

Making the  
impossible possible.



BEYOND BATTEN DISEASE  
FOUNDATION

necessary

**FAMILY, FRIENDS AND COMMUNITY**  
respond instinctively to a child in need.

**\$15.5 MILLION** over the last seven years has been invested in research by leveraging donations, co-funding and partnerships, leading to new avenues to a cure and **SIX POTENTIAL** drug compounds for treatment.

possible

impossible?

See our **STRATEGY FOR A CURE** on page 25. Today, we have more treatment options than ever before!



## DEAR FRIENDS,

**WHAT AN AMAZING CONCEPT** to be able to put a question mark after impossible. When Beyond Batten Disease Foundation was founded seven years ago, the task of finding a cure or treatments for juvenile Batten disease seemed daunting and improbable. Now more than ever before, eradicating Batten disease is a real possibility. And that is all because of your collective effort. You are making the impossible possible!

Francis of Assisi said, "Start by doing what is necessary; then do what is possible; and suddenly you are doing the impossible." This quote perfectly illustrates our success story at Beyond Batten Disease Foundation. When you heard about a child affected by this devastating disease, you did not stand idly by and accept the prognosis. Instead you did what was necessary, responding to families in need of hope, support and a cure. Because of the resounding response to do the necessary and in turn the possible, collectively we are on the brink of the impossible. Every small action from a lemonade stand to a Facebook post has played an integral role in getting us where we are today. Over the last seven years, you have enabled over \$15.5 million in funding for juvenile Batten disease research. Your support has led to six potential drug compounds, resulting in two lead candidates, as well as many new and promising avenues for treatment.

*Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible. — Saint Francis of Assisi*

This report represents the encouraging progress we have made over the last twelve months and highlights some exciting things happening in the upcoming year. Because you did what was necessary and possible, we have come a very long way in a short time. We are so grateful for your efforts to further our mission and know none of this would be possible without you. Please take a minute to read our report and don't hesitate to ask questions. With so many exciting advances happening at BBDF, I would love to share the good news and get your input. Thank you for continuing to give us hope. While we have made great strides, our fight is not over until we have a cure for Batten disease. We are on our way to making the impossible possible!

With gratitude,

Mary Beth Kiser  
President and CEO



**ON THE COVER:**  
Christiane Benson and Grace Meinzer cross the finish line at the Run to the Sun 2K, held in April 2015.

## CONTENTS

### Necessary

Leadership .....	4
Development Board.....	5
Youth Leadership Committee.....	7
Events .....	8
The Will Herndon Fund.....	10
Third Party Events.....	14

### Possible

Research .....	19
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### Impossible

Strategy .....	25
Mother's Story.....	26
Donors.....	29



BEYOND BATTEN DISEASE  
FOUNDATION

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*Founding Director*

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*Founding Director*

**Cherie Flores**

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**Jeff Hunt**

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*Board Member*

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*Principal Scientist*

**Berkley Kingman**

*Communications Manager*

**Carolyn Donovan**

*Development Manager  
of The Will Herndon Fund*

INFO@BEYONDBATTEN.ORG



necessary

# Our mission is to eradicate juvenile Batten disease.



**CHARLOTTE AND CRAIG BENSON** established Beyond Batten Disease Foundation in August 2008 after their then five-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 treatments or a cure for Will and the many children affected by Batten disease.

## 2014-15 DEVELOPMENT BOARD

**TWO YEARS AGO**, Beyond Batten Disease Foundation created the Development Board out of the necessity to sustain our momentum. Over the past two years, the Development Board has been integral to the fundraising success of the foundation. These active volunteers and community leaders are doing

what's *possible*, helping us 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 second year, this dedicated group was led by **President Kelley Daniel**.

