Piper Jaffray  
Hiam & Dean Reinschmidt  
Cheryl & Mike Renna  
Ann & Pryor Robertson  
Daryl Rogers  
Jinous Rouhani  
Linda & Karl Scheible  
Sylvia & Dan Sharplin  
Laura Sheffield  
Lori & Joe Sikorra  
Ann & Rich Smalling  
Carol & Witt Stephens  
Margaret Tarone  
Stacy & Mike Toomey  
The Vaughn Foundation  
WaterStone Foundation  
Weaver Tidwell Foundation  
Mary & Mark Williamson  
Shannon & Jimmy  
Windham  
Rochelle & James Woodard  
Anne-Elizabeth Wynne





# BOARD OF DIRECTORS

BBDF is proud to have the support and contributions of our Board of Directors who have not only a diverse set of skills and expertise, but also a genuine dedication to our cause. We are excited to announce the addition of 3 new board members: Sabrina Brown, Caroline Goodner and Scott Young.



## **T. Craig Benson - Chair and Founding Director**

Craig has been the CEO and Managing Director of Callaway Partners, LP since 2004. Callaway Partners is engaged in various private investments in the areas of banking, specialty finance, oil and gas, and healthcare. Craig was CEO and President of Rules-Based Medicine Inc. a life sciences/diagnostic company, from January 2002 through December 2013, after directing its spin-off from Luminex Corporation. The business was acquired by Myriad Genetics in 2011. During 2000-2004, he also served as Chairman of the Board for Equity Resource Partners, LLC, a private investment company. From 1987-2000, Craig was employed by Service Corporation International. During his tenure with SCI, he held various senior executive management positions, as well as serving as President of SCI International Ltd., SCI's International holding company. From 1990-1994, Craig served as President of Investment Capital Corporation, the private equity arm of SCI, which held over \$350 million in assets. From 1984-1987, he held management positions with Pulaski Investment Corporation. Craig has served on the Board of Directors of various publicly held entities, including Florafax International, Tanknology Environmental Inc., Equity Corporation International and Pinnacle Global Group Inc. He received a BBA degree from Southern Methodist University in 1984. He currently serves as a founding member of the Board of Directors for Rock Bancshares Inc., the holding company for Heartland Bank. Craig and his wife Charlotte live in Austin with their two children, Garland and Christiane, who has Batten disease.



## **Jeff Hunt**

Jeff is a partner and co-founder of PulsePoint Group. During the course of his 25-year career, Jeff has lived and worked in every major region of the world, counseling CEOs and other top executives at numerous multi-national companies including DuPont, IBM, AT&T, Coca-Cola, Johnson & Johnson, McDonald's and Motorola. He specializes in a range of boardroom services, including crisis management and preparedness; CEO and CFO communications; branding, positioning, reputation management and social media. His work with Dell, Nike and Whole Foods, among others, has kept him on the leading edge of the social media space developing programs for everything from customer listening/response and corporate blogging to digital influencer relations and crowdsourcing. Prior to co-founding PulsePoint Group, Jeff was the president of Cohn & Wolfe, a global public relations firm formed following a merger with GCI Group. Prior to the merger, Jeff spent three years as president and chief executive officer of GCI Group. He joined the company following the firm's acquisition of Read Poland Associates, for which he served as president and CEO. Before returning to Texas to lead Read-Poland, Jeff had an 18-year career with Burson-Marsteller. Jeff holds a Bachelor of Journalism, with honors, from the University of Texas at Austin and serves as an adjunct professor at the University's College of Communications. He also is a frequent guest lecturer for the University's McCombs School of Business. Jeff and his wife Anne live in Austin and have two grown children.



## **William Murphy, Jr.**

Will Murphy has worked as a Financial Advisor to select individuals and families since moving to The Woodlands in 2005. He is currently recognized as a Premier Advisor, a designation held by a select group of Financial Advisors who have demonstrated a high level of professional achievement based on many factors including production. Before joining Wells Fargo Advisors in 2008, Will was a Financial Consultant for Capital One Advisors. He graduated from The University of New Orleans with a Master's degree in Business Administration and a degree in Business Management. Will has also earned the Certified Financial Planner professional designation. For this designation, he had to complete approved educational programs, pass rigorous examinations and meet stringent experience requirements. Will's mission is to provide every client with targeted, comprehensive financial advice and portfolio management — delivered with the highest level of personal service and professional integrity. This commitment to service also carries over to his involvement with his local community. Will has been a valuable volunteer for the Will Herndon Fund of Beyond Batten Disease Foundation since its inception. Away from the office, Will enjoys spending time with his family and playing golf. Will and his wife, Nicole, live in The Woodlands with their two children.



### Caroline Goodner

Caroline Goodner's most recent professional role was CEO of UpSpring Baby, a growth-stage consumer products company that focused on the health, wellness, and safety of mother's and babies. She joined UpSpring in February 2009 after taking a year off following the sale of two companies in 2007. In 2005, Caroline founded MendelWorks, a mouse genotyping laboratory that served the scientific research community, and sold it at the end of 2007. Prior to that, Caroline founded Identigene in 1993 and sold it in 2007. Identigene is a DNA identification laboratory that provides paternity testing to consumers and forensic DNA testing for law enforcement and defense attorneys. Currently she is an advisor with Everly in Dallas, a Mentor with Incubation Station in Austin, Texas, and is on the Steering Committee for the Austin Chapter of the Rice Alliance. Caroline earned her BA from Duke University and her MBA from Rice University's Jones School of Business. Additionally, she has received a number of certificates, as a Master's of Business Dynamics, from the Massachusetts Institute of Technology's renowned Sloan Executive Education program. Caroline and her husband Sam live in Austin with their two children.



