

*Welcome to the PFN e-newsletter written with you in mind by PFN committee members and NEDA staff.  
Best to you and yours,  
Laurie Vanderboom, Program Director*

Dear Parents, families and friends,

We hope the flowers are opening where you are. Here in the great Northeast winter is, at last, turning into spring! While some were hibernating, many PFN/NEDA members celebrated National Eating Disorder Awareness Week all around the nation. You can see pictures of many of the interesting activities at the NEDA website: [nationaleatingdisorders.org](http://nationaleatingdisorders.org).

Inside this newsletter you will find:

- \* A note from Lynn Grefe, CEO of NEDA
- \* Information on an eating disorders Photo Recovery Project
- \* A description of MEDA, one of NEDA's partner agencies
- \* Information about the World Charter for Action on Eating Disorders
- \* Information on upcoming conferences
- \* News from NEDA

## Greeting from Lynn Grefe, NEDA's CEO

Dear PFN Members,

Indeed, it is spring and the first blossoms of our new strategic plan are budding. Our new website is launching any day, thanks to our Dad's Technology Campaign, led by PFN members Buddy Howard and David Charron. Their commitment to lead that effort made it possible for us to create this new site and completely overhaul our database infrastructure. Our efficiency will greatly improve as a result of these changes while our website will hopefully be more welcoming and easier to navigate, enabling individuals and families to more easily find information, resources and referrals as they search for answers and treatment possibilities. Even more exciting is that it will include our new "toolkits" for parents and educators. Thanks to members of the PFN and educators who participated in the focus groups as we developed these kits, telling us what they wanted



Lynn Grefe

and needed, and how they wanted to receive the information. It is a significant start to matching program goals to our mission of supporting those affected by eating disorders. With assurances of continued funding, we hope to expand and update these toolkits as needed and add more target audiences like nurses and coaches who need vital information in a way that relates to their needs to help those affected.

In line with our new mission and strategic priorities is our commitment to support and build our Parent Family and Friends Network. The PFN is our ground force of supportive and concerned parents, families and friends willing to assist us in achieving our program goals. The PFN is so needed for support of our families at the conference and networking throughout the year, sharing information with others and helping people to know that they are not alone in these challenges. Our PFN members are our greatest messengers, best support system for others and our invaluable resource to ensure that NEDA provides vital information and programs in your communities.

As the PFN evolves, it is important to take a moment to thank those who first created and launched the PFN, Past Board Members Dr. Doug Bunnell and Carolyn Costin in partnership with family member Steering Committee Co- Chairs Jaye Arouty and Jennifer Sawhill. Through these past several years the PFN members stated their case for treatment center accreditation, and there is now a strong task force underway; they asked NIMH to give them “proof” of the medical seriousness of eating disorders in writing, and they received the letter from Dr. Tom Insel, Director of the National Institute of Mental Health, on the record; five years ago at the conference they started a welcome area with a spattering of a few moms, greeting new people, and today they have built their conference efforts into a family room of hope and remembrance and a real plan for helping new families; and, finally, M.B. has created a PFN newsletter, to directly connect to all PFN members, with a keen sense of what parents, family and friends want to hear. All volunteer hours spent in support of the goals, all very impressive.

I am honored, as a member of the PFN myself, to know that so many people find some personal time to support and assist other NEDA friends, families and the programs – whether it be working on the Helpline; through advocacy and a letter written to a legislator; delivering informational brochures to our own doctors office; asking our hairdresser to participate in NEDAwareness Week or holding a garage sale to help raise funds to support these important programs; to making new members of the NEDA family feel welcome at our conference; to taking our message of the need for “patients” rights for those affected to every policy maker in the country. There is something for everyone who is ready to give back; even a few hours that you donate a year in support of NEDA’s work helps us make a difference for others and we are grateful. Keeping our lens focused together has the potential to create a genuine picture of progress in this field. For those who are challenged and looking for information and support, we hope that all of these efforts will assist you though this difficult journey. One of our top priorities is to support those affected by eating disorders, and it is through our programs that we hope to deliver on that promise.

Thank you....you helped us create the vision through responding to our surveys and with your help, we will all be a piece of the reality as we try to change the course of these difficult illnesses not only for our own loved ones, but also for others to come.