Mr. and Mrs. Jamil Alam  
Mr. and Mrs. Wick Alexander  
Mr. and Mrs. Jarrett Anderson  
Mr. and Mrs. Chad Auler  
Dr. and Mrs. Mark Auler  
Mr. and Mrs. Craig Benson  
Mr. and Mrs. Paul Benson  
Mr. and Mrs. Danner Bethel  
Ms. Lynn Boswell and  
Mr. Burton Baldridge  
Mr. and Mrs. Jay Brown  
Ms. Sheri Bryant  
Mr. Bruce E. Butler  
Mr. and Mrs. Stephen Butter  
Mr. and Mrs. Chris Carrige  
Dr. and Mrs. Mark Chandler  
Mr. and Mrs. Randy Chupik  
Ms. Katy Copley  
Ms. Ashley Crider  
Ms. Emily Cunningham and  
Mr. Larry Chauvin  
Mr. and Mrs. Tom Daniel  
Mr. and Mrs. Bill Davenport  
Mr. and Mrs. John Daves  
Mr. and Mrs. Scott Daves  
Mr. and Mrs. Colby Denison  
Ms. Darby Denison  
Mr. and Mrs. John Donovan  
Mr. and Mrs. Kelly Dowell  
Mr. and Mrs. Marshall Durrett  
Dr. and Mrs. Drake Fason  
Mr. and Mrs. Bill Fowler  
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Mr. and Mrs. William Geisler  
Mr. and Mrs. Ben Hanson  
Mr. and Mrs. Reg Hargrove  
Mr. and Mrs. Charlie Hill IV  
Mr. and Mrs. Richard Hojel

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Ms. Diane Humphreys  
Mr. and Mrs. Jeff Hunt  
Dr. and Mrs. Kyle Janek  
Mr. and Mrs. Ross Jessup  
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Mr. and Mrs. David Middleton  
Mr. and Mrs. Kevin Nater  
Mr. and Mrs. John Nelson  
Mr. and Mrs. Chris Newton  
Mr. and Mrs. Charles Pace  
Mr. and Mrs. David Phillips  
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Ms. Elissa Watts  
Mr. and Mrs. Jamey Whitlock  
Mr. and Mrs. James Windham



Ashley Crider, Kelley Daniel, Charlotte Benson



Christopher Martin, Lance Thompson



Amber Meinzer, Laurel Hooper, Ashley Putman

# 2014-15 DEVELOPMENT BOARD



Andy and Laurel Hooper, Craig Benson



Julia Sunde, Mary Beth Kiser, Jimmy Windham



Anne Newton, Anna Hargrove



Larry Chauvin, Emily Cunningham, Sheri Bryant



Stacy Toomey, Pam Staples



June Chandler, Kristin Alexander



Jimmy Windham, Wick Alexander



Darby Denison, Clary Auler



Kristin Fason, Ann Hojel

# YOUTH LEADERSHIP COMMITTEE

**RECOGNIZING THE MANY** young philanthropists in our community, Beyond Batten Disease Foundation took the *NECESSARY* step to create the Youth Leadership Committee in October 2014. In their inaugural year, they helped us grow and get closer to finding a cure for Batten disease by hosting two exchange station and creating three teams, which raised \$13,725 for Run to the Sun.



- Mills Alexander
  - Clay Anderson
  - Chris Ault
  - Caleb Barton
  - Ellie Brumley
  - Joe Bryant
  - Ellen Campbell
  - Catherine Carrigee
  - Sarah Carrigee
  - Katie Chandler
  - Grayson Clifton
  - Francis Copley
  - George Copley
  - Steven Crider
  - Keaton Cruzcosa
  - Travis Daves
  - Carlisle Dunnam
  - Lawson Fish
  - Merritt Fish
  - Claire Gill
  - Grace Gilmour
  - Max Keliehor
- Mary Frances Kocurek
  - Will Kocurek
  - Cal Long
  - Susie McCartt
  - Sophia Menyhert
  - Carter Pace
  - John Schneider
  - Kathryn Sharplin
  - Will Snell
  - Cameron Thompson
  - Michael Toomey
  - Walker Weedon
  - Hannah Windham
  - Jack Windham



**36 KIDS FROM 7 SCHOOLS  
RAISED \$13,725**

# RUN TO THE SUN

ON APRIL 11-12, over 200 runners and 250 volunteers stayed up through the night to raise awareness and funds for juvenile Batten disease research. Our community came together in strength and numbers. More than ever before, the **5TH AND FINAL RUN TO THE SUN RELAY** showed the importance and fortitude of our community. With participants representing seven Batten families, their communities and pharmaceutical company BioMarin,

the event illustrated the power of partnership and team work. Runners were cheered on by the 16 exchange stations along the way, which ranged from a fiesta to a Cajun cookout. The 90-mile relay ended with a sunrise celebration and 2K at Camp Mabry. Over 100 2K runners joined in the morning to show their support by participating in the carnival and run. Together, we raised over \$1.6 million in the five years of Run to the Sun.



Mike Rosenthal readies the start line at the kids' 2K Fun Run.