### Sabrina Brown

With over twenty years of hands-on experience in Texas government and politics, Sabrina is an accomplished government affairs consultant and lobbyist. Sabrina's expertise in the state's legislative, regulatory, public affairs and appropriations arenas provides a variety of businesses and organizations—from aeronautics giants to groundwater districts to Fortune 50 companies—with vital political and governmental guidance. Prior to opening her own practice, Sabrina was a lobbyist for an Austin-based law firm, and previously spent a half-dozen years at the Capitol, working for the Texas House of Representatives. As a government relations specialist for the firm of Bickerstaff, Heath, Smiley, Pollan, Kever & McDaniel, Sabrina represented over 20 clients before the Texas Legislature, state agencies and local governments. As a research analyst for the Texas House Select Committee on Revenue and Public Education Funding, Sabrina oversaw the interim study of taxes. Sabrina also served as a research analyst for the Texas House Committee on Appropriations, directing the budget analysis of all public and higher education institutions, and education-related agencies. Sabrina earned her Masters in Public Affairs at the Lyndon B. Johnson School of Public Affairs at the University of Texas, and her bachelor's degree at Texas A&M University. Sabrina and her husband Jay live in Austin with their two children.



### Scott Young, DDS

Dr. Scott Young has displayed a passion and talent for dentistry since his college days. A 1999 graduate at the University of Texas Dental Branch in Houston, he has spent his career providing personalized individual dental care in The Woodlands, Texas area. He has worked extremely hard to build an exceptional dental team that has garnered respect from clients and the community alike, as the most caring and dedicated professionals in their field. Dr. Young is also a graduate of the Las Vegas Institute (LVI), one of the most renowned cosmetic dentistry schools in the world; an achievement reached by less than 1% of cosmetic dentists. His LVI courses enabled him to study each aspect of cosmetic dentistry with a hands-on approach, affording him the opportunity to learn from some of the most renowned cosmetic dental practitioners in the country. Dr. Young has also completed advanced courses in implant dentistry, allowing his practice to offer virtually every type of dental service available. Scott and his wife Amy live with their two children in The Woodlands.



### Mark Chandler, PhD - Board Member Emeritus

The board established the position of Emeritus Board Member to honor those individuals who have served the foundation with dedication and distinction and we are proud to bestow the title on Dr. Mark Chandler. As a founding board member he worked tirelessly to advance the mission of the foundation. His eight years of service on the board are directly tied to our successes to date. His thoughtful and creative approaches to problem-solving, communicating complex information, constructive feedback and leadership resulted in the growth of the organization and have established the foundation as the nonprofit world leader in juvenile Batten disease research funding. Mark's creativity and entrepreneurial spirit led to the idea for the rare disease genetic test and put BBDF on the map. The test, named one of Time Magazine's Top 10 Medical Research Breakthroughs for 2012, is available to patients today. It is being used to quickly diagnose children to determine if they have one of over 795 medically devastating diseases. This will end the diagnostic odyssey that until now took an average of 2 to 3 misdiagnoses and 7.6 years for Batten patients. His legacy will be saving patients and families this heartache. Together with your generous support, the test has brought much needed attention to the foundation and our mission and has served as a springboard for working with other disease groups.

# 2015-2016 DEVELOPMENT BOARD

Three years ago, Beyond Batten Disease foundation created the Development Board out of the necessity to sustain our momentum and reach new audiences. Over the past three years, the Development Board has been integral to the fundraising success of the foundation. These active volunteers and leaders are helping grow and accomplish our mission by extending the reach of our community and raising awareness and research funds to find a cure or treatment for juvenile Batten disease. In its third year, this dedicated group was led by President Ashley Crider.

## Executive Committee

**President: Ashley Crider**

**President-Elect: Ashley Putman**

**Secretary: Thresa Nasi**

**Hospitality Co-chairs: Laurel Hooper and Kristin Cowden**

**Family Night Chair: Lisa Magids**

**Grant Writing Chair: Amber Meinzer**

**Historian: Kasandra Keyes**

**Nominating Chair: Kelley Daniel**

Brandy and Richard Agnew  
Paige and Jamil Alam  
Kristin and Wick Alexander  
Tracy and Jarrett Anderson  
Stacy and Chad Auler  
Clary and Mark Auler  
Charlotte and Craig Benson  
Elaine and Britt Benton  
Sabrina and Jay Brown  
Carolyn and Scott Bryant  
Bruce Butler  
Lucy and Steve Butter  
Mary Carrigee  
June and Mark Chandler  
Katy Copley  
Kristin and Allen Cowden  
Ashley Crider  
Kelley and Tom Daniel  
Lori and John Daves  
Lynne and Scott Daves  
Susanne and Colby Denison  
Darby Denison  
Shannon and Kelly Dowell  
Beth and Marshall Durrett  
Leslie and Brandon Easterling  
Cari and Monte Ezell  
Kristin and Drake Fason  
Lynn and Bill Fowler  
Katie and Will Fowler  
Hillary and Bill Geisler  
Anna and Reg Hargrove  
Courtney and Charlie Hill  
Ann and Richard Hojel  
Laurel and Andy Hooper  
Diane Humphreys

Grace and Adam Ingram-Eiser  
Jocelyn Johnson  
Katherine and Patton Jones  
Jackee and Tony Kayser  
Kasandra Keyes  
Dana and Jeff Kocurek  
Kathryn and Kam Kronenberg  
Julie and Derek Lewis  
Lisa Magids  
Jenna and Christopher Martin  
Laura and Mark McKnight  
Amber and Neal Meinzer  
Thresa and Mike Nasi  
Monste and Kevin Nater  
Heather and Jack Nelson  
Kristen and John Nelson  
Anne and Chris Newton  
Monique and Scott Norman  
Kendall and Charlie Pace  
Jackie and Eric Price  
Ashley and David Putman  
Lauren and Reagan Reaud  
Anne and Richard Smalling  
Ellie and Bill Snell  
Amy and Charles Stephens  
Julia and Marty Sunde  
Dawn and Lance Thompson  
Stacy and Michael Toomey  
Jill and Carlton Wade  
Laura and Todd Wallace  
Ali and Trey Watson  
Heidi and Jamey Whitlock  
Shannon and Jimmy Windham  
Susan and Reid Wittliff  
Lisa and Wes Youngblood



