



# Jenyis REPORT

**Genius:** Someone who is dazzlingly skilled in any field



"I am"

by Christiane Benson  
3rd grade assignment

Christiane

an animal  
Lover

I funny.  
I am

Sibling of Garland

I am Jenny's



*Christiane believes in her own J<sup>E</sup>nyis . We want to recognize yours. Your talent, creativity, generosity – your unique genius – is what created and propelled the foundation. This report reflects the cumulative J<sup>E</sup>nyis of our community. Thank you!*



Dear Friends,

As Beyond Batten Disease Foundation celebrates its fifth anniversary, we are taking this opportunity to reflect on our accomplishments and celebrate our progress. We also want to recognize you, our friends and supporters, who have made our success possible.

As we enter the next phase in the life of the foundation, we want to acknowledge how far we have come in a very short time and provide an update on the research and discoveries your contributions have funded. Inside this comprehensive progress report you will find highlights of some of our proudest accomplishments from the past five years. Your donations are being thoughtfully and carefully spent on promising research and are being leveraged through collaborations and partnerships to secure more funding for our strategic research plan. Where little was known about the disease before, there are now incredible developments, insights and discoveries happening every day. Because of your J<sup>E</sup>nyis we have hope. We will continue to build on these milestones until we have a cure.

Our goal is that the work we are doing and the success we are having honors your involvement and that you will continue to support the foundation. Congratulations and Happy Anniversary BBDF! Here's to another great year.

All the best,

*Mary Beth Kiser*

Mary Beth Kiser  
President and CEO



## WHAT IS BATTEN DISEASE?

Juvenile Batten disease, also known as Juvenile Neuronal Ceroid Lipofuscinoses (JNCL), is a rare, fatal, inherited disorder of the nervous system that begins in childhood. The condition initially causes blindness and seizures, progressively impairs mental and physical capacities, and then ultimately results in death during the late teens or 20s.<sup>17</sup>

## OUR MISSION

Beyond Batten Disease Foundation (BBDF) was established to eradicate Batten disease. We seek to accomplish our mission in two ways:

1. Diagnosis and Prevention: Develop and commercialize an easy and inexpensive blood test to detect mistakes in the DNA that lead to Batten and hundreds of other rare, devastating, genetic diseases that claim the lives of thousands of children each year.
2. Treatment and Cure: Raise awareness and money to accelerate research to create treatments and to find a cure for Batten disease.



The Benson family

## THE PROBLEM

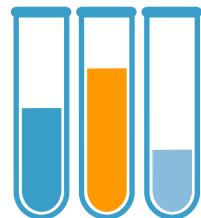
On average it takes \$1.3 billion dollars and 12 years to shuttle basic science discovery down the drug development pipeline to a clinical trial. Very few medical research groups have had success and rare diseases are not getting cured. This is due in large part to a lack of funding, infrastructure and resources.

## OUR JENY'S PLAN

In an effort to overcome obstacles that have hampered other organizations, the foundation took a critical look at the best practices of nonprofit groups that are successfully finding treatments, and discovered six key elements of success.

We have developed a comprehensive research strategy that incorporates all six key elements of success that informs everything we do. Our efforts have increased the average grant for Batten disease research from \$40,000 to \$100,000, raising awareness of and interest in the disease. We have implemented a thoughtful, deliberate and strategic approach to funding research. We have instituted an objective review process to ensure that all grants have potential for treatments. By hiring experts, consulting and collaborating with like-minded groups such as the American Academy of Neurology, other neurodegenerative disease foundations, and other Batten families, we are pooling the resources and funding necessary to drive treatment-based research. For us, there will only be one clear measure of success: providing treatments and a cure for Batten disease.