Jimmy and Jack Windham



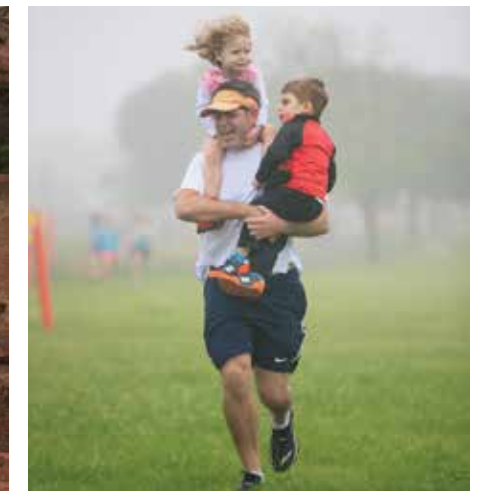
Bailey Cartwright



Team Live Like Ross



Team Maroon



Mark and Shelby Auler with Crawford Rogers

# HOPE COMMITTEE



**SIX YEARS AGO**, over 80 women came together, pledging their *necessary* support to the Herndon family in the wake of Will's devastating juvenile Batten disease diagnosis. They planned the first HOPE Under the Stars with a zero dollar budget, collecting all *possible* donations from everyone they could ask. That event generated \$220,000 and set The Will Herndon Fund into motion. Since then, this group of 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  
Inger Berger  
Angie Blake  
Ashley Boudreaux  
Pam Bryan  
Bridget Buck  
Jennifer Bulovas  
Jessica Catani  
Marilou Catani  
Elvira Cauthen  
Misty Clow  
Julie Comeaux  
Krista Cook  
Jennifer Coyle  
Kathy Croom  
Alexa Currie  
Mary-Kathryn D'Agostino  
Nikki De Boer  
Julia Dell  
Colleen Dippel  
Carol Durkee  
Johnna Edone  
Chrissie Elmendorf  
Arlene English

Haley Garcia  
Angela Gibbs  
Emily Gogineni  
Natalie Greene  
Jennifer Grigsby  
DeAnn Guidry  
Dina Hafley  
Paige Halberdier  
Tracy Halverson  
Kecia Haseman  
Alison Henderson  
Michelle Hewgley  
Jennifer Hiser  
Audra Hoegemeyer  
Rachel Honeyman  
Colbie Hubenak  
Jennie Hughes  
Polly Hunt  
Lauren Hunter  
Noelle Jahncke  
Janine Jones  
Alison Judge  
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  
Kimberley Lee  
Nancy Decker Lent  
Julia Lile  
Denise Lipar  
Kelly 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 Muehsler  
Nicole Murphy  
Sarah Nanick  
Emily O'Shaughnessy  
Claire Orewiler  
Julie Perugini

Pat Sanders  
Stacey Schexnaildre  
Tammy Schroder  
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  
Heather Webster  
Yvette Williams  
Cheri Young  
Amy Young

# HOPE UNDER THE STARS

**IN SEPTEMBER 2014**, HOPE Under the Stars raised over \$575,000 for Batten research. With 850 in attendance, the 6th annual event was the most successful night to date. Missy Herndon provided a comprehensive research update, allowing supporters to see first-hand what they made *possible*.

From Texas Hold 'Em to music by the Bucktown All-Stars, the event had entertainment galore. Most importantly, all in attendance were provided with HOPE and supported our *necessary* efforts to find a cure for Will, Christiane and hundreds of children affected by Batten disease.



Scott Young, Will Murphy, Corey Gibbs, Chris D'Agostino



Meredith Sipko, Heather Weiss, Tara Wheeler, Julie Warrington, Tiffany McClurb



Missy, Will and Wayne Herndon



Wayne and Missy Herndon, Dr. Antonella Pignata, Dr. Marco Sardiello, Charlotte and Craig Benson

# HOPE ON THE GREEN

**ON APRIL 20TH**, The Will Herndon Fund hosted its 6th annual golf tournament, HOPE on the Green, at The Woodlands Country Club Palmer Course. With 52 sponsors, 210 players and 50 volunteers, HOPE had its most successful tournament to date, helping make

the *impossible possible*. With a helicopter ball drop and an outfit competition, the event was filled with spirit and HOPE and raised over \$125,000.