Cari Ezell and Carolyn Bryant



Craig and Charlotte Benson, Ashley Crider, Mary Beth Kiser



Anne Smalling and Ashley Crider



# 2015-2016 DEVELOPMENT BOARD



Reid Wittliff, Lucy Butter, Kelley Daniel, Kirstin and Allen Cowden



Andy Hooper, Neal and Amber Meinzer, Scott Bryant, Richard and Brandy Agnew



Tony Kayser and Allen Cowden



Charlotte and Craig Benson, Kelley Daniel



June Chandler, Darby Denison and Dawn Thompson



Lance Thompson, Craig Benson



Kristen Nelson and Laurel Hooper



Kelley Daniel, Ashley Crider, Lucy Butter



# HOPE COMMITTEE



Seven years ago, over 80 women came together, pledging their support to the Herndon family in the wake of Will's diagnosis. They planned the first HOPE Under The Stars with a zero dollar budget, collecting donations from their surrounding community. That event generated \$220,000 and set The Will Herndon Fund into motion. Since then, this group of dedicated women has grown to well over 100 members and is responsible for the planning, development, and execution of

three annual events as well as raising awareness in The Woodlands community and beyond. They are the heart of HOPE and one of the main reasons Will wakes up each morning with a smile.

Christen Argueta  
Amy Atnipp  
Charla Balette  
Angela Banzhaf  
Darcy Bass  
Carey Bell  
Jerissa Belsha  
Inger Berger  
Angie Blake  
Ashley Boudreaux  
Pam Bryan  
Tania Bryngelson  
Bridget Buck  
Jennifer Bulovas  
Jessica Catani  
Marilou Catani  
Elvira Cauthen  
Daneli Cherie  
Misty Clow  
Julie Comeaux  
Jennifer Coyle  
Jessica Cribbs  
Kathy Croom  
Alexa Currie  
Mary-Kathryn D'Agostino  
Nikki De Boer  
Nancy Decker Lent  
Julia Dell  
Colleen Dippel  
Carolyn Donovan  
Erin Doré  
Meg Doyle  
Carol Durkee

Johnna Edone  
Christine Elmendorf  
Arlene English  
Gina Ferrell  
Kassi Foster  
Haley Garcia  
Angela Gibbs  
Emily Gogineni  
Natalie Greene  
Jennifer Grigsby  
DeAnn Guidry  
Dina Hafley  
Paige Halberdier  
Michelle Harper  
Kecia Haseman  
Alison Henderson  
Missy Herndon  
Phillomina Herndon  
Michelle Hewgley  
Jennifer Hiser  
Audra Hoegemeyer  
Rachel Honeyman  
Colbie Hubenak  
Jennie Hughes  
Polly Hunt  
Lauren Hunter  
Noelle Jahncke  
Lindy Johnson  
Janine Jones  
Alison Judge  
Wendy Judy  
Teresa Keating-Walker  
Wendy Kemp

Jessica Kemp Park  
Melissa King  
Martha Klie  
Beth Landgraf  
Kelli Laney  
Gina Lattimer  
Michelle Leavitt  
Kristi LeBlanc  
Kim LeBlanc  
Amy LeCrone  
Kimberly Lee  
Julia Lile  
Denise Lipar  
Kelli Lunn  
Coco Mahoney  
Alicia May  
Jena McCrann  
Jennifer McDonald  
Marissa Mettauer  
Bobbi Jo Miller  
Christy Miller  
Shannon Mills  
Stephanie Milstead  
Whitney Montgomery  
Natalie Moon  
Stacey Morcos  
Emily Morgan  
Shea Muehslar  
Nicole Murphy  
Sarah Nanick  
Emily O'Shaughnessy  
Amy Odom  
Claire Orewiler

Stephanie Parke  
Julie Perugini  
Carolyn Price  
Patricia Sanders  
Stacey Schexnauldre  
Brooke Schmitt  
Tammy Schroder  
Krista Schuelke Cook  
Jennifer Seeger  
Cheryl Sevin  
Jennifer Sieracki  
Audra Simpson  
Jenni Skipper  
Melissa Stanosheck  
Tricha Stilley  
Iram Taylor  
Amy Thedinger  
Amy Torres  
Honey Tucker  
Misty Twellman  
Stevi Venable  
Theresa Wagaman  
Sarah Watson  
Lizzy Weaver  
Heather Webster  
Courtney West  
Kyla Wilder  
Yvette Williams  
Mallory Yartym  
Amy Young  
Cheri Young



# THE WILL HERNDON FUND

The spirit of giving is alive and strong in The Woodlands community. Our corporate sponsors have hosted numerous give back days throughout the year.



Kendra Scott - Market Street



Nails of America Ashlane Way



Cake Walk Style Shop



Alex & Ani - Market Street



Donoho's Jewellers



Party City Shenandoah & Humble



Texas Academy of Dance Art



# YOUTH LEADERSHIP COMMITTEE

Recognizing the many young philanthropists in our community, Beyond Batten Disease Foundation created the Youth Leadership Committee in October 2014. In just their second year they helped us grow and move closer to finding a cure for juvenile Batten disease. This year's committee was made up of over 60 students from 7 different Austin-area High Schools. President, Hannah Windham, led the 2015-2016 YLC.