**Our efforts have increased  
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## 6 KEY ELEMENTS OF A JENY'S STRATEGY

1. **Raise the standards of university based drug target research**
2. **Invest in drug discovery**
3. **Incorporate cutting-edge methods and create platform technologies**

4. **Strategic placement of funds to initiate research growth capable of leveraging MAJOR funding**
5. **Access to experts across the continuum in each step of the drug development pipeline**
6. **Partner, partner, partner**

## THE PROGRESS OF Jeny's

When the foundation was created in 2008, there was still very little known about JNCL. Juvenile Batten disease was first described over 180 years before, but because rare disease research is woefully underfunded, the gene causing the mutation wasn't discovered until 1995.<sup>14,15</sup> With no known treatment and no cure, the path ahead looked long and bleak. Thanks to your continued support and generous contributions we were never alone on our journey. With your help, the foundation has made great progress toward our goal of eradicating Batten disease. Here are just a few of our proudest accomplishments from our first five years:

### 2008

- Charlotte and Craig Benson establish the foundation after their then five-year-old daughter, Christiane, is diagnosed with juvenile Batten disease. Craig, who works in the world of science and medical research, has colleagues with relationships all over the world. He and his network are in a unique position to do something. BBDF will serve as a vehicle to raise the funds necessary to support the research essential to ending this condition.
- Dr. Mark Chandler, Chairman and CEO of Biophysical Corporation, and Dr. Kyle Janek, Executive Commissioner of Texas Health and Human Services Commission, join the BBDF board as founding directors.
- World-renowned Italian researcher Andrea Ballabio, MD, PhD, Marco Sardiello, PhD, and their colleagues discover a genetic program that controls the functions of lysosomes, the cell's recycling centers that are damaged in JNCL.<sup>16</sup>



## MEET OUR BOARD Jeny's



Mark B. Chandler, PhD  
BBDF Founding Director  
Chairman and Chief  
Executive Officer,  
Biophysical Corporation

Forbes Magazine named Dr. Chandler the "Indiana Jones" of medical research in a 1994 article that examined his search through jungles in Southeast Asia and South America for deadly toxins that became cutting-edge treatments for cancer. In 1982, he founded Inland Laboratories Inc. to provide plant and bacterial toxins to the medical research community. As president and chief executive officer of Inland, Dr. Chandler received the KPMG High Technology Entrepreneur of the Year award in 1987. Following the success of Inland Laboratories, Dr. Chandler channeled his interest in discovering new methods to evaluate blood-based biomarkers as important health indicators to found three successive companies to develop innovative biological testing technologies, primarily for academic and pharmaceutical research. In 1995, he co-founded Luminex Corporation (NASDAQ: LMNX), a company that develops, manufactures and markets innovative biological technologies to clinical researchers. Dr. Chandler served as chairman of the board and chief executive officer of Luminex until 2002. He founded Rules-Based Medicine, Inc. in 1998 to further identify and develop multi-analyte testing protocols, where he continues to serve as founding director. Dr. Chandler now leads Biophysical Corporation as chairman and CEO to make this testing directly available to consumers and physicians.

Dr. Chandler received his doctorate in immunology from the University of Texas Southwestern Medical School in Dallas, Texas. He serves on the Board of the East-West Institute, the National Center for Genome Resources, and is a fellow of the New York-based Explorer's Club.

**2009**

- February 28, 2009 is named Batten and Rare Disease Day by Texas Governor Rick Perry.

# OVER 90%

of foundations never make  
it to the \$1 million mark  
necessary for real and  
permanent change.



- **Giving J<sup>E</sup>nny's**: Cherie and Jim Flores donate **\$2 million**, the biggest gift in Batten disease research history, and BBDF contributes \$500,000 to establish laboratories for Drs. Ballabio, Sardiello and their colleagues at the Jan and Dan Duncan Neurological Research Institute of Texas Children's Hospital.
- Missy and Wayne Herndon establish the Will Herndon Fund at Beyond Batten Disease Foundation to join forces to raise funds for a cure after their son, Will, is diagnosed with JNCL.



The Herndon family

- Craig Benson joins the board of Batten Disease Research and Support Association (BDSRA) to promote partnerships and further collaboration efforts with affected Batten families.

## MEET OUR BOARD J<sup>E</sup>nny's



Kyle Janek, MD  
BBDF Founding Director  
Executive Commissioner,  
Texas Health and Human  
Services Commission

Dr. Kyle Janek was appointed Texas Health and Human Services executive commissioner on Sept. 1, 2012, by Gov. Rick Perry. As head of the Texas Health and Human Services Commission, Dr. Janek provides leadership and strategic direction to the health and human services system in Texas. The executive commissioner oversees the operations of the five health and human services agencies, including more than 56,000 employees and combined annual budgets of \$30 billion, serving more than 4 million Texans.