Hope Ladies and Will Herndon



**52 SPONSORS + 210 GOLFERS + 50 VOLUNTEERS**

**\$125,000 IN REVENUE**

# THE WOODLANDS MARATHON

**THE WILL HERNDON RESEARCH FUND** at Beyond Batten Disease Foundation was chosen as a spotlight charity of The Woodlands Marathon Series by Fleet Feet Sports. Training began at the Warrior Run & Rally in January, sponsored by Jo Anne Johnson & Associates. On race day, Warriors participated in the Family 2k,

5k, half and full marathons, raising over \$14,000 in honor of Will. As part of her quest to run a race in all 50 states raising awareness of Batten disease, special guest Laura King Edwards of Taylor's Tale ran the half marathon for Will and her sister, Taylor. Thank you for **RUNNING on WILL POWER!**



Missy Herndon, Lindsey Perkins of Fleet Feet Sports, Will Herndon and Jo Anne Johnson of Jo Anne Johnson & Associates



Jake Lile and Steele Herndon



HOPE supporters gather at The Warrior Run and Rally



# THIRD PARTY EVENTS

**BBDF'S ADVOCATES** span the globe. We are grateful for the many supporters who take it upon themselves to do what's *possible*, hosting events in their communities and raising funds for research. Using their talents and integrating Batten disease awareness into their runs, parties and more, they are helping us accomplish our mission of curing Batten disease.

## CASIS FOR CHRISTIANE

**PARENTS AND TEACHERS** from Casis Elementary have done what's *necessary* to provide support and encourage Christiane by creating new learning opportunities for her to thrive. Over the last seven years, they have spread awareness and raised funds for juvenile Batten disease research. In preparation for Run to the Sun, Team Casis for Christiane hosted a party at Tom's in South Austin. The team has participated all five years, hosting events leading up to the relay and **RAISING OVER \$109,600**.



David and Ali Phillips



Team Casis for Christiane



## BATTLIN' BATTEN IN BAFFIN

This year's Battlin' Batten in Baffin Fishing Tournament **RAISED OVER \$30,000**, bringing the total raised since 2009 to more than \$150,000. Thank you to **Neal Meinzer**, who has graciously hosted this third party fundraiser for seven years. Pictured is this year's winning team: Jim Arnold, Kelly Dwyer, Baron Unbehagen, and Len Wright.



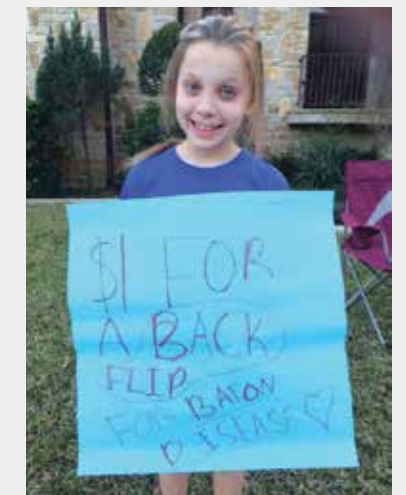
## WHOLE FOODS PREVIEW NIGHT

The Will Herndon Fund was honored at The Woodlands Whole Foods Market Preview Party. Attendees visited the new store while supporting HOPE, **RAISING OVER \$5,000**.



## FACULTY FOLLIES

**Mitchell Intermediate School** produced their first ever Faculty Follies in support of The Will Herndon Fund last spring. The event **RAISED OVER \$8,000** and showcased the faculty, staff and students' knack for comedic timing, as well as their talented artistic skills and genuine love for their fellow Mustang, Will.



## BACKFLIPS FOR BATTEN

In preparation for Run to the Sun, **Quincy Alam** created her very own fundraiser doing backflips for Batten in her front yard. Not only did she help raise awareness, she provided hope to her friend, Christiane.



### #BEATBATTEN CARNIVAL

In February, the HOSA club at **Buchholz High School** in Gainesville, FL, hosted a carnival to raise research funds for BBDF. They were able to **RAISE OVER \$2,000** for our cause.



### MIGHTY LIKE A ROSE

Moved by the Benson's story and the foundation's work, **John Edson** wanted to help spread awareness. Turning to what he knows best, music, John gathered some of Austin's finest musicians, including **Emily Gimble** and **Floyd Domino** to record his family's favorite lullaby, "Mighty Like a Rose" and made it available for download on CD Baby, iTunes, and Amazon. All sale proceeds benefit BBDF and our efforts to find a cure. Thank you John and Mary Ann Edson for sharing your talents to help fight Batten disease!



### BIRDIES FOR BATTEN

Through the American Junior Golf Association's program Birdies for Charity, Austin High golfer **Will Ezell** **RAISED OVER \$4000** for juvenile Batten disease research. Birdies for Charity allows junior golfers to pick a charity important to them. They then secure one-time donations and pledges for the amount of birdies they have in any tournament where the USGA rules of golf apply. Will unselfishly combines his passion for golf with giving back to the community.