2015-2016 Youth Leadership Committee



Will and Wyatt Ezell



Ireland Tendler, Susie McCartt, Merritt Fish, Ella Nasi, Laney Phillips, Claire Peterman



Emma Breckwoldt, Cailan Kelly, Mary Margaret Oden, Mallory Clifton

**President: Hannah Windham**  
**Secretary: Kathryn Sharplin**  
**Community Outreach Chair: Susie McCartt**  
**Leadership Development Chair: Will Snell**

Mills Alexander  
 Walt Alexander  
 Clay Anderson  
 Chris Ault  
 Caleb Barton  
 Emma Breckwoldt  
 Buddy Brumley  
 Ellie Brumley  
 Joe Bryant  
 Max Burnett  
 Ellen Campbell  
 Katie Chandler  
 Grayson Clifton

Mallory Clifton  
 Jack Collins  
 Francis Copley  
 George Copley  
 Steven Crider  
 Keaton Cruzcosa  
 Caroline Daniel  
 Casey Daves  
 Drew Dowell  
 Carlisle Dunnam  
 Will Ezell  
 Wyatt Ezell  
 Lawson Fish

Merritt Fish  
 Claire Gill  
 Grace Gilmour  
 Ellen Hagen  
 Brandon Hetherly  
 Thad Hutcheson  
 Reagan Jackson  
 Will Janek  
 Sophie Johnson  
 Taylor Josey  
 Max Keliehor  
 Cailin Kelly  
 Cole Kocurek

Mary Frances  
 Kocurek  
 Will Kocurek  
 Jaxon Kronenberg  
 Olivia Late  
 Cal Long  
 Ella Nasi  
 Grace Northway  
 Mary Margaret Oden  
 Carter Pace  
 Claire Peterman  
 Laney Phillips  
 Molly Pitts

John Schneider  
 Clara Sherman  
 Hasie Sherman  
 Anna Claire Smith  
 Molly Smith  
 Ireland Tendler  
 Cameron Thompson  
 Michael Toomey  
 Walker Weedon  
 Lee Whitehead  
 Jack Windham  
 Natalie Youngblood





# FAMILY NIGHT AT SCHLITTERBAHN

In September 2015, over 450 supporters attended Family Night at Schlitterbahn Waterpark in New Braunfels. With the park exclusively open for BBDF, families enjoyed a “fast pass” experience with smiles and laughter, dinner buffet, including unlimited Ices and Dippin’ Dots. Kids and adults alike enjoyed this special experience, benefiting a cause near to their hearts. From the squeal-inducing Skycoaster, to the crowd favorite Master Blaster water slide, the inaugural event was a huge success. Thank you Chair Lisa Magids and the Family Night Committee for all your hard work making the event unforgettable!



Sophie Johnson, Margarita Matta and Elle McCartt



Garland Benson, Thomas Bryant, John Torres, Luke Foster



Shannon Windham, Lori Johnson, Erika Herndon, Kristin Cowden



Charlotte and Craig Benson, Lisa Magids



Paige Johnson, Julianna Hooper, Ella Johnson, Georgia Jaros, Kaitlin Zimmerman



# HOPE UNDER THE STARS

The 8th Annual HOPE Under The Stars raised over \$630,000 making it our most successful event ever! Will is working hard to stay strong while we pursue clinical trial approval. Thank you so much for the many sponsors, volunteers and guests who make this possible every day!



Missy, Will and Wayne Herndon



Wayne Herndon, Mark and Nicky Sorenson, Missy Herndon



Donoho's Diamond Raffle



Guests with DJ Lucy



HUTS Planning Committee



HUTS Leadership: Angela Banzhaf, Niocle Murphy, Missy Herndon, Noelle Jahnke



# WILL HERNDON FUND

## Warriors for Will

HOPE friends working hard to #savewill!



Mitchell Intermediate School Faculty Follies



Maverick Fantasy Fit Camp



Halloween treats for Will



Magnolia High School Business Class



Mitchell Intermediate School Student Service Group



The Woodlands High School Improv Troop



# WILL HERNDON FUND

## HOPE on the Green

What a beautiful day to SAVE WILL! Thank you to everyone who came together and helped raise over \$125,000 for research!



Will Johnson Team



Missy, Will and Wayne Herndon



AtnippTeam



Wendy Judy, Amy Atnipp, Julie Lile, Charla Balette



# YOUTH LEADERSHIP COMMITTEE CONCERT

Spearheaded by President Hannah Windham, the Youth Leadership Committee in Austin combined a love of music with philanthropy to raise over \$8,500 to benefit Beyond Batten Disease Foundation. Musician Rob Baird graciously accepted the invitation to partner on the event, and the rustic charm of the Historic Scoot Inn was the perfect venue.



Mia Cooper, Laney Phillips, Ruth Mewhinney



Garland Benson, Craig Benson, Christiane Benson



Caroline Daniel, Mallory Clifton, Mary Margaret Oden, Emma Williams, Cailan Kelly, Taylor Josey, Emma Breckwoldt, Hannah Brannon



Reagan Jackson, Susie McCartt, Alex Swartz, Elle McCartt, Mia Cooper, Ruth Mewhinney, Ireland Tendler, Claire Peterman



Rob Baird Band



Guests enjoying the show



# COMMUNITY FUNDRAISERS

BBDF's advocates span the globe. We are grateful for the many supporters who take it upon themselves to Be the Change, hosting events in their communities and raising funds for research. Using their talents and integrating Batten disease awareness into their runs, parties, lemonade stands and more, they are helping us accomplish our mission.

## A Cure in the Nick of Time

Jessica Curran, organized the first annual A Cure in the Nick of Time Run in Duxbury, MA in honor of her brother who has juvenile Batten disease. With Nick and his father leading the first lap, the event raised over \$25,000 to support BBDF's research strategy. Thank you to the Curran's community in Massachusetts who showed their support for Nick!