A lifelong Texan, Dr. Janek was born and raised in Galveston. Kyle served as a Texas lawmaker from 1995 to 2008. After eight years in the Texas House of Representatives, he was elected to the Texas Senate in 2003. During his tenure, Dr. Janek juggled a broad range of responsibilities, including the Committees on Finance, Business and Commerce, Education and Health and Human Services. Most recently, he was chairman of the Senate Subcommittee on Emerging Technologies and Economic Development.

Dr. Janek received a bachelor's degree and graduated magna cum laude from Texas A&M University in 1980. He went back to his hometown to attend medical school at the University of Texas Medical Branch in Galveston. After earning his medical degree, he took a residency in anesthesiology at UTMB, where he served as chief resident his final year. A board-certified anesthesiologist, Dr. Janek has been in private practice since 1986.

Dr. Janek has been a sponsor of medical missions to Central America and has been an active sponsor of numerous civic and community organizations. He and his wife, Shannon, live in Austin and are the proud parents of three sons.

# 95%

of medical research foundations in the U.S. lack full-time scientific leadership.



- Meet our Scientific Jenny's : BBDF hires full-time neurobiologist, Danielle M. Kerkovich, PhD, to determine the "State of Science," a comprehensive repository of JNCL research studies throughout history. By identifying gaps in our understanding she is able to design a plan for clinical trials that starts with the most promising research available and avoids repeating past efforts.
- The foundation, in partnership with the Alzheimer's Drug Discovery Foundation, BDSRA, and NCL-Stiftung sponsors a conference focused exclusively on drug discovery in Batten disease. This meeting forges new collaborations between academic scientists and drug discovery experts who turn research findings into therapy.<sup>17</sup>

## 2010 - 2011

- BBDF hosts the inaugural Run to the Sun Relay. The event was inspired by Lance Thompson, who continues to chair the relay annually. His dedication and support allow the event to be an ongoing fund-raising success, raising almost \$700,000 in donations.



Run to the Sun Chair Lance Thompson with Christiane

- The foundation delivers a grant to King's College London researchers to explore new drug targets that improve brain function in JNCL.

## 2012

- BBDF, in partnership with BDSRA, designs a state of the art scientific merit review process utilizing objective experts that ensure every research grant proposal we fund includes the potential for drug treatments.
- The foundation hosts Date Night with Keith Urban, bringing international exposure and raising over \$800,000 in donations.



Date Night Co-chairs Shannon Janek and Sabrina Brown with Keith Urban

- The Will Herndon Fund and their community in The Woodlands, Texas raises over \$1 million for Batten disease research.



Will Herndon Fund Hope Volunteers with Will

***"The American Brain Foundation is honored to co-sponsor the 2013 Clinical Research Training Fellowship in Juvenile Neuronal Ceroid Lipofuscinosis with Beyond Batten Disease Foundation. By leveraging collaborations with other foundations to support the careers of promising young researchers, Beyond Batten Disease Foundation is using its energies and resources to have the greatest possible impact on research that will improve the treatment of patients with Batten disease."***

*— Dr. Robert Griggs, Chair of the American Brain Foundation Research Committee*

**2013**

- The foundation hires Mary Beth Kiser as executive director to lead the organization.
- Preliminary data made possible by BBDF funding leads to multiple additional grants totaling over \$3.2 million for Batten disease research.
- The foundation's scientific merit and translational review process leads to almost \$2.1 million in collaborative research funding from Ireland, Great Britain, Germany, Finland, Belgium, Australia, Denmark and the US.

**Research discoveries  
funded by BBDF result in**

**\$25 million**

**in additional funding from  
pharmaceutical companies  
for other diseases,  
enhancing the global  
effort to cure rare disease.**



- Beyond Batten Disease Foundation, the Alzheimer's Drug Discovery Foundation and the National MS Society collaborate to support the creation of a shared repository between 11 drug discovery centers. This gives Batten researchers access to thousands of neurological drug compounds to test for efficacy in JNCL, saving millions of dollars and precious time in the drug development process.
- Jeff Hunt and Cherie Flores join the BBDF board.
- The board conducts a strategic planning session, utilizing community stakeholder input, to determine the trajectory of the foundation over the next 3 to 5 years.