### AUSTIN HIGH GLOBAL STUDIES

Austin High students **Maddie Durrett**, **Sarah Wells**, and **Drew Beathard** chose to study Batten disease for their Global Studies capstone project. Through meetings with BBDF staff and doing their own research, they were able to learn about the disease and help us spread awareness. They also gathered their classmates for a Run to the Sun exchange station. Thank you for helping us envision a world beyond Batten.



### BRACELETS FOR BATTEN

**Marissa Gamel** and **Melanie Kocurek** made rainbow loom bracelets and sold them to raise money for Batten disease research. They **RAISED \$32** and helped spread awareness.



### CUT FOR A CAUSE

In October, **HairCrafters** in South Bend, Indiana, hosted their 18th Annual Cut for a Cause. Choosing Team Tyler as the beneficiary, the salon provided blue extensions, haircuts and braids in exchange for a donation in honor of Tyler Allman.

possible

# The impact of BBDF...

This year:

**\$1.8 MILLION**  
FOR BATTEN DISEASE  
RESEARCH

We spent **\$1.1 MILLION** on research in 2014-2015. And, leveraged **\$698,000** more through partnerships and cofunding. Totaling almost **\$1.8 MILLION** for Batten disease research this year.

Over the past seven years **\$15.5 MILLION** has been invested in research by leveraging donations, co-funding and partnerships. Leading to new avenues for treatments or a cure and **SIX POTENTIAL** drug compounds for treatment. With a comprehensive strategy to advance all potential treatments and supporting projects, we are preparing for clinical trial success.

Over the past  
seven years:

**\$15.5 MILLION**  
FOR BATTEN DISEASE  
RESEARCH

## RESEARCH



Danielle Kerkovich, PhD  
BBDF Principal Scientist

**WHEN THE FOUNDATION** was created, there was little on the horizon to treat juvenile Batten disease. Today, we are advancing the development of six potential drug compounds and have determined our two lead candidates. To prepare for clinical trial success, we are simultaneously supporting the coordination of international patient registries.

Additionally, we are providing Batten-specific resources to individual investigators as well as to the Pharmaceutical Industry to explore the potential of new discoveries to treat juvenile Batten disease. Our research strategy brings together all stakeholders, including affected families, like-minded foundations, and other neurodegenerative disease groups. BBDF Principal Scientist Danielle Kerkovich, PhD, together with experts in all levels of drug discovery and approval, continues to lead and manage our comprehensive research strategy to ensure that we stay on track. With their *necessary* guidance and your support, we are doing the *possible* and building a structure that funnels promising findings into new medicine for clinical trials until we are suddenly doing the *impossible* and curing juvenile Batten disease.



"Exciting novel approaches to drug discovery could mean that treatments for JNCL are just around the corner." – Liora Braiman-Wiksmann, PhD, CEO of XoNovo Ltd, developer of small molecule drugs to treat JNCL



**6** DRUG  
COMPOUNDS  
EVALUATED



**2** LEAD  
CANDIDATES

### BBDF PARTNERS WITH EVOTEC TO GET CLOSER TO FDA APPROVAL

**BEYOND BATTEN DISEASE FOUNDATION** funded Evotec, a specialized contract research organization, to evaluate the six potential drug compounds discovered at Texas Children's Hospital and they have identified **TWO LEAD CANDIDATES** to advance to validation studies. They now have a two-year plan to validate those compounds and, if successful, advance an application to FDA for approval of clinical trials.



## PATIENT REGISTRY – PREPARING FOR CLINICAL TRIAL SUCCESS

**BBDF RECEIVED A PEER AWARD** from Genetic Alliance for our registry efforts. PEER enables individuals to share health information with researchers and each other on their own terms to advance an understanding of health and disease and to accelerate the development of criteria for clinical trials. A patient registry is a collection of standardized information about a group of patients who share a condition. Currently, there is not one single, standardized registry for juvenile Batten disease; instead, there are multiple registries around the globe. While these programs have led to increased understanding of Batten

disease, each one records unique information associated with only a small number of patients. There is a critical need for cooperative infrastructure and standardized practices in measurements, recording and other practices. By standardizing and coalescing available clinical information, researchers will accelerate innovation, produce faster knowledge gains, and present pharmaceutical companies with much-needed, high-impact, statistically significant information. BBDF is coordinating information across multiple registries and clinical sites in support of individual and group research efforts.

