

2nd & 3rd Quarter



2nd & 3rd Quarter 2014 Newsletter for One Breath, One Hope Inc.

Save The Date!

Harvest Pie Bake Off and Fundraiser!

Date: Saturday, October 4th 2014

Location: 5 Marguy Street, Quaker Hill CT

Time: 12:00 - 5:00 pm

Pie submissions must be in by 2:00 pm,
awards announced at 4:00pm



On Saturday October 4th, OBOH is excited to be hosting a *Harvest Pie Bake Off and Fundraiser!* Please join us for a fun filled day complete with a pie baking contest, games, and some great vendors!

We will have three categories of pies: "Apple", "Pumpkin", and "Pecan" with an award for each category as well as an award for best overall pie of the day! All entries must be a pie, no cakes, breads, or other types of baked goods please. A panel of three judges will have the pleasure of tasting these wonderful pies and will announce the awards at the end of the day!

In This Issue...

- Harvest Pie Bake Off And Fundraiser
- Get Cooking with OBOH
- What Can I Do To Help?
- In The Spotlight
- Relief Report
- Quarterly Support Group

Tickets to the event are \$5 per person, no more than \$20 per family (children 7 and under are free) and can be purchased in advance or at the door that day.

There will be a hot dog lunch special for \$5 which includes, a hot dog, bag of chips, fruit, and a drink.

For more info, to register as a pie baker (in any or all categories), or to reserve tickets, please send an email to info@onebreathonehope.org

Vendors: Please send an email with your name, company name (if applicable), email, and what your booth is selling to info@onebreathonehope.org.

The vendor charge for the day is \$25 and includes lunch!

Visit our Events page on our website www.onebreathonehope.org for more details.

Get Cooking With OBOH!

Do you have a great recipe that you think should be shared with the world? We want to hear it! Anything goes, dinner, desserts, breads, ANYTHING! Send us Grandma's cookies, or Aunt Sue's pasta sauce...we will proudly put your recipes into an OBOH cookbook and have them for sale at our future events, starting in the fall!

Your submission should include:

- Recipe (detailed, with instructions and measurements)
- Your food memory (where the recipe came from or how it developed...did your Mother make it every Sunday, did your best friend bring it over when you needed someone to talk to, did your child make it up and it actually worked??)
- Source (please include if you took the recipe or derived the recipe from a publication or other source so we can properly note that, even if the source is Grandma Jane!)
- Send your submissions to info@onebreathonehope.org by Sunday, September 15th.

What can I do to help?

The most common question that we are asked when we talk about OBOH, visit members, and hear from families is "What can I do to help?". The initial reaction is to want to help those who we know are in need and struggling. Almost always, my answer to this question is the same. Share our story, share our website, share our name. Make our mission, your mission. The more exposure we get into your communities, the better it is for our organization and its members. Fighting the rare disease battle is a constant uphill climb. We hear about families and individuals who are going through so much and working to overcome so many obstacles. Spreading the message about what OBOH does gives us the opportunity to give those people some much needed support and relief.

With this in mind, the OBOH Board had pens and mini-flashlights made with our organizations info printed on them. These are a great way to pass on our info and share your story with those you meet in a non-invasive way! Both items are for sale, just email in the order form found at www.onebreathonehope.org with how many you would like and we will ship them out to you! We will also have them for sale at our Harvest Pie Bake Off and Fundraiser this fall. Please come out to support us and enjoy a great day with other PCD and rare disease families.

As always, thank you for supporting the work we are doing here within the rare disease community, and thank you for spreading the OBOH name!

Meghan Montana
CEO - One Breath, One Hope Inc.

In The Spotlight...



Katelyn celebrating her birthday!

Meet Katelyn! She is another beautiful member of our OBOH family. Katelyn began showing symptoms of some sort of chronic problem soon after birth. She would turn blue when feeding, had chronic ear infections and developed RSV. At 4 months, she was tested for cystic fibrosis and was negative. Shortly before her first birthday, Katelyn got ear tubes but still suffered from numerous cases of bronchitis and pneumonia. She was sick with a 104 degree fever on her first birthday and was admitted to Yale for the first time the day after. Shortly after that, she went through surgery to remove her adenoids and the Drs. also performed the biopsy that gave her the official PCD diagnosis. Going through several bouts of IV antibiotics over the next year, and constantly battling infections, she got used to being poked and isolated. Even after all of this, Katelyn loves to pretend to be a doctor! After several years of having to stay home and not be around other kids, things are starting to get a little better. Katelyn and her family have gone to the PCD center at Boston Children's to get a better handle on her

disease and to help her cope with her diagnosis better. Despite all that she has to go through Katelyn is one happy, smart, and strong 5 year old who also loves to do gymnastics! We are so proud to be able to share her story with you!

If you or your child would like to be featured on our "In the Spotlight" section for the next newsletter, please email info@onebreathonehope.org!

Relief Report...

Because of your generous support of our organization, OBOH was able to help two members this quarter. We were able to assist one family to buy an adjustable bed for their child, giving her the ability to sleep upright and not let fluid settle, it has made a real difference! We were also able to help another family with their first visit to the PCD Center at Boston Children's Hospital by taking care of their hotel expense and sending them with some additional funds for incidentals like gas and food.

Without your support these families would not have been able to feel these moments of hope and relief and we are so thankful to have been able to be a part of their story.

Thank you!

We also had two "In Memoriam" gifts given to OBOH for which we are very honored. They were in memory of Joe Iwaniec and also Willard C. "Lucky" Newlin, Jr. Our thoughts are with their families.

Quarterly Connecticut Support Group!

Do you live in the Connecticut area? Would you like to have an opportunity to meet and talk with other PCD and Rare Disease families? OBOH would like to start hosting a quarterly support group that will meet at different locations around the state. Please let us know if you would be interested in joining this group to have an opportunity to chat with people who know exactly what you are going through.

Email info@onebreathonehope.org to be added to our list!



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Our Mission:

One Breath, One Hope Inc. is a Connecticut based non-profit organization serving the PCD (Primary Ciliary Dyskinesia) and 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.

Visit Us Online...

Website: www.onebreathonehope.org

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