## MEET OUR BOARD



**Cherie Flores**  
BBDF Board Member

Cherie is the third daughter of Don and Ruby Hair and is married to Jim Flores. She graduated with a Bachelor of Science degree in Marketing from Louisiana State University, where she and Jim endowed the Flores MBA School, to provide business education for future generations.

The Floreses are generous supporters of many charitable organizations in the Houston community, including Baylor College of Medicine, MD Anderson and the Texas Heart Institute for ground breaking research and excellence in patient care. Also special to Cherie and Jim is the Texas Children's Hospital, specifically Fraser Friends and the Jan and Dan Duncan Neurological Research Institute's research of Batten and other children's neurological challenges.

Cherie and Jim are very active supporting and volunteering at St. John's School where Jim served as a Trustee. Cherie also serves as a Museum of Fine Arts Trustee, Rienzi Collections committee member and Trustee on the University of Texas Fine Arts Advisory Council in Austin. Cherie serves on the Hermann Park Garden Center Advisory Board, is a member of the River Oaks Garden Club and an active volunteer at Bayou Bend. Cherie is also a sustaining member of the Junior League and an active member of the Chi Omega Sorority foundation. The Flores are also members of St. Luke's United Methodist Church.

In addition to the numerous charitable and philanthropic activities, Cherie is also a full-time mother of four children.

**On average it takes \$1.3 billion** and 12 years to shuttle basic science discovery down the drug development pipeline to a clinical trial.



**In 4 years we're almost 3/4 of the way down the pipeline.**

The American Institute of Philanthropy reports that the most highly efficient charities spend

**75%**

or more on programs.

BBDF spends

**84%**



## OUR JENY'S FOR THE FUTURE

BBDF is extremely proud of our accomplishments and the great strides that have been made over the past five years.

We have advanced quickly and more efficiently and cost effectively than most other groups. Today, we can identify mistakes in the DNA that cause juvenile Batten disease, allowing us to understand much of what goes wrong in the cells. Researchers are even able to slow the disease in animal models. However, we know the battle is not over yet.

With your support and BBDF funding, researchers have identified six potential compounds that may be used to treat children with juvenile Batten disease and are looking for more. We are preparing for clinical trial success by engaging world experts in drug discovery, validation, and approval to ensure we stay on track. With their help and your support, we are building a structure that funnels promising research to clinical trials until children and their families no longer have to confront this terrible disease.

Our strategic plan for the future builds on these accomplishments and continues to integrate the six key elements of success. In addition, our priorities will be to:

- continue to lead and elevate Batten research
- engage donors actively in our mission
- engage all with a passion and interest in batten and related diseases
- ensure continued strong leadership of the foundation

Beyond Batten Disease Foundation is committed to our mission of eradicating Batten disease and providing a brighter future for children and families affected by this disorder and hundreds of other rare diseases.

With your help, we have accomplished so much, but our work is not done. Please continue to support us and our research to find a cure for juvenile Batten disease. However you choose to support our mission, we need your special *Jeny's*

To learn more about getting involved, visit [www.beyondbatten.org](http://www.beyondbatten.org).

For a list of references see [www.beyondbatten.org/references](http://www.beyondbatten.org/references)

## MEET OUR BOARD Jeny's



### Jeff Hunt

BBDF Board Member  
Partner & Co-founder,  
PulsePoint Group

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, ascending the ranks and ultimately serving as chief operating officer for Europe, with responsibility for 16 offices throughout the continent. In addition, he served both in London and New York as vice chairman of Client Services Worldwide. He also established the firm's presence in Korea and Mexico, living in each country for three years, and ran its Latin America operations out of Miami.

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 on "managing intangible assets" in the University's McCombs School of Business. Jeff is active in civic affairs, serving on the boards of Ballet Austin and The Blanton Museum of Art.