“Recent breakthroughs in treating the Late Infantile form of Batten disease give us experience, tools and hope for developing treatments of other forms of Batten disease, including CLN3.”

– Chuck O’Neill, PhD, Vice President, Pharmacological Sciences, BioMarin Pharmaceutical Inc.

While **40%** OF SCIENTIFIC PEER REVIEWED ARTICLES are never cited, by 2015 BBDF-funded research has been published **18 TIMES** and cited **1500+ TIMES**.



Craig Benson

## CRAIG JOINS THE NRI INTERNATIONAL ADVISORY BOARD

Beyond Batten Disease Foundation is pleased to announce **Craig Benson’s** appointment to the International Advisory Board at the Jan and Dan Duncan Neurological Research Institute (NRI) at Texas Children’s Hospital. Consistent with BBDF’s strategy and goals to connect our research with top-ranked institutions, Craig is eager to join the NRI in its mission.

With the promising research happening not only in Batten disease but also other neurodegenerative diseases, Craig is excited to serve in an advisory capacity at the NRI. Joining Nancy Chang, Albert Chao, Robert Graham, Prisca Chen Marvin, Anthony Petrello, Charif Souki, and chair Michael Wilsey, Craig will bring his experience and dedication to the board.

## BBDF HOST WORLD-RENOWNED SCIENTIFIC EXPERTS TO FOCUS ON BATTEN

**IN OCTOBER 2014**, Beyond Batten Disease Foundation and the New York Academy of Sciences brought together over 55 research leaders from multiple diseases, like Cancer, Parkinson’s and Alzheimer’s, to collaborate and focus their efforts and expertise on juvenile Batten disease. At the “Drug Targeting the

Lysosome Workshop,” which was held at the NYAS Conference Center at the World Trade Center, both academic and pharmaceutical researchers discussed how to work together towards common goals. There were many action items resulting from the meeting as well as an accessible and educational podcast.



Attendees at the Drug Targeting the Lysosome Workshop.

**55** WORLD RENOWNED RESEARCHERS

REPRESENTING **9** COUNTRIES

CONNECTING **17** DISEASES

**FOCUSED ON JUVENILE BATTEN DISEASE**

# ONGOING RESEARCH PROJECTS

**BEYOND BATTEN DISEASE FOUNDATION** funds many multi-year projects. At any given time, BBDF's principal scientist is managing over 35 projects at various stages on the drug discovery pipeline from academic tools and scientific resources for Batten research to advancing new discoveries.



## FURTHERING RESEARCH AT TEXAS CHILDREN'S HOSPITAL

**LAST YEAR,** Beyond Batten Disease Foundation awarded a **\$1.75 MILLION GRANT** over three years to the Jan and Dan Duncan Neurological Research Institute at Texas Children's Hospital in Houston to explore whether the pharmacological activation of TFEB can be used to activate the lysosomal system, promote cellular clearance and slow disease progression. Building off the \$2.5 million award from Cherie and Jim Flores and Beyond Batten Disease Foundation in 2008, Drs. Ballabio and Sardiello continue to make significant strides in juvenile Batten disease research. This research led to our two leading drug compounds.



Garland and Christiane Benson visiting Dr. Marco Sardiello's laboratory at NRI.

## STEM CELLS FOR RESEARCH

**BEYOND BATTEN DISEASE FOUNDATION** is funding the creation of the largest and most genetically diverse collection of induced pluripotent stem (iPS) cells in juvenile Batten disease. iPS cells are produced by reprogramming skin cells into brain cells. In other words, iPS cells will give researchers the first opportunity to watch juvenile Batten disease develop directly in human brain cells. Beyond Batten Disease Foundation collected the samples needed to complete the collection at the Batten Disease Support and Research Association's Annual Family Conference.

impossible?

# Finding a treatment or cure...

## BBDF RESEARCH IMPACT

ONE YEAR AGO	TODAY
<b>3</b> drug compounds under consideration	<b>6</b> drug compound options evaluated by industry partner Evotec and 2 lead candidates chosen for treatment
<b>0</b> pharmaceutical companies with programs in Batten disease	<b>3</b> pharmaceutical companies with active programs or programs under development
<b>0</b> large-scale, genetically-diverse Batten human brain cell platform for discovery and drug testing	<b>1</b> large-scale, genetically-diverse Batten human brain cell platform for testing drug safety and efficacy
<b>1</b> promising approach to treatment for juvenile Batten disease	<b>4</b> promising approaches for treatment and possibly a cure

impossible?

