



Parent, Family & Friends Network Newsletter

Fall 2008

The 2008 Every BODY is Beautiful Online Auction is now open. Remember, every single dollar we raise helps support vital programs, so have fun, bid often, bid up! To find out how, click here: [Every BODY is Beautiful on-line auction](#). And now, enjoy the latest edition of the PFN Newsletter!

*Warmly,
Laurie Vanderboom, Program Director*

Dear Parents, Families and Friends,

I hope this letter finds all of you enjoying the comfort of fall weather. The colors are brilliant here in the Northeast this year. It is hard to believe that another NEDA conference has come and gone. However, I know that many of us will carry the good memories of meeting and sharing support and hope with each other. It was so good to see familiar faces, connect faces to names we have only met virtually prior to the conference in Austin, and meet new family members that we hope to stay connected to by e-mail/phone until the 2009 NEDA conference. Inside this issue you will find:

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New! NEDA Ad Campaign is available!



The National Eating Disorders Association realizes to change the culture we must educate and spread awareness by raising the consciousness in America. This is no easy task. Let's face it, lasting change is not instant. We have developed, with the generous help of Ogilvy and Mather in NYC, a new ad campaign targeting the general public. It features a number of ads ready for placement in magazine, on billboards, text messages and more!

We need your help to raise funds for placement and connections for pro-bono ad space. If you want to help, please contact us at media@myneda.org

NEDA Network: NEWS AND INFORMATION

Years in the making, the NEDA Network was introduced at our 2005 Conference in Denver. Some great regional leaders met and shared their ideas, successes and goals. The NEDA Network is essentially a membership level created by and for eating disorder organizations that wish to harness the power of our combined forces, share a common brand identity with the NEDA Network logo and collaborate on many levels.

The NEDA Network is currently ten organizations committed to collaborating, sharing resources, knowledge and expertise to better serve our individual and collective missions, programs and constituents. The key is collaboration as it fuels the strength of our combined voices to create a powerful force for change. The synergy, trust and vibrant exchange of information, resources and expertise by the individuals from each organization is truly humbling. As one member sums it all up, "It is a great way to collaborate with others throughout the country and make sure that we are supporting each other and sharing our ideas in a non-competitive environment" to help parents, family and friends.

Stay tuned...Upcoming newsletters will include specific information regarding individual member organizations. [Click here to view the NEDA Network](#)

PFN Steering Committee meeting in Austin

Parent members of the PFN steering committee met with NEDA Program Director, Laurie Vanderboom, Robbie Munn, NEDA Board liaison working with the PFN program, and Roberta Katz, NEDA Board Chair-elect, who facilitated a "visioning session" to set goals for the year. Current Board Chair, Don Nielsen, Lynn Greffe, CEO, and the new STAR Program manager, Lara Gregorio also joined our discussion.

We addressed the need for the PFN program to grow as we "convene to connect" families throughout the country. Currently, programs that directly support families and friends include the toll-free Helpline, NEDA web site loaded with information, links and resources, educational materials, links to Gurze's book store, treatment referrals, toolkits, NEDA's annual conference, and the PFN

e-newsletter. Discussion focused on how the information for parents, families and friends on the web site could become more user friendly to meet the varying levels of need of the PFN members, how we might begin to find ways for more direct member to member contact, and how we can begin to cultivate local, state-wide and regional networking of the PFN members. All present were in agreement that the PFN needs to establish guidelines and form committees to cultivate what is necessary to allow for the growth of the PFN. This will be accomplished through membership surveys and suggestions, steering committee e-mails & phone conferences and possibly a one day steering committee planning session. As goals are defined and committees form, we will be soliciting assistance from the membership at large.

HIGHLIGHTS FROM THE 2008 NEDA CONFERENCE



There were many new and familiar faces in Austin with over 500 attending. There was much to be learned including new research re: etiology, genetic factors, medical complications and evidence based treatment. Judith Banker, President of the Academy for Eating Disorders, shared a video, made by Laura Collins, supporting the fact that there is no evidence that parents cause ED's. It was

a very powerful moment. Laura's video is available on the F.E.A.S.T. Web site (information below). The majority of the conference sessions will be available on CD-ROM through NEDA soon. What you can't experience from the CD is the bonding and support felt by meeting other family members, sharing their joys and sorrows, and gaining the knowledge that you are not alone on this journey. We've included touching comments of some family members:

Reflections from a sibling perspective

The 2nd Beginning of a Friendship:

Emily, 21 Iowa State University, Ames, IA

I was 13 when I began the darkness that would be my eating disorder. I am 21 now and only in the last six months would I consider myself in stable recovery. My sister has always been my best friend, and at 16, I stopped having real conversations with her. Working to recover this summer, she and I began the mending process to heal our relationship. In our conversations she reminded me that she had been to the 2007 NEDA conference and really learned a lot and enjoyed herself. We discussed going to the 2008 conference together and decided that if one went, the other would go.