The Curran Family



Huge crowd at the start line in Duxbury, MA



Roberto Espinosa's winning catch

## Battlin' Batten in Baffin Fishing Tournament

Congratulations Roberto Espinosa on catching the winning trout at the 8th annual Battlin' Batten in Baffin Fishing Tournament in April. Chair Neal Meinzer along with 52 fishermen raised over \$48,000 to fund a treatment for juvenile Batten disease. This year's fundraising set a new high-water mark for the BBB and pushed the total aggregate amount of donations to the Foundation across its eight-year existence to over \$200,000! Thank you to all who participated.



Mary Caroline Nelson, Caroline Daniel and volunteers at the Austin Marathon water station

## Austin Marathon

Runners at this year's Austin Marathon raised over \$22,000 for BBDF Research! A huge thank you to the runners and volunteers that came together to make our first year at the Austin Marathon such a great success! We are extremely grateful to have such dedicated volunteers.





## Liz James Design Necklace

Thanks to Jamie Pope at Liz James Designs for donating over \$1,800 to BBDF. Jamie designed a necklace made of colored stones progressing from dark to light to signify the transition from a diagnosis of Batten disease to the light and hope for a cure. She named it The Christiane. If you would like to order a necklace, please visit [www.lizjames.com](http://www.lizjames.com).



## Fun Run for Kids

This year's event took place at Camp Mabry and raised over \$10,000 for research! Special thanks to Young Guns and the event committee: Larry and Emily Chauvin, Courtney Ewing, Kim and Brandon Batiansila, Sheri Bryant, Jan Jackson, Alli Phillips, Cindy Samok and Sandra Yancer for making this event such a success.

## Caprice Richards Riding Class

Last November RIDE Indoor Cycling instructor, Caprice Richards, and Development Board members, Katherine and Kam Kronenberg, Lucy and Steve Butter, Thresa and Mike Nasi, Kristin and Wick Alexander and Jocelyn Johnson raised over \$1,720 for research!



## Batten Basketball Tournament

Students at Trinity Middle School in Austin raised over \$2,100 for BBDF research! The Batten Basketball Tournament was the perfect way to educate kids about Batten disease.

Special thanks to all the kids and parents who participated and organized the event, especially Development Board members Lucy Butter and Jocelyn Johnson.

## Father Son Ranch Weekend

Organized by Allen Cowden, 6 father and son pairs participated in a ranch weekend that raised over \$11,000 for research!





# A MOTHER'S STORY

by CHARLOTTE BENSON

In 2008 when our daughter Christiane was learning to read, we noticed that she was bringing books really close to her face and we thought she needed a pair of glasses. We took her to the eye doctor, which led to a series of appointments with other doctors including a neurologist and a genetic specialist. Six weeks later, my husband Craig and I received the devastating news that Christiane had been diagnosed with a very rare neurodegenerative condition called Batten disease for which there is no treatment or cure. In a single moment, our lives were shattered by a word we had never heard of.

Batten Disease causes blindness and seizures and is physically and mentally incapacitating and ultimately terminal by the late teens or early 20s. Eight years later, it still takes my breath away to write all of that in one sentence.

What I remember about the day of her diagnosis was the shocking numbness that seemed to freeze that terrifying moment, and every racing emotion as we fell to our knees in horror and disbelief. While we were on our knees we began to pray. We prayed for strength, direction, comfort, and sustenance. The months that followed came with the incredible support and love of our family, friends, and community who joined us in forming Beyond Batten Disease Foundation. The foundation has become a life

purpose for us and we believe we are a vehicle for something so much bigger than ourselves. It has also been an opportunity for virtually everyone we know who wants to do something to help make a difference; channeling talents, gifts and resources to find a cure. For our family, this has been a



story of God's provision, the power of humankind and community, and a shining example of what friends do for friends.

Today, through the research that BBDF has funded over the last eight years, we now have a treatment in sight! To think, that the small circle

of friends who surrounded us at our darkest moment has grown into a far reaching community of people who have enabled us to accomplish so much in such a short period of time is overwhelming.

Not only is Christiane the inspiration for the foundation, but she is also a complete metaphor for who we are as an organization. Even though Christiane has learning challenges and is visually impaired, she has never let these hurdles stand in her way of doing what she believes she can. She continues to be determined, resolute in her beliefs, and she simply never quits trying. For the second year, Christiane is a cheerleader at O. Henry Middle School, she enjoys snow skiing and horseback riding, and what she loves most is spending time with her two dogs, Queenie and Piper.

Christiane's vision is declining and she sees blurry shapes, light and dark, and struggles to focus up close. While she **should** be walking with a cane, she refuses to do so and chooses instead to take her daily walks around the neighborhood with her dogs...who are **not** Seeing Eye dogs. Christiane's low vision teacher has told her that in order to have a Seeing Eye dog, she must first master the cane. But so far, that has not changed her mind about doing things her own way.

Christiane rarely lets me accompany



her on her afternoon walks, but recently she invited me to come along and I had a chance to take the route she follows every day. When we got to a place in the sidewalk where a tree root had buckled the pavers, and before I could even warn her, she trotted across, without missing a beat. I asked her how she was able to navigate the bumps so effortlessly, and she answered, "After I pass the low hanging branch by the Thompson's house, there is another low hanging branch, and then there is the broken sidewalk." She has memorized the details of the same route that she takes daily as a way to compensate for her vision loss.

Several days later, she was riding on the front seat of the car with me and she said, "You know, Mom, as dogs get older they lose their vision". And I replied, "Oh you're right Christiane, I have heard that before. Sometimes dogs go blind in their old age." I was wondering perhaps if she was trying to draw a parallel between herself and her dog, or having an introspective insight as it relates to her vision loss. But instead, she turned to me and said "Well, I think we might need to take Queenie to the vet to have her eyes checked because she sure has been running me into a lot of parked cars lately!"

