



New England Connection for PKU and Allied Disorders, Inc.

A Non Profit Organization – Tax Exempt No. 043265289

www.NECPAD.org

Saturday May 17, 2008

NECPAD "Prepared for Life" Conference

What a great conference! Other than some (actually only 1) technical difficulty, the conference went nice and smoothly! We got a great turn out in numbers and all of the presenters provided some really good information. We started a little bit late thus keeping everything a little bit behind schedule, but the rest of the day and weekend made up for it.

After Denise's welcome to everyone, Dr. Mark Korson was introduced as our MC...Dr. Levy (our New England PKU community's "Patriarch") updated us on some new therapies that are being explored which included the Kuvan medication and the "Large Amino Acid" therapy! After a late break and visit to the vendors, Dr. Korson came up and spoke about the experiences of Kuvan at the Floating Hospital...unfortunately, a couple of us missed much of his talk due to the technical problems arising :/ Sorry Dr. Korson!! Due to those issues, the schedule was rearranged a bit. (Thanks Mark, for keeping us on track!!) Donna gave a little speech and honored Lynn for her dedication to NECPAD and PKU community with an award. Lynn seemed to be pleasantly surprised... Lynn, you rock! Dr. Berry and Dr. Weiner spoke about disaster preparedness and electronic filing, an intriguing idea. Finally, before lunch, Rachel and Maggie Davis spoke about weight loss, maintaining phe levels and nutritional therapy's role in this process. Maggie is a great addition to our PKU clinician community! After a great lunch with low protein and higher protein options available, Dr. Susan Waisbren gave a great talk about the PKU Toolkit now available and the importance of facilitating adult transition. Thanks so much for your everlasting dedication to this field, Susan! We love you! The rest of the day was a little less structured but not any less informative. The feedback received from the breakout sessions and the cooking demonstrations were all very positive. I think the only complaint would have been that it would have been great if we could attend all of the breakout sessions at the same time! Obviously that can't happen...lol

At the end of the day, we had quite a few items to raffle off including tickets to the Drop Kick Murphy's, HYLine cruises from Cape Cod, novelties, books (one co-



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written by Maggie Davis), and low protein foods provided by Cambrooke and others. Meanwhile, David provided us with a great slide show of past events, it was great! Dinner at Dux and the rest of the evening proved to be fun time had by all, to say the least!. (No need to go into details!)

Sunday May 18, 2008

NECPAD Leadership Forum with Maddie Bragar

The Leadership Forum commenced on time with approximately 18 attendees! Maddie Bragar facilitated the meeting with great energy and enthusiasm. After going over our expected outcomes of the meeting, Maddie broke us out into work groups to discuss the following:

- Write a more effective and acceptable mission statement for our organization
- List all of our strengths and weaknesses
- List all of our opportunities and threats

After we came back together as a group, Maddy helped us identify committees for the targets of change and improvement. With all of the additional attendees (besides the current board members) interested in joining the board, we re-energized and created fresh new ideas and goals for us in the coming year! We welcome Ashley Sullivan, Brandon Garde, Michael and Kerri Simonelli, Linda Merchant, and back to the board, Sarah Foster. Our working mission statement that we left with is as follows:

"We as consumers (people diagnosed with PKU), family members and professionals, inspire learning, social support, research and public policy to help develop the full potential of people affected by PKU and Allied Disorders."

Thanks Maddie, for all of your guidance and wisdom!
And thanks to everyone for joining us and making the weekend a memorable time!



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~The NECPAD Board members