I'll admit that I was incredibly nervous to immerse myself in an eating disorder-centered gathering for more than an hour of therapy. I wasn't sure that I was far enough away from my eating disorder to attend without going under. As it turns out, the conference was the best thing that has happened to my recovery process.

I met some of the most amazing people, and my self-confidence grew. People I'd never met before were encouraging me to stay strong and telling me they were proud of my progress. It was an incredible feeling. I learned about treatment, about problem solving, about myself, and most importantly, I learned about my sister.

When I was sick, I never thought about what it would've been like to be in her position. I didn't talk to her because I didn't want to hear anything she had to say about my disorder. But we went to a few of the conference sessions together which started communication between us about the messy subject of eating, and how our family fell to pieces for awhile. The closing night of the conference, she and I had the most intimate and healing conversation I think we've ever had. We were finally both in places in our lives where we were able to share forgiveness and hugs and tears that made the darkness that both of us had felt seem somehow lighter. It was the first time in my life that someone in my family had told me they were proud of me without me scoffing at them. I knew she meant it, and I knew we were healing.

Being at the conference helped me to be proud of myself, and proud of my sister. I grew so much as a person, but we grew as a family too, and I can't be more thankful.

Anna, 24, RN, Denver, CO

My youngest sister and only sibling had always been my closest friend, playmate, and confidant, but when I reached high school, I felt her slipping away from me in a way I had not anticipated. Never in a million years did I dream that she had an eating disorder. When the carefully hidden truth came out when I was in college, I tried everything I could to help her and my family. But nothing I did seemed to make a difference.

After graduating nursing school, I moved to Seattle and started volunteering in the NEDA office. I also worked as a nurse on a pediatric psychiatry unit that included an eating disorders

program, and NEDA seemed like a natural fit. But what I really found in my volunteering was a way to help others affected by eating disorders even as I felt I was failing to help my own sister.

I attended my first NEDA conference at San Diego in 2007 and came out feeling amazingly empowered by the eating disorder community, but I was still unable to communicate with my sister. After 7 years of struggle, I began to grieve the loss of our relationship, but even as I did, she came to me this summer suggesting we go to the conference together. I realized a chance for change and was determined to support her – if she committed to going, so would I.

At the conference, I watched her blossom from the unhappy young woman I'd seen for so many years into a confident and determined individual, ready to stand up and fight the disease that had darkened her world. I was inspired by her motivation and willingness to share openly with strangers and recognized, finally, the sister I thought I'd lost. I am so proud of her for making the decision to not only attend the conference with me but also to continue her recovery daily.

We both acknowledge that there is still work to be done in our family and with each other, but I am hopeful that this is the (2nd) beginning of a beautiful friendship. I am so thankful to NEDA for bringing together both the professional and the personal each year and for freely offering a welcoming place of support for those who need it.

Reflections from mother/daughter perspectives

It is always comforting to meet a person in recovery attending the conference with a parent. Here are notes from two mother/daughter duos we met in Austin.

Carrie Arnold (daughter) and Cynthia Arnold (mom)

Bio note: Carrie Arnold is in recovery from anorexia and maintains a blog about her recovery.

“This was the second NEDA conference we have attended as mother and daughter. Although we have always learned a lot, the networking among professionals and other families struggling with eating disorders has been the most rewarding. We decided to go to NEDA together because we have fought Carrie’s anorexia as a team, and now we are experiencing life and recovery as a team.”

Taryn Benson (daughter), author, Naples, FLA. Lorri Benson (mom), author, Naples, FLA

Bio note: Lorri and Taryn Benson co-wrote the book “Distorted” and were presenters together at the conference.

Lorri told us:

“It was the first time we ever presented a workshop together and it was an amazing experience for both of us. Our peak experience however, was being invited to dinner by a group of other people from our state (Florida) who were previously strangers to us. We were warmly welcomed into this new network of friends. We feel like these are people we will be connected to from here on in!”

Introducing F.E.A.S.T.

A new national family organization, F.E.A.S.T., attended the NEDA conference for the first time. When you go to their web site, please read their report from the conference in Austin and be sure to check out Laura's video: Parent's don't cause eating disorders. Here is basic information from their director, Laura Collins:

Families Empowered and Supporting Treatment of Eating Disorders (F.E.A.S.T.) at: www.FEAST-ED.org was formed in early 2008 by an advisory board of parents who have seen their children through to recovery. F.E.A.S.T. was a first-time exhibitor at the recent NEDA conference in Austin, and all eight FEAST volunteers enjoyed the experience and plan to return next year. In addition, we were very grateful to NEDA for donating the use of a conference room for a get-together before the conference that brought scores of people together to meet in person many who had only been "virtual" friends.