## RESEARCH STRATEGY

**BECAUSE YOU** have responded to what is *necessary* and done what is *possible*, we are positioning ourselves to accomplish the *impossible*. Science is moving at an incredibly rapid pace, and BBDF is doing everything it can to harness the potential of new discoveries and apply them to Batten disease. Many of the things we thought were impossible seven years ago have been accomplished. As we look forward, we see possibilities where before there were none. Truly, scientific progress provides a solid basis for our hope for the future.



**“New technologies appearing in just the last 10 years may make the impossible, possible.”**

– *Michelle Hastings, PhD, creator of antisense and exon-skipping drugs for CLN3 disease, is working with corporate and private sponsors to develop this approach as a treatment for JNCL.*

**TO CONTINUE** our quest to make the *necessary possible*, our strategy is to:

- Discover new drug targets** and medicines for treating Batten
- Pursue new avenues** of research with potential for a cure
- Validate all existing and emerging discoveries** according to pharmaceutical industry standards
- Establish resources**, gather expertise and meet the criteria necessary to receive permission from the FDA to conduct clinical trials

However, success comes at a price. As we move through these steps collecting data needed to attract industry partners willing to support clinical trials, the process will become more and more expensive. **Due to this, our need for funding is going to increase.**

### OUR FOCUS AND CRITICAL FUNDING NEEDS OVER THE NEXT 12 MONTHS ARE:

- Validate two of six lead drug compounds and prepare for FDA approval to conduct clinical trials
- Develop tools, such as biomarkers and animal models for continued understanding of juvenile Batten disease and the identification of new medicines to treat the disease
- Complete development of the human brain cell platform with NYSCF
- Coordinate international patient registries to prepare for clinical trials in Batten disease
- Advance newly discovered approaches to treating Batten

**We believe we can make the impossible possible.** Stay with us as we bring you more exciting news on our programs, as well as those of our colleagues and partners.

# A MOTHER'S STORY by CHARLOTTE BENSON

## Possible

Have you ever wondered if you are relevant, significant, or if anything you do really matters? Sometimes I get moving so fast, occupied with my daily activities, and whirling in a million directions, that I wonder at the end of the day, if any of it really mattered...does anything I do count?

I received a card in the mail the other day from Whitney, a childhood friend, and the cover read:

*"Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible."*

— Saint Francis of Assisi

That gave me pause for reflection because certainly Craig and I know that Beyond Batten Disease Foundation was created by a "necessary" response to give hope to our child, Christiane. What came next was the "possible" with the creation of the foundation and the extraordinary contributions of our friends and community. While our destination is certainly to accomplish the "impossible," what's striking to me is how amplified that concept becomes when an entire community is simultaneously contributing to that phenomena.

I never think of what I do in a day being amplified by what someone else may be doing while whirling through their day. I never think about how my seemingly small accomplishments may be contributing to a bigger picture and perhaps an incredible feat.

What a notion! When you have multiple people doing what is necessary, then doing what is possible, suddenly you have the collective potential to do the impossible.

Not only has that been the case with our foundation and its mission, but most

**What started as a response to do what is necessary has become a beautiful picture of what is possible, and now the child we thought would never learn to read has accomplished what we once thought to be impossible.**

recently, I have seen that same principle manifest itself in the culture surrounding Christiane. Batten disease is a neurodegenerative condition that causes seizures, blindness, cognitive and physical decline and is terminal by the late teens or early 20s. There is currently no medical treatment or cure. What could one person possibly do to make that diagnosis better? You might not think there is much, but when you see the collective effort of individual people responding simply to a necessity by doing what is possible, you begin to then see what is nothing short of a miracle.

A couple of weeks ago, we had Christiane's annual visit with her ophthalmologist to assess her vision and see what changes have occurred. Last year, we received the very good news that Christiane's vision had only decreased marginally in one eye and this year her vision was virtually unchanged since last year! This is more than we could have possibly hoped for. When I told the doctor about the nutritional supplements we give Christiane, she said that she never sees this sort of stabilization in Batten patients and then she asked who our nutritionist was. I could hardly wait to call Richard Abdo, our nutritionist, and tell him the good news. He has done a phenomenal job addressing the effects of Batten disease through Christiane's diet and supplementation. Richard has never had another patient with Batten disease, but applies what he does know about nutritional support for her

brain based on other neurodegenerative conditions he has treated. Just by knowing what is necessary and doing what is possible, he is making an indelible impact on Christiane's life by improving and extending her quality of life.