While Christiane is still coming to terms with the loss of her eyesight, at least I know that as her mother, I can speak for her in a way that she cannot speak for herself. I have the awesome responsibility of being Christiane's voice, and in so many ways I am the voice of every mother who has a child

with Batten disease who does not have the platform of this foundation. I am the voice for every mother who feels hopeless, and trapped, and unable to dream of a future because no matter what, it includes the unthinkable reality of life without her child. I share my story on behalf of every mother who is caring for a child with special needs and is unable to find the time or energy to do anything more than that.

*"This treatment is our chance at life for Christiane and all of these children. And, as long as there is a chance, I have a duty as her mother to do whatever I possibly can."*

I know this intimately because there is also a new reality emerging for us. Christiane's condition is changing and I know that the opportunity to make a meaningful difference in her life is fleeting. This year Christiane had her first seizure, her vision is deteriorating and she is requiring more and more of my help. As her needs increase, I am finding that I have other obligations as her mother and of course, she will be my first priority.

But for now, we are standing in front of a short window of time staring at a treatment that could prolong function and extend her life. This is our chance. This treatment is our chance at life for Christiane and all of these children. And, as long as there is a chance, I have a duty as her mother to do whatever I possibly can.

Fundraising is certainly not my gift and \$6 million in 24 months is a steep hill to climb. But I have come to know that a mother's instinct to save her child trumps everything else. So I am asking for your help and I hope you might consider pausing your other philanthropic obligations to give to our efforts now. We all have so many good charities to contribute to, but this one has urgency for a group of kids who need our help today.

I hope that you will share our story with your family, and consider making a gift on behalf of your own children as an expression of your love to them. I hope that you will tell your children that if you found yourself in our shoes, you would not hesitate to do the exact same thing for them.

Let us all look back on this moment in time with no regrets knowing that we did everything we possibly could to give Christiane and all of these children the life that they deserve.

Please join us for the Be Project and be a donor, be the hope, be the change, be a hero, be a leader... but more than anything, let's all take a page out of Christiane's book and believe that we can.

# BIG HEARTS

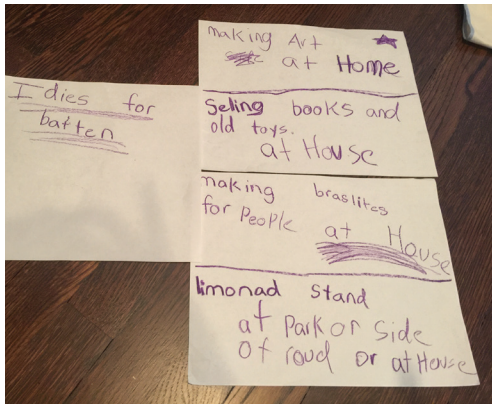


## An Art Project raises \$4,000

Lucy Cowden set out to help fund the treatment for Batten disease by creating her own fundraising campaign. Lucy and her mom, artist Kristin Cowden, invited Christiane over for painting. The result was a beautiful watercolor that they turned into bookmarks and postcards. Lucy then mailed a letter with a heartfelt request to help fund the treatment for her friend Christiane. Lucy enclosed the bookmarks and postcards and asked for notes of encouragement to be mailed to Christiane on the postcards they had created together. The result was over \$4,000 in donations to the foundation and a treasure trove of cards expressing love and support from people whom Christiane has never even met.

## Everything big starts with an idea

Daisy Auler is 8 years old. Her parents, Clary and Mark Auler serve on the Development Board and have been talking about the Be Project at home. After overhearing their conversation, Daisy headed to her room and did some brainstorming on her own. She was inspired to list some new fundraising ideas to help reach the fundraising goal. When Clary went to check on her, this is what she found:



## Be a Winner

Julianna Hooper and her brother Henry also set out on their own fundraising campaign. They wrote handwritten letters to friends and family asking for help raising money for the Be Project to honor their friend, Christiane. They enclosed a picture of them together with Christiane. Not only was their venture a success, raising almost \$3,000, but Henry won the iPad mini prize drawing for the kids' "Be the Change" contest. When Henry received the prize, he chose instead to donate it back to the foundation and said that he and his sister, Julianna, could just share hers.



Courtney Houston & Henry Hooper



Christiane Benson and Henry Lambert

## Let's Dance

At a recent family wedding, the ten year old nephew of the bride, Harrsion, was very keen to dance with Christiane. Adorably dressed in a red bow tie, he repeatedly asked her to dance without much luck. When Christiane was asked why she said no, she replied "I think he's too young for me, don't you"? The next evening, the Benson's family friend and avid dancer, Henry Lambert, asked Christiane if she might like to dance. Henry very sweetly placed her hand in his and guided her other hand to his shoulder. They slowly swayed around the dance floor until the song ended. And, just as it did, Harrison appeared for one last try. Henry did not miss a beat and smoothly exchanged his hand for Harrison's. Henry led the pair around the dance floor with hands on their backs and then gently let go. For the next two hours, Christiane and Harrison danced without stopping and never left the dance floor until the evening was over. Thanks Henry for seizing the moment, making a memorable evening and sparking a passion for dancing in Christiane.





# RESEARCH

## Rare Disease Genetic Test Commercialized

In 2009, BBDF funded the initial development of a rare disease genetic test at the National Center for Genome Resources in Santa Fe, New Mexico. The development team later moved to Children's Mercy Hospital (CMH) in Kansas City where "TaGSCAN" (for Targeted Gene Sequencing and Custom Analysis) has been clinically validated to identify 795 devastating rare diseases, including the juvenile (CLN3) form and other forms of Batten disease. The test was further developed and commercialized within the Pediatric Genome Center at CMH. In 2012, Time magazine named the technology one of the Top Ten Medical Breakthroughs of the year.