# A MOTHER'S STORY

## *The Blind Vest, by Charlotte Benson*

Have you ever wondered what it would be like if the whole world knew your pain? Would you feel exposed or liberated? Would you be embarrassed or relieved? Would others treat you differently? I frankly never gave it any thought until 3 weeks ago when Craig and I took the children to Colorado for their first ski trip.

We enrolled Christiane in a program called Challenge Aspen, where children with special needs are taught to ski. Her instructor, Chloe, had worked with children with all sorts of disabilities and turned out to be a perfect choice for Christiane. While Christiane is not totally blind, her vision is blurry with dark spots; she sees shapes and shadows and struggles to focus on objects up close. Chloe asked me how Christiane would feel about wearing a fluorescent vest that indicated she was visually impaired. At first I felt exposed and uncertain about drawing so much attention to Christiane, but the obvious necessity to alert other skiers that she was skiing with a visual impairment made it an easy decision. So off they went, in matching orange and green vests, with Christiane's reading "Blind Athlete" and Chloe's reading "Guide for the Blind." I followed behind and watched in awe as Christiane began to trust her instructor as she was led down the slope holding on to Chloe's pole that was extended horizontally in front of her.

After the first day, Christiane was skiing independently and following behind Chloe's outstretched arms as she slowly called out in the most soothing and melodic voice, "left turrrn, right turrrn."

I watched them wind their way down through the bare leafed Aspen trees covered in shelves of snow and captured an image of her blossoming confidence that I will never forget.

For the next 3 days, Christiane shuffled in and out of ski lines for chair lifts and gondolas, she carried her skis and she side-stepped down stairs independently, calling out, "I can do this by myself, Mom." We were greeted with empathetic smiles, patient helpfulness, and kind gestures from everyone we encountered. The chair lift operators slowed the lift for her to dismount at the top, attendants helped her in and out of moving gondolas, and

there were spontaneous and encouraging words from people we didn't know.

Yes, people stared and whispered, but then I realized that there was more to it than people just responding to Christiane's handicap. They weren't whispering simply because she was blind, but rather because she was skiing in spite of it! The amazing thing was that the patience, kindness, and helpfulness of others responding to her handicap fostered a sense of gratitude, humility, and community for us.

So with skis dangling from the chair lift, and a pensive gaze at the snow covered evergreens cascading down the mountain, a new perspective emerged for me. What would the world be like if EVERYONE wore a vest inscribed with their own pain and hardship?

Would we complain and be critical if only we knew the burdens and weight others carry, but are persevering in spite of them?

Would we be more patient in traffic if we knew that last week the driver ahead of us was the surviving passenger of a fatal accident and now driving in spite of it?

Would our words be softer and kinder if we knew that the grocery store clerk just found out she has cancer, but is finishing her shift in spite of the news?

The last day we were there, I myself could have worn a vest titled "Fearful Mom," but I found myself pressing on in spite of it. Chloe had to leave early and Garland and Craig had gone back up the mountain for one last run. As Chloe departed, Christiane looked up at me and said, "Come on Mom, let's go down together one last time." Without hesitation I said, "Let's do it!" I immediately started reeling from the commitment I had just made. "WHOA, how's that going work?" I silently asked myself. I say left, Christiane says right, I say up, she says down. We're talking about a fiercely independent child! I mean, I'm not an expert skier and certainly not versed in leading a visually impaired, strong-willed child down the slope, but I simply knew we had to do it.



So, back up we went on the gondola, the whole while I was praying silently that God would lead us and give me the words, skill and leadership to get us down safely. We hopped off the gondola, and made our way to the side for me to help Christiane put her skis back on. With nervous anticipation, I was down on my knees in the snow, snapping her boots back onto her skis, praying that God would cover us with his presence. In that moment, she popped her goggles over her face and with 100% confidence proclaimed, "COME ON MOM!! FOLLOW ME!!" Can you imagine the faces on the bystanders who overheard the child in the blind vest calling out for her mother to follow HER??!