Warmly,  
Lynn Grefe  
C.E.O. and member of the PFN

## Photo Recovery Project

At the 2007 NEDA conference, Caitlin Scafati shared her photo project on eating disorder recovery. Caitlyn tells us what it is all about:

*“I created the emBODYment project because I wanted to show that recovery from eating disorders is possible. This may seem like a simple statement, but for so long in my own illness just the opposite seemed true. Whenever I was shown a picture of someone with an eating disorder, the person was usually emaciated. Through the emBODYment project I wanted to show strong, healthy individuals who were in recovery or recovered.*

*Initially, the project was conceived to be presented at the 2007 NEDA conference in San Diego. Since its creation, I have been fortunate enough to share the emBODYment project on NBC’s “Today Show” as well as at Dartmouth College, where it is currently hanging through Winter Quarter 2008.*

*There are currently 10 photos in the project although I received an enormous response from across the country and from one individual in Canada. The individuals included are from Boston, San Francisco, Los Angeles, and New Hampshire among others. I have received wonderful feedback from both families and individuals in recovery, including one woman who was inspired to retroactively fight her insurance company now that she is in recovery.*

*I continue to receive requests for information and volunteers for participation and hope to find funding to continue the project in 2008. The initial project was entirely self-funded. Please visit [www.emBODYmentproject.com](http://www.emBODYmentproject.com) for more information.*

We hope this project continues to grow and is seen by many!

## NEDA Network Provider Information

MEDA (Multi-Services Eating Disorder Association) is a member of the NEDA Network. Its headquarters is located in Newton, MA. However, they are there to assist patients and families anywhere. Here is a brief description of MEDA and the services it provides from Beth Mayer, MEDA’s director:

The Multi-service Eating Disorders Association (MEDA) is a national nonprofit organization that treats individuals and families struggling with an eating disorder and works to prevent the proliferation of eating disorders within our society. MEDA takes a three-pronged approach to diminishing the pervasiveness of eating disorders, uniquely offering a combination of education, prevention and treatment. Based in Newton, MA and established in 1994, MEDA is a critically necessary organization that annually serves thousands of people from across the nation. Many of

MEDA’s professional staff, clinicians, and volunteers have recovered from eating disorders.

MEDA provides individuals and families with treatment referrals and plans in a quick and efficient manner.

MEDA offers phone and in-person consultations and assessments while also facilitating a number of weekly support groups. MEDA also offers coaching sessions for parents and loved ones as well as a weekly group specifically for this affected population. The MEDA helpline and website are wonderful ways to become familiar with MEDA and the types of programs that are run. For more information on MEDA please visit

[www.medainc.org](http://www.medainc.org)

## World Charter for Action on Eating Disorders

The annual meeting of The Academy of Eating Disorders will take place in Seattle this May. At that meeting, NEDA & AED will launch the World Charter for Action on Eating Disorders. You will find a copy of the Charter at the AED website: [here](#)



To assist this project, you may make copies and distribute them to all of the people you know that work with and for eating disorders. Lynn Grefe notes: “We are very excited to invite all members of the PFN to partner with our professional members to take the Worldwide Charter for Action on Eating Disorders, authored by the Academy for Eating Disorders, to every state expressing the need for insurance coverage for treatment, educational funding for prevention and expanded research. Hopefully launching this charter will be our strong introduction to policymakers in the US, letting them know that we insist on more attention and funding to begin to solve the challenges of eating disorders.” I will include more information about this project after the May AED conference.

## NEDA Conferences/Seminars

On May 14<sup>th</sup>, NEDA will sponsor an incredible Educators Seminar that is unprecedented in that a group of international experts in the field of eating disorders are in town and have been invited to provide this seminar to local educators, parents, and others who work with youth. For more information and to register on the NEDA website, go to: [Educators Seminar Registration Page](#)

**BREAK THE SILENCE:**  
*Tools for Help, Hope and Healing*



Renaissance Austin Hotel · Austin, TX  
September 18-20

Save the date! September 18-20. Registration is opening soon. The program is now being finalized. A great conference is developing that will bring PFN members together to network and learn from the top speakers, educators, authors and leading practitioners in the field. Watch your email for a MyNEDA update, or visit our website [conference page](#) often for news.

## NEDA News

### **NEDA's Online Store has a homecoming.**

A strategic partnership has been created between the National Eating Disorders Association (NEDA) and Gürze Books, LLC, a Carlsbad, CA company that has specialized in publications about eating disorders since 1980. In the first phase of the agreement, Gürze Books will provide distribution and fulfillment services for NEDA, by processing their consumer sales for NEDA products, such as jewelry, t-shirts, and promotional items for National Eating Disorder Awareness Week. These items will also be available through [Gürze's online store](#) and comprehensive eating disorders resource website. Later, the store—including more than 350 books related to this subject—will be accessible through [NEDA's new website](#).

“The NEDA board and staff are really excited and honored to be working with Gürze Books, because it brings the eating disorders family of pioneers full circle,” said CEO Lynn Grefe, referring to the early 1990's, when

the organization was run by Lindsey and Leigh Cohn, owners of Gürze Books and members of the NEDA Founder's Council.

Leigh Cohn, Publisher of Gürze Books, also expressed enthusiasm, "We've always been supportive of NEDA's mission