

bound by hope

March 2010



Band of Parents
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The Band of Parents, Inc. is a 501(c)(3) non-profit organization founded by parents of children diagnosed with a deadly pediatric cancer called Neuroblastoma.

Meeting with Dr. Cheung Thursday, March 25th

The next meeting between the BOP and Dr. Cheung is Thursday, March 25th at 5:30. It will be held in the Zuckerman Building, 410 E. 69th St. between 1st and York Avenues in room 105. This will be the first meeting available through webinar for those that cannot physically attend. Please email merkelk@mskcc.org stating you are registering for the webinar meeting on Thursday with Dr. Cheung so you are sent the necessary information to get online for the meeting. If you can attend in person, please email Caryn Franca at carynfranca@aol.com. This will be an exciting meeting with many topics on the agenda. As BOP members, we are all anxious to hear what he has to say. We encourage all to attend.

\$48,000 Fundraising Success!!

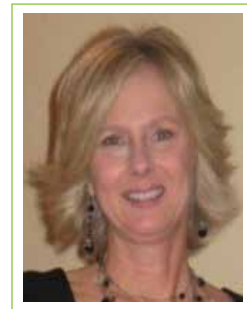
In one weekend, just over \$48,000 was raised for the Band of Parents. The Love family in Virginia were part of an Abby Miller musical evening Saturday, February 27th. Abby's band and another local band dedicated the evening to Band of Parents. There was also a raffle and donation jar. The night raised almost \$3,000.00. Abby Miller is an amazing young musician and has dedicated so much of her time and talent to her little friend Taylor Love and Band of Parents. Thank you Abby. You can search for Abby Miller on Youtube.com to hear her sing.

That same day in California, the Lynch family had their 3rd annual Nick Lynch NED Celebration Dinner event. The incredible night raised over \$45,000. A tremendous thank you to the Lynch family and their fantastic team for throwing yet another wonderful event.



First Newsletter for the Band of Parents

This is our first newsletter for the Band of Parents. Every month we will update BOP members here with the latest information from Dr. Cheung as well as fundraising efforts. We will also be featuring children of the BOP each month so we can get to know every child we are fighting for. New members will be welcomed as well. This will also be a way for the Band of Parents to keep members informed of the ongoing efforts between MSKCC and the Band of Parents. I hope you will all find it to be very informative. We welcome your input and are happy to receive emails at bopnewsletter@gmail.com.



Welcome to Our New President

- After a very busy year, BOP President, Larry Witt, has stepped down and taking his place is Caryn Franca. Caryn, as many of you know, has been in charge of fundraising for the Band of Parents for the past two years. She has a drive and ambition that is greatly admired. Her son, Nick, diagnosed at 15 years old, has battled relapse and is now a freshman in college and on maintenance treatment. Caryn, throughout Nick's relapse treatment, has always been on top of her game and continued to do her part to raise funds and awareness for the Band of Parents. We welcome her with open arms and look forward to seeing what she can bring to the BOP as President in the next year. **Congratulations Caryn!**

Welcome New Members!

Recently we have had many new members join our cause. We'd like to welcome them all. We are sorry you are in this fight, but happy you have found us.

The Przekurat Family – California
Donna, Mark and Megan, diagnosed June 2005
www.caringbridge.org/visit/meganprzekurat

The Winnefeld Family – Indiana
Mike, Carol, Lauren and Cole, diagnosed April 2009
www.caringbridge.org/visit/colewinnefeld

The Denberg Family - New Jersey
Kate, Matt and Alexander, diagnosed October 2009
www.carepages.com/xanderdenberg

The Gaines-Maziarz Family – South Carolina
David, Robin and Lauren diagnosed May 2009

The Byrd Family – Alabama
Lynn, Melissa and Jensen, diagnosed December 2007
www.caringbridge.org/visit/jensenbyrd

The Miller Family – Colorado
Lori, Jeff and Justin, diagnosed September 2006
www.caringbridge.org/visit/bunkyspage

The Christenbury Family – North Carolina
Amy, Jeff and Grier, diagnosed March 2007
www.caringbridge.org/visit/grierchristenbury

The Murray Family – California
Carmen, Scott and Ty, diagnosed May 2008
www.caringbridge.org/visit/tymurray

The Williams Family – New York
Leslie, Jim and Kyle, diagnosed November 2009
www.caringbridge.org/visit/kylejameswilliams

 **Featured Children**

Every month will be a featured child whose parent(s) are members of the Band of Parents. If you would like your child featured please send an email with permission and your child's site to bopnewsletter@gmail.com.



Ila Jean Rathbone – Survivor
Ila Jean was diagnosed August 2006 at 18 months old. She went through 3 years of treatment and just celebrated her 5th birthday and 2 year NED anniversary. She is a little spitfire with an amazing will to live
www.caringbridge.org/visit/ilajejan

 **Upcoming Fundraisers**

The 1st Annual Arms Wide Open Golf Outing will be held at the South Shore Country Club on Staten Island, New York. The event will be held on Thursday, June 17, 2010 at 7 a.m. and will cost \$250 per person. The price includes registration, continental breakfast, light lunch, luncheon in the main ballroom and goody bags.

Hole in One Contests and Prizes include a chance to win \$50,000 cash, a golf package, an electronics package and a cruise for two, among other prizes. Three top golfers will participate in a shoot out for \$100,000 and putting contest for \$2,500. If anyone is interested in sponsoring a hole, the cost is \$150. Checks can be made out to Arms Wide Open, PO Box 258, Marlboro, New Jersey 07746.

RUMORS, RUMORS... Having just spent a week at MSKCC for scans, I heard plenty of rumors about new treatments and changes in protocols. I believe it is important to get answers to these rumors we hear so we are all on the same page and misinformation does not get out of hand. If you have a question about something you are hearing, please email me and I will do my best to get the answers from the "powers that be". Please send any questions to bopnewsletter@gmail.com.

Newsletter written & edited by
Jennifer Rathbone
Board Member, Band of Parents

Coming Soon!

Our new website is in the works and will be up and running in the near future. It will be user friendly and full of information along with some new graphics. I know you all will be pleased. So please be patient as we finish up the final touches and stay tuned to find out when it will be launched.

Band of Parents Officers and Board Members

President – Caryn Franca
Vice President – John Bartosz
Treasurer – Doris Godfrey
Secretary – Dena Sherwood
Chairman of the Board – Marc Winthrop

Board Members

Landon Holden	Jennifer Rathbone
Ken Lynch	Larry Witt
Gavin Lindberg	Lucas Wall
Stephen Pannone	Ranan Wolff