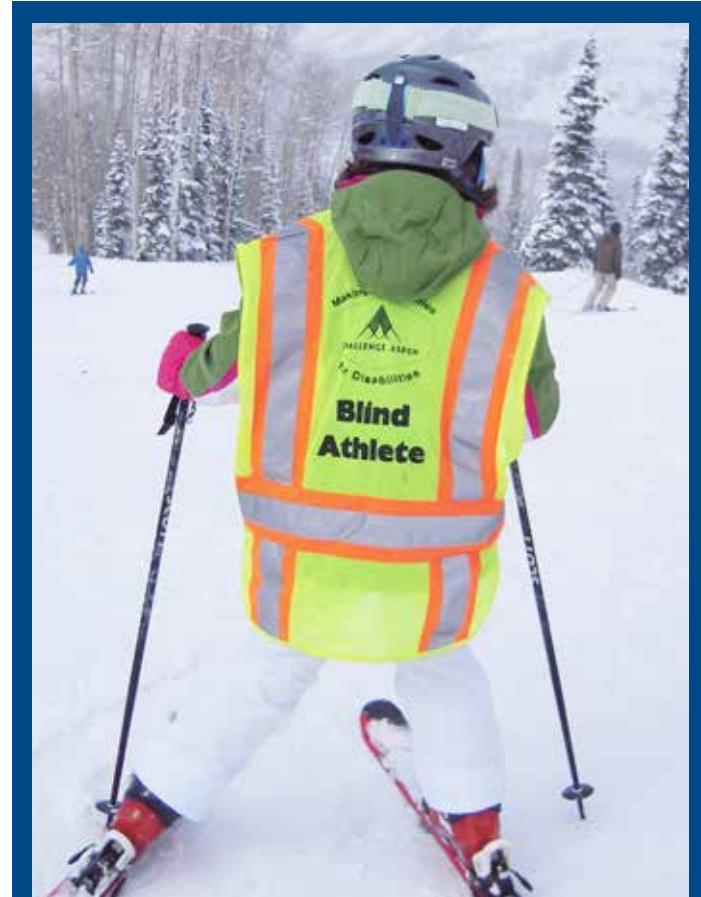
We made it down safely without incident, and I was reminded and confident of God's presence, and tickled by His sense of humor.

Don't you just love the way God surprises us and speaks to us in the most unexpected ways?? Trusting God in difficult circumstances seems to be the best place to find His blessings! I never cease to be amazed at the way He shows up. It is never the way and never the timing we expect it to be, particularly in this instance. I surely didn't expect it to come from Christiane herself. After all, how can He lead our steps if we are not stepping and trusting that He will provide? Leave it to a child to show us how to do that!

Perhaps we should not only trust that He will provide, but trust that the vest we are cloaked in has purpose. Sooner or later, we will find someone else cloaked in the same vest to encourage and love and inspire. Or perhaps, we will inadvertently encourage someone else faced with a completely different challenge.

As for me, losing my vision is not the vest I wear, but I'm inspired nonetheless. I will forever recall the beautiful image of my child facing her own challenge, gracefully gliding down the mountain, trusting, and pressing on in spite of the vest she has been chosen to wear. I am grateful.

To read more, visit Charlotte's blog at  
[www.beyondbatten.org/category/news/a-mothers-story](http://www.beyondbatten.org/category/news/a-mothers-story)



I am  
Jenny



## Prevention and Diagnosis: Update on the Test

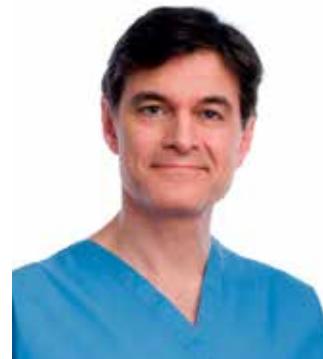
"The idea for this test came to Dr. Mike Spain and me after wondering what Craig and Charlotte could have done to thwart this fate. Could they have said 'Let's get screened for Batten.' Their physician would have said "Why Batten instead of a thousand other different inherited diseases?" and the physician would have been right. The solution was to screen for all of them because individually, yes, they're rare. Collectively, they're not so rare," said Dr. Mark Chandler.

BBDF initially funded and led the development of a genetic test for over 620 medically devastating rare diseases. The team of scientists engaged to create the test at NCGR moved to Children's Mercy Hospital for ongoing support of the product. The test is in a pre-launch phase, the final step before commercial development.

