

breathe

"11 years of inspiring hope."



Welcome

Welcome to the first edition of the new chILD Foundation newsletter. We will be issuing this newsletter quarterly through email, Facebook and the chILD Foundation website. If you have anything that you would like to contribute to future editions, or have questions or comments, please contact us at social@chILD-foundation.com. Thank you for reading. Hope you enjoy it.

Executive Director Update Programs & Education

The past few months have been an important time within the Foundation. We have been working hard to create a robust programming plan that involves engaging families, expanding physician outreach and education, supporting research, and building a strong medical and scientific advisory platform. We will be announcing the program plan at the conference and will outline the opportunities in the next newsletter, so stay tuned!

In the meantime, we need your help!

August 2-8 is Surfactant Deficiency Awareness week and September 13 to 19 is NEHI Awareness week. If you are interested in helping to plan an awareness event in your area or would like to suggest topics for the educational



Claire, 5, NEHI

webinars for those weeks, we would like to hear from you.

Over the next few months, we will be working to identify 4 cities around the US to host small regional meetings in 2016 for families sponsored by the chILD Foundation. These will be short mini-conferences with a few hours of education or outreach with your local hospital that will be paired with a social event for families to get to know each other. If you might be interested in helping plan a meeting in your area, please let us know!

We also need people with development/fund-raising experience, event planning, non-profit governance experience, and people to help write stories for the newsletter. If you are interested in getting involved in any way, please contact me at agettys@chILD-foundation.com

Looking forward to seeing everyone in Boston.

- Ann Gettys, Executive Director

UPCOMING EVENTS

July 17-19
Annual Family and
Physician Conference
Boston, MA

July 23
Rare Lung Disease
Consortium
Cincinnati, OH

August 2-8
Surfactant Deficiency
Awareness Week

September 13-19
NEHI Awareness Week

Featured chILD Family The Steiners

Our family's initial interest in the chILD Foundation was no different from other chILD families. We sought guidance, advice, and answers as we navigated ourselves through the landscape of childhood interstitial lung disease. Over the past 18 months, however, our journey has taken us to a more active role within the foundation to support the initiative to find cures and treatments for children in an environment where rare pediatric disease research is too often overlooked.

A year and a half ago, our family began our journey with chILD when our youngest child, Harry, was diagnosed with Post-Infectious Bronchiolitis Obliterans. After suffering a sudden and severe onset of mycoplasma pneumonia and adenovirus, Harry was left with a debilitating loss of lung capacity. Within a three-week period, Harry went from playing flag football, three days a week, to not being able to walk across a room without the assistance of oxygen. His condition would be permanent with no treatment or cure and faced a possible double lung transplant if his condition worsened. Obviously, we were devastated with this prognosis and motivated to find support and advice.



With the chILD Foundation, we found that support and much more. We were impressed with the foundation's vision, accomplishments, and impressive list of well-respected doctors, researchers, and institutions. Since the Spring of 2014, we have dedicated ourselves to applying our knowledge and skills to help chILD reach their objectives and maximize their potential as a leader in chILD research and care. It's an objective we both share.

Currently, my role within chILD is Chair of the Bronchiolitis Obliterans Family Group where I try to engage families to play a role in chILD foundation and raise awareness and funds for BO research. Unofficially, I enjoy researching underlying causes of BO. I am interested in the role that genetics and immunology plays in the etiology of ILD's in children. I am also very interested in the role physical therapy and exercise testing plays with ILD kids. It is my great hope that I can facilitate research in these areas.

As for the rest of the family, Harry and his three older brothers, Reed, Ben, and Sammy, life continues as usual. Harry has completed 3rd grade, and despite his disabilities, he has reclaimed some of his active life. He swims and dives, two days a week, plays the piano, plays 4 square during recess, participates in PE, and a basketball clinic one day a week. He may not be in the run for first place in any of these activities, but he certainly tries his best. His enthusiasm keeps his father and I and his 3 brothers optimistic about the future.

- Daisy Steiner

Research \$100,000 Bronchiolitis Obliterans Research Grant

In May, chILD Foundation joined forces with chILD Foundation UK to partake in the Million Dollar Bike Ride in Philadelphia, PA. Through the efforts of families and friends, we were able to raise enough funds through this event to offer \$100,000 for research grants for Bronchiolitis Obliterans. Thank you to everyone who participated on the ride or fundraised!