In addition to the support Christiane is getting nutritionally, she is surrounded by an incredible Special Education team, family friends, tutors and teachers of all sorts who encourage her learning and create new opportunities for her to thrive, by simply doing what they know to be possible. They are fluid and flexible and willing to explore the impossible with every challenge Christiane faces.

As Christiane began losing her vision, my dear friend Cherie sent her a Nook, which is an audio device that reads books aloud. The intent was for her to learn through reading without having to struggle to see through one spot in her left eye and be challenged phonetically by every word. As her vision declined, we removed the academic goal through Special Education for her to read in a conventional way and became solely focused on her ability to learn. Two mothers and a team of teachers responded by simply knowing what was necessary and then doing what was possible. Once we allowed all of her reading to be accessed audibly, her learning skyrocketed. At the beginning of this year, Christiane was assessed on a 4th grade level for vocabulary and reading comprehension. Just last week she was re-assessed and has now elevated to an 8th

grade level even though she is only in 6th grade! What started as a response to do what is necessary has become a beautiful picture of what is possible, and now the child we thought would never learn to read has accomplished what we once thought to be impossible.

I always thought that playing the piano would be a great tool and a natural place for Christiane to explore through touch and sound and have the opportunity to express herself through music. We found the perfect teacher, but after many lessons, Christiane began to refuse practicing, digging her heels in and absolutely refusing every attempt I made to try to help her learn her assignments. I don't quit easily, but I finally surrendered with a phone call to her teacher saying that I thought it was time to give up on piano as all of my efforts to encourage her to play seemed to be in vain.

To my surprise, her teacher, Mrs. McHorse, so sweetly but firmly said, "Well, we just need to try something else..... but she can't quit." Those words, "she can't quit" echoed like music to my ears and I thought, "I love this woman; she's got gumption and a whole repertoire of possible." For the next couple of weeks, Mrs. McHorse came to our house to add an extra lesson. Slowly, but surely, Christiane came around and began enjoying playing the piano and now takes pride in performing for her grandparents.

I believe that music is wonderfully enriching for the brain and the combination of all these activities are helping Christiane thrive by staying engaged in a multitude of ways.

I am awed by how a simple collection of people, doing simple every-day tasks, can have a monumental collective effect on my child. I wonder if any of them ever doubt at

the end of a hard day, if anything they do matters or counts? I wonder if they ever get lost in the mundane decisions, minutiae and ordinary tasks of a day and ponder whether or not they are significant or relevant. All of these people contribute because they recognize what is necessary for a child who



Christiane Benson

has special needs. Individually, a group of people, who don't even know each other, simply do what they know to be possible and are unknowingly making an impossible difference in Christiane's life.

I am inspired by their devotion, and now remind myself that although my ordinary daily routines at times seem fruitless, I must continue to do what is necessary, no matter how small, and do what is possible. There

is also a new appreciation that I am only a small part of a much bigger picture, and there is purpose to my seemingly routine activities. After all, the simple act of a friend sending a card has inspired and created a new awareness for me, and perhaps now also for you. And, what's more, through Christiane's own belief in what is possible, I find myself taken by her confidence and belief that anything is possible.

Last month, Christiane came home from school and pulled out a yellow sheet of paper from her backpack announcing that she was going to try out for cheerleader. I wasn't completely sure how that would work out for a kid with very little vision, but she had her sights firmly set on those pom-poms and short skirt and absolutely no interest in conversations about possible disappointment should it not work out. She never wavered in her decision, so despite any reservations that I had, we encouraged her to follow her dreams. For the next two weeks, she spent every day after school practicing her sideline chant and cheer. She told me that the coach told her that she could just clap in parts if she got stuck during try outs and that was going to be her trick to persevere through any difficulty.

The announcement day finally arrived and Christiane had, in fact, made cheerleader. The excitement in her twinkling eyes and her contagious broadening smile as she heard the good news will be treasured among my favorite memories. We were delighted for her of course, but mostly inspired by her own belief in what was possible.

And, after it was all over, I couldn't help but ask: "Christiane, what would you have done if you hadn't made cheerleader?" She looked up at me and dryly said "hmm.....probably golf. Have you ever seen me hit a 7 iron?"

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-Christiane

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 necessary; then do what’s



possible;  
 and suddenly  
 you are  
 doing the  
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— Saint Francis of Assisi





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