

# Summer 2016



## Summer 2016 Newsletter for One Breath, One Hope Inc.

### Lily Pad Paint Night Fundraiser!

The Board of One Breath, One Hope came across a story about a young boy named Nick who fought a long battle with leukemia and a childhood brain tumor since the age of 4. Nick noticed, at one of his many visits to the hospital, a little girl having trouble managing her IV pole. The IV pole, a necessary accessory, goes wherever they do. This sparked Nick into action to create what are now known as “lily pads”. The lily pads are colorful and fun skateboard like platforms that slide onto the wheels of an IV pole so a child can sit and ride it instead of struggling to walk alongside. Nick teamed up with his wood working class at school and formed a project with the goal of making one lily pad for every kid in his hospital. Sadly, in September 2015, at 17, Nick died of his illnesses. However, his classmates and Nick’s Mom Christina carried on, completed the project, and continue to make them today in his memory.



At OBOH, we have requested and received 20 blank lily pads, ready to be painted at our event! We will host a paint night fundraiser on **Thursday, July 14th at 7:00 pm.** at Catalyst Art Studio: 88 Center Street, Wallingford CT. Tickets are \$35 per person and include drinks, snacks, supplies, and an artist who will walk us through making 20 beautiful lily pads that we will be delivering to local hospitals! But wait, there’s more...the studio holds up to 30 people, so an additional 10 people will be able to paint a canvas that we will donate to people OBOH supports. Please contact any OBOH Board member for reservations, or email [info@onebreathonehope.org](mailto:info@onebreathonehope.org).

The lily pads that we make at our event will be donated in memory of an amazing little girl from East Lyme, Connecticut named Madeline Guarraia, who recently lost

her battle with childhood leukemia (all childhood cancers are considered rare diseases). Maddie was a stunningly vibrant spirit who touched so many lives through her contagious positivity and fighting heart. Madeline’s family shared their many terrible, beautiful, and inspiring experiences of the battle with this disease on the “Mad About Madeline” Facebook page which is followed by thousands of loyal supporters, both in their community and beyond. We at OBOH are hoping that these lily pads will bring fun and joy to the children and families that use them as Maddie always brought a bright light and a fearless smile to every life she touched.



### In This Issue...

- Lily Pad Paint Night
- Summer Update from OBOH
- Christmas in July
- Relief Report
- In The Spotlight
- Food For Hope



# In The Spotlight...

## Angelina Update!

One of the first questions many of us on the OBOH Board hear when we talk to people is “How is Angelina?”. For those who might not know, Angelina Manwaring is the brave little girl whose story prompted the formation of One Breath, One Hope. So in this newsletter, we thought we’d give you all an update on our very first rare disease warrior!

Angelina has ended her 3rd grade year of school with only a little under 20 absences. This is a record low for her and a great improvement from her 38 last year. She has been able to enjoy time with her friends, and also do her school work, which she loves and excels at. Angelina’s school continues to support her abundantly in many ways such as allowing her to bring a friend to play inside if the weather is too hot or cold for her to be out. Her classmates learned how to wash hands correctly and enjoyed a detailed presentation from the nurse on how to make sure they keep each other healthy each year, something we can ALL benefit from!

In regards to Angelina’s health, she is still seeing the amazing staff at Boston Children’s Hospital (BCH) and has, since our last update, received a 2nd diagnosis of Primary Immunodeficiency in addition to her existing PCD diagnosis. Primary Immunodeficiency is a rare genetic disorder where the immune system does not function properly and cannot protect the body in the ways in which it should. In many cases, and in Angelina’s case, part of the treatment is immunoglobulin therapy, where the individual receives a regular infusion of plasma. Plasma is found around the red blood cells, and can be collected from any approved blood donor through a process called plasmapheresis. One treatment of plasma is collected from 10,000 - 50,000 individual donors!

Angelina is doing well and responding positively to the treatment plan that she is on. She originally received infusions at home once every 4 weeks. However, Dr. Lee, from BCH saw her in January, and between her blood work results and her lack of energy moving into the last week before her infusion, he has decided to increase infusions to once every 2.5 weeks or sooner, as needed. This seems to have eliminated a very difficult week in between the two infusions where she was experiencing extreme fatigue. So far, Angelina’s side effects from her infusions seem to be pretty predictable. Headaches, stomach issues, and a very bloody nose can almost be counted down to the hour. Right now the plan is to proceed with infusions on this schedule until next year and then start to move them apart gradually. Angelina recently had her nurse Daisy come over to do an infusion early, due to a cold she was fighting. Daisy is now a member of the family, and they enjoy her visits very much. She is an emergency room nurse at the Hospital of Central Connecticut, and takes very good care of Angelina during her home infusions.

Currently, Angelina's lungs have been a bit crackly and she is on 14 days of antibiotics. She is half way through them and hoping she can start having some productive coughs soon! Changes in weather are, as always, a bit difficult!

Angelina and the whole Manwaring family wish their OBOH friends an amazing restful summer filled with fun, short to-do lists, and infrequent doctor’s visits!



Angelina getting an infusion with Daisy her nurse!

## Food For Hope

OBOH is launching a new program this year called “Food For Hope”. Sometimes in the midst of managing doctor visits, treatments, and every day life, we forget about the importance of a home cooked meal. OBOH believes that when you feed someone’s body, you are also helping to restore their spirit. With this in mind, individuals or families affected by rare disease diagnoses, can request either 5 home-made meals delivered to their home, if they are in the CT area; or a \$200 gift card to a local grocery store, if they are a little farther away. See our website [www.onebreathonehope.org](http://www.onebreathonehope.org) for more information and to request this new service for you or someone you know who could use some food for hope!



## **One Breath, One Hope Inc.**

6 Huntington Ridge Rd.  
Wallingford, CT 06492

Phone: 203-640-2386

E-mail: [info@onebreathonehope.org](mailto:info@onebreathonehope.org)

## ***Our Mission:***

**One Breath, One Hope Inc. is a Connecticut based non-profit organization serving the rare disease community by providing financial support for treatments, advocating for medical research, and helping families get in touch with the information and support groups they need.**

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