Artist Shares Her Work and Her Heart in Austin

Judith Shaw was the featured artist in the PFN Hospitality Room at the conference. Her work tells the poignant story of her recovery from an eating disorder she developed as an adult.



She told NEDA that the most touching thing she experienced in Austin as a result of her art display being there were the many people who voiced their heartfelt thanks to her for revealing her journey in this personal way. They were helped by just viewing the artwork. Judith said, "I was utterly not expecting that I would be helping people and connecting in so personal a way. It was gratifying and totally worth every moment being there"

New! Meet PFN Members In Action

The PFN's e-newsletter's layout specialist and co-chair of maudsleyparents.org, Jane Cawley, also attended the meeting in Austin. Little did we know that she is a woman with many talents and a special interest in getting new research information out to families through video. While we were in Austin, Jane uploaded two of her new videos to the NEDA web site. You can view them [here](#).

The videos feature leading researchers Dr. Walter Kaye of UCSD, member of NEDA's Board of Directors and NEDA's Research Committee, and Dr. Cynthia Bulik of UNC Chapel Hill, recipient of NEDA's 2008 Price Family Award for Research Excellence. Here are a few words about this project from Jane:

"There is so much more information available about eating disorders than in 2004 when my daughter was diagnosed with anorexia nervosa. My goal is to help get that information into the hands of families fighting these illnesses. I hope to add to the series over time with new research-based videos. I am delighted to see them on the NEDA website where they will reach so many.

It was a pleasure and a privilege to sit down with top researchers in the field and learn more about their work. Scientists are turning a corner in understanding eating disorders. The new work is exciting and we seem to be on the brink of a new, more hopeful era. As yet, ED research is woefully underfunded and there is a dire need for research-based information to help guide efforts in so many areas. I hope sufferers and families will take the message of the videos to heart, move beyond stigma, and focus on solutions to these serious illnesses.”

STAR Program

The STAR program state leaders are leading the charge to get out the message about the Patient Bill of Rights (Worldwide Charter for Action on Eating Disorders)! These are PFN members, connected by their hearts and their desire to see relief and real change for families affected by the devastating financial and emotional hardships of eating disorders. The first of many rallies at the steps of state legislatures were in California this week. The members there reported a sense of enthusiasm and inspiration at being together. They witnessed a “good vibe” that will carry the message across the nation that it’s time for eating disorders to be recognized as the serious mental health disorders that they are. They must receive the same level of attention as other comparable diseases from insurance providers.

Report : Eating Disorder Coalition’s Press Release on Mental Health Parity

The EDC tells us they applaud Congress for their commitment to eliminating discrimination in health care coverage against people suffering from mental disorders.

After tireless negotiations between differing House and Senate versions, both chambers came together to pass mental health parity this year.

This bill requires group health plans that currently offer coverage for mental health and substance-use disorders to provide those benefits in the same manner as benefits provided to all other medical and surgical procedures covered under the plan. It also

prohibits group health plans from imposing discriminatory annual/ lifetime dollar limits, co-pays and deductibles, or day and visit limits unless similar limitations or requirements are imposed for other medical and surgical benefits.

For More Information: [Mental Health Parity](#)



The passing of the mental health parity bill is very exciting. However, it is just the beginning. It has its limitations, which we hope to address in one our next newsletters so that we can continue to assist with advocacy, as needed.

I hope the stories in this letter regarding all of the events that took place in Austin have each of you starting to think that you'd like to join NEDA next year! It was so wonderful to meet and connect with so many family members who understand what we're talking about. We gain knowledge, support, & strength and are empowered to stand up for our loved ones and ourselves and speak with one voice to encourage the growth and change needed in the field of eating disorders. Once again, I was grateful to all of the dedicated professionals in this field and appreciate that they are working as hard and as fast as they can to help their patients recover their lives.

In our Dec. newsletter we will be brief and will focus on "Helpful hints to survive the holiday season" and begin planning for National Eating Disorder Awareness Week (NEDAW) at the end of February. Please send us:

- Hints that helped your family get through and even enjoy the holiday season
- Ideas you might have for NEDAW! Did you sponsor or attend an event that you thought worked well?

We'd love to hear your ideas and see your pictures! PLEASE SEND all ideas to: pfn.newsletter@myneda.org by November 21st so that we can share them with the entire PFN membership. Also, e-mail us any feedback re: what the PFN can do for you, or how you can help the PFN with your talents and interests. We will begin to connect people with similar interests to members of the Steering Committee so that we can all play a part in the mission "To support those affected by eating disorders and be a catalyst for prevention, cures, and access to quality care"

Keep networking,

MB Krohel



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might be interested.*

*Joining the PFN is free and just one click
away...Join PFN here*