One beneficial aspect of this test is that it can be used to quickly diagnosis children to determine if they have these diseases. This will end the diagnostic odyssey that, until now, took an average of 2 to 3 misdiagnoses and 7.6 years. Another benefit is that it can prevent the occurrence of Batten and other rare diseases in future generations by allowing parents to partake in family planning screening to determine if they are both carriers of the diseases.

BBDF has collaborated with expert scientists to develop and provide this comprehensive test for physicians. The test was beta launched in 2012 and is currently being used as a diagnostic tool within Children's Mercy Hospital's network.

We are continuing discussions with several potential commercialization partners and intend for the foundation to benefit financially from the eventual public launch of the test.



*"As a physician I can tell you this is the kind of game-changing health initiative that truly excites me. This will be a tool that can profoundly affect the health of children by preventing the occurrence of these illnesses that have challenged us for decades. Ten years ago, I would have thought that a world without genetic killers like Batten, cystic fibrosis and hundreds of others was a dream. Beyond Batten Disease Foundation is making this a reality."*

— Mehmet Oz, MD, *The Dr. Oz Show*



**The average patient with a rare disease will see  
8 physicians  
and get 2 to 3 misdiagnoses  
before being correctly diagnosed.  
On average, this takes 7.6 years.**



# Board of Directors

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Kyle Janek, MD

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Jeff Hunt

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## Staff

Mary Beth Kiser, CAE, President and CEO

Danielle Kerkovich, PhD, Principal Scientist

Carolyn Frank, Development Assistant

Lizzy Franey, Development Assistant



Salt Lick Event, 2010

***"We are grateful to have such a powerful transatlantic friend working toward our common goal - to eradicate this brutal disease. We are amazed by the professionalism and the deep impact on research acceleration resulting from the various activities of BBDF"***

*— Frank Stehr, PhD, Executive and Scientific Director, NCL-Stiftung, Germany*



Run to the Sun Relay, 2011



Lemonade stand for Batten Disease, 2012

Be a Jennyis



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[www.beyondbatten.org](http://www.beyondbatten.org)



Hope on the Green, 2013



Battlin' Batten Baffin Fishing Tournament, 2012

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Individuals who contributed \$2,500 or more between August 2008 and June 2009 to establish the foundation.

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Beyond Batten Disease Foundation would like to recognize and thank those who have supported us in our mission to eradicate Batten disease. Our accomplishments over the past five years would not have been possible without you. We thank you for your continued support and **JENYIS.**

BBDF makes every effort to ensure the accuracy of your listing. Please email any changes or corrections to [info@beyondbatten.org](mailto:info@beyondbatten.org)

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1-800-Dryclean of The Woodlands	The Honorable & Mrs. Alan Albright	Jimena Alverde
25 Twenty	Melda Alcala	Mr. & Mrs. Charles Alvord
31 Roots Clothing and Accessories	Liz Alcocer	AM Restaurants
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Vanessa Agnew	Elizabeth Allen	Elisabeth Anderson
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The Hillcrest Foundation  
The John Cooper School  
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The Nelson Puett Foundation  
The Perry Foundation  
The Prudential Foundation Matching Gifts  
The Robinson Foundation, Inc.  
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Jennifer Valderas  
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Meg Valentine  
Valentine's Too  
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Linda Walsh  
Walter Allan Studios  
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Kate Walters  
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Ann White  
Austin White  
Beth White  
Brent White  
Brian White  
Chad White  
Demetri White  
Jane White  
Jeanne Shaffer White  
Kristen White  
Leisa White  
Linda White  
Michael White  
Rodney White  
Ron S. White  
Taylor White  
White Rock Farm  
Annie Whitehead  
Tom Whiteside  
Emily Whiting  
James Whitlock  
Cynthia Whitlock  
Rebecca Whitlock  
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Mr. Bryan Zubler  
Daniel Zuch  
Mr. & Mrs. Brian Zucker  
Lauren Zugaro  
Phil Zusi



I wish

I wish the homeless  
had a home.

I wish I wouldn't have  
to get my blood drawn.

I wish that there was  
no more Batten.