This grant will be awarded to the best research proposal in post-infectious Bronchiolitis Obliterans. The application period will begin this Fall and the grant will be awarded by the end of 2015 by Penn Medicine Orphan Disease Center.

International grant applications will be accepted so this is truly a world-wide effort to support Bronchiolitis Obliterans!



Events

2015 Family & Physician Conference

This July, chILD Foundation will host its 11th annual Family and Physician Conference in Boston, MA. Join us to meet other chILD families, form friendships, and gain valuable information about living with chILD from experts from around the U.S.

When: July 17-19, 2015
Where: Boston Marriott Newton, Newton, MA
Registration: Adult - \$150-300
 Child - \$70-140

Registration is now open! Please visit:
www.child-foundation.com/home/annual-conference

On the conference website you will find:

- Information about fundraising opportunities to help offset registration and accomodation costs
- Tentative event and speaker schedule
- Information about the OxyKids childrens camp
- Links to register
- Accomodations booking links
- Information about the Physicians CME

We look forward to seeing you there!



Fundraising

Recent Family Fundraisers

HUNT FOR A CURE

Fall River, Kansas

Thank you to the Bush family for organizing a pheasant and quail hunting event at Flint Oak. Thirty-eight hunters participated at this weekend event, and through donations and registration raised over \$43,000 for the chILD Foundation.



ONE SWING/ONE BREATH AT A TIME CHARITY GOLF TOURNAMENT

Lawrenceville, Georgia

Thank you to the Knobloch family and the sponsor Window World Atlanta for hosting the inaugural golf tournament supporting the chILD Foundation. Through registrations, donations and silent auction, this event raised over \$3,000. These funds will be split evenly between NEHI and ABCA3 research.

BASKET RAFFLE

Stockbridge, Vermont

Many thanks to the Austin family for hosting their annual basket raffle fundraiser at Stockbridge Central School. There was great community support for the event, and over 70 prizes were awarded, raising over \$2,700.

NORMAN E. DAY ELEMENTARY FUNDRAISER

Westford, MA

Thank you to the McCarthy family and assistant principal Chris Louis Sardella for organizing a class fundraising challenge at their school. Individual classrooms collected donations to support the Foundation. Dr. Alicia Casey and Dr. Martha Fishman visited the school to raise awareness of chILD. The children raised over \$1,500.

Fundraising cont'd

FISH-A-THON

Tekamah, Nebraska

For the third year the Jarecki family raised money to support the chILD Foundation through their day long fishing event. This year a second event was held, the first ever chILD Foundation Bass Fishing Tournament. Thirteen teams participated in the tournament and the winner was our chILD patient, Michael Jarecki and his partner Jim Beiermann with a total weigh in of 14.95 pounds! Over \$7,200 was raised for the Foundation. We would like to thank the Jarecki family, the event sponsors, participants in the tournament and all friends and family who donated in support of Michael and the chILD Foundation.



EAT, SLEEP AND BREATHE BASKETBALL FUNDRAISER

Westford, MA

Thank you to Creed family for organizing and hosting a basketball game fundraiser where sold chILD bracelets, t-shirts and collected admission to a local high-school alumni game. Over \$1,300 was raised to support chILD.

Ask the Doctor Questions?

We would like for you to have the opportunity to ask the chILD doctors medical questions. Please submit your questions to social@chILD-foundation.com and your question with a response by one of the chILD doctors may be featured in a future newsletter edition.

Healthy Eating "No Cook" Oatmeal

This delicious recipe is great for the summer months when a steaming hot bowl of porridge is not overly appealing. The addition of chia seeds makes this meal rich with nutrients and Omega 3 fatty acids.

Best made in individual half pint (1 cup) mason jars, and left to sit in the fridge overnight.

Ingredients:

- 1/4 cup uncooked old fashioned rolled oats
- 1/3 cup skimmed milk
- 1/4 cup Greek yogurt
- 1-1/2 teaspoons dried chia seeds
- 1/4 teaspoon vanilla extract
- 1 tablespoon raspberry jam
- 1/4 to 1/3 cup raspberries

Directions:

1. Add oats, milk, yogurt, chia seeds, vanilla and jam
2. Put lid on jar and shake well
3. Remove lid, add raspberries and stir until mixed
4. Put lid back on and place in the fridge overnight.
5. Eat cold.

You can substitute different fruit options or fortify with various nuts and seeds.



Got a favorite recipe you'd like to share? Please email us and we will feature it in the upcoming newsletter.