Today the test is being used to quickly diagnose children to determine if they have these conditions preventing or ending the diagnostic odyssey so many families face. Until now, the average patient with a rare disease would see 8 physicians and receive 2 to 3 misdiagnoses over the course of 7.6 years before being correctly diagnosed. Since its launch, the test has helped thousands of children and families touched by rare disease. More recently, the test has been licensed to PerkinElmer, one of the world's largest life sciences and diagnostic services companies. In the future, BBDF will be entitled to receive royalties from commercial sales of the test.



## Scientific Report

Why is the research landscape so different today than when BBDF was founded 8 years ago? We can point to scientific leadership. Since 2009, Danielle Kerkovich, PhD, has led the Foundation as its Principal Scientist. Only 5% of the 225,000 medical research foundations in the US employ a full time scientist. Early in her tenure, Dr. Kerkovich reviewed the "State of the Science" in Batten disease research. In addition, she met with the most highly successful medical research foundations in the US to determine how successful foundations achieved their goals of bringing treatments or cures to the patient communities they serve.



Danielle Kerkovich,  
PhD

By creating a logistical plan of action tailored to the needs of juvenile Batten disease research that identifies gaps in our scientific understanding, focuses on the discovery of drug targets, and incorporates best practices for moving discoveries into care, she was able to design a strategy to reach clinical trials.

## Today Beyond Batten Disease Foundation is the nonprofit leader in juvenile Batten disease research funding

Creating a strategy and managing its outcomes is not enough. Much of BBDF's success is tied to the coordination of and partnering with Batten and other like-minded and neurodegenerative disease groups. To ensure that BBDF is aware of and has the ability to respond to emerging discoveries, Dr. Kerkovich supplements her expertise with input from leaders in research and development across the entire therapeutic pipeline for Batten, as well as for adult forms of neurodegeneration (e.g. Alzheimer's and Parkinson's disease), genetics, lysosomal, and other relevant disorders. As a result, Batten families raising funds for research, have a list of scientifically vetted projects from which they can choose to contribute.



# RESEARCH AWARDS 2015-2016

The following recommendations for funding were approved by the Board of Directors between July 1, 2015 and June 30, 2016:

**Emyr Lloyd-Evans, PhD | Senior Lecturer  
Cardiff University, Cardiff Wales,  
United Kingdom  
\$12,000**



Dr. Lloyd-Evans will explore a new hypothesis that has implications for opening new approaches to treatment in juvenile Batten (CLN3) disease research. Based upon findings in genetically-engineered Batten mice, investigators hypothesize that affected children experience toxic levels of Ca<sup>2+</sup> in their brains suggesting that CLN3 protein plays a role in Ca<sup>2+</sup> regulation. This project has the capacity to describe a previously unknown aspect of the disease, to highlight new functions for CLN3, and to develop new therapeutic strategies in juvenile Batten disease.

**Susan Cotman, PhD | Assistant Professor  
of Neurology  
Massachusetts General Hospital and  
Harvard University, United States  
\$235,444**



Dr Cotman's research project focuses on 2 of our 5 topic areas: 1) supporting fundamental discovery to improve and open up new approaches to treatment and 2) creating, improving, and disseminating research tools with the potential to accelerate the development of treatments for Batten disease. Dr. Cotman proposes to establish reagents and optimize methods for the detection of the endogenous (naturally-occurring) human CLN3 protein, whose absence leads to juvenile Batten disease. Furthermore, she proposes to use these and other advanced methods to define, in detail, the subcellular location and turnover of CLN3 protein in brain cells. Understanding the normal location and turnover of a protein is key to the development of rational, targeted, therapy to treat disease where that protein is missing.

**Evotec AG | Manfred Eigen Campus  
Hamburg, Germany  
\$2,200,000**



Evotec AG is a drug discovery alliance and development partnership company focused on rapidly progressing innovative product approaches with leading pharmaceutical and biotechnology companies. They operate worldwide covering all activities from target-to-clinic. Evotec is a critical part of BBDF's

portfolio validating BBDF-funded research at Texas Children's Hospital and other sites and establishing therapeutic proof of concept that derisks investments to interest pharmaceutical companies in Batten disease. Evotec has discovery alliances with Bayer, Boehringer Ingelheim, Roche, Genentech, Astra Zeneca and now, BBDF.

**Angela Schulz, MD | Clinical Expert in  
Pediatric Neurodegeneration  
University Medical Center Hamburg-  
Eppendorf, Hamburg, Germany  
\$67,804**



DEM Child is a global network (Argentina, Brazil, Denmark, Finland, France Germany, India, Israel, Italy, Japan, Netherlands, Norway, Poland, Serbia, Spain, Turkey, United Kingdom, United States) of Batten researchers and clinicians collaborating to collect and characterize the largest set of Batten patient histories. An understanding of key patient familial and disease characteristics including the natural history of the disease is critically important for the identification of biomarkers capable of measuring disease progression or response to treatment. BBDF has awarded University Medical Center Hamburg-Eppendorf with a 2 year grant to collect, share, and standardize patient information among its 18-member countries under the guidelines and direction of Dr Schulz and DEM Child's Advisory Board. Not only have researchers joined together, BBDF is working closely with Batten Disease Support and Research Association, Noah's Hope, Hope for Bridget, Batten Disease Family association and others to support this program and others in preparation for clinical trials.

**Martin Grootveld, PhD | Professor of  
Bioanalytical Chemistry and Chemical  
Pathology  
De Montfort University,  
The Gateway, Leicester, United Kingdom  
\$174,026**



BBDF awarded a grant titled "Identification of New Biomarkers for the Metabolomics Classification of Juvenile Batten Disease: A Drug-Targeting Strategy" to De Montfort University in Leicester City, United Kingdom under the direction of Drs. Martin Grootveld, Daniel Sillence, and Frances Platt of Oxford University. Together, these researchers will employ proton Nuclear Magnetic Resonance (1H NMR) Spectroscopy, a powerful method used to detect biomarkers important for measuring an individual's response to treatment. Without biomarkers, we will not be permitted to conduct clinical trials.

# UPDATES

In 2014, BBDF, together with the New York Stem Cell Foundation, (NYSCF) began the creation of the most genetically diverse collection of induced pluripotent stem (iPS) cells in juvenile Batten disease. IPS cells are produced by artificially “turning back the clock” of skin cells to a time when they were stem cell-like and capable of becoming any cell in the body. With a pharmaceutical nudge, these cells will be pushed to become, not the skin cells they once were, but brain cells. In other words, iPS cells give researchers the first opportunity to watch Batten disease develop directly in brain cells. Thus far, efforts to study Batten disease have been done using rodent models or human skin cells; neither of which accurately represents disease in the brain, leaving researchers without proper tools to study the disease or a solid platform for testing drugs that will prevent, halt, or reverse its progression. We now have cell lines available to academic and pharmaceutical investigators. By harnessing the power of technology for which the 2012 Nobel Prize in Physiology or Medicine was awarded, BBDF is disseminating research tools with the potential to accelerate the development of treatments for Batten disease

Also in 2014, BBDF, together with the New York Academy of Sciences (NYAS), hosted a “Drug Targeting the Lysosome Workshop” at the NYAS Conference Center at the World Trade Center in New York. This unique think-tank conference gathered both academic and pharmaceutical researchers who share an interest in designing safe and effective therapies that target lysosome activity to treat a wide spectrum of human diseases including lysosomal diseases like juvenile Batten disease, adult neurodegenerative diseases such as Alzheimer’s and Parkinson’s disease and cancer. The hard work of attendees during and following the workshop has led to:

- A Podcast for nonscientists available on BBDF and NYAS websites as well as iTunes.
- A Special Interest issue of the Annals of the New York Academy of Sciences. Continually published since 1823, the Annals carries a high impact factor and is available to more than 10,000 research institutes world wide.
- Interdisciplinary collaborations in Batten research funded by BBDF, the National Institutes of Health (NIH), and others.

BBDF’s award of \$1.75 million in June of 2014 to the Jan and Dan Duncan Neurological Research Institute at Texas Children’s Hospital in Houston is proving to be money well-spent. Drs Sardiello and Ballabio have advanced the work done during their \$2.5 million grant awarded in 2009 during which they discovered that TFEB can be pharmacologically activated and that doing so is beneficial to animals with lysosomal storage diseases like Batten. The addition of these funds has led to the validation of TFEB as a drug target, the screening of thousands of potential drugs, and studies in partnership with Evotec.

Dr. Tammy Kielian, a professor at the University of Nebraska, is reporting exciting efficacy and safety data from her laboratory describing intravenous gene therapy for children with juvenile Batten disease. Her work showing that gene therapy is able to improve motor and cognitive deficits in an animal model of Batten disease has led to a licensing agreement with Abeona Therapeutics with the goal of a clinical trial to begin in 2017. In April of this year, BBDF supported Dr. Kielian’s expenses to attend the British Society for Cell and Gene Therapy satellite meeting on inherited Metabolic Diseases at University College London, Institute of Child Health. Support for Dr. Kielian resulted in the opportunity to share her results with investigators and clinician scientists from around the world.

## Statement of Functional Expenses as Reported on the IRS Form 990

	Fiscal Year End 2015 audited	Fiscal Year End 2016 pending audit
<b>Revenue</b>		
Direct Contribution/Fundraising Revenue	\$1,011,861	\$2,271,230
<b>Collaborative Contribution Revenue</b>	<b>\$91,000</b>	<b>\$111,355</b>
<b>Total Revenue</b>	<b>\$1,102,861</b>	<b>\$2,382,585</b>
<b>Expense</b>		
Direct Research Services	\$1,184,343	\$1,006,639
<b>Collaborative Research Services</b>	<b>\$91,000</b>	<b>\$111,355</b>
Management/General Administrative	\$175,153	\$142,739
Fundraising	\$251,511	\$304,481
<b>Total Expense</b>	<b>\$1,702,007</b>	<b>\$1,565,214</b>





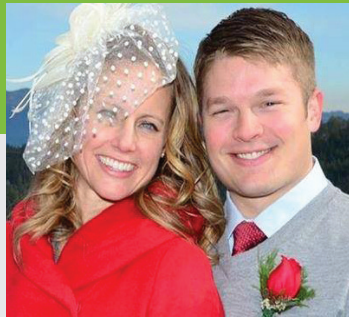
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### Zachary Killinger

Zachary passed away on December 29, 2015. With mom, Michelle, and Team Zach, he was an annual participant in Run to the Sun and we'll miss seeing his smiling face at the start line. Memorial donations in Zach's honor are funding research for a cure.

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John passed away on September 24, 2015 at the age of 24. One can't think of John without seeing his big, infectious smile and sensing his calm and peaceful demeanor. He was quick to laugh, full of love and affection. Our hearts are with Lori, Joe, Ben and the Sikorra family. Donations in memory of John are supporting research efforts to find a cure.

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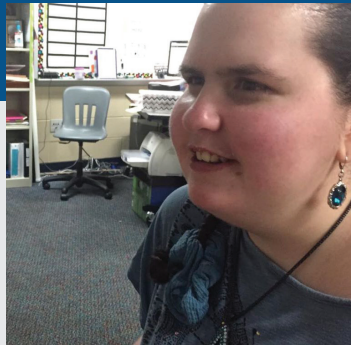
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## Be Remembered

### Rachel Watson

In August, sweet Rachel Watson passed away. The Luke & Rachel Batten Foundation has been a tireless partner in our efforts to fund research for a treatment and cure. Our thoughts and prayers are with Melinda, Sam and Luke Watson. Rachel will continue to be an inspiration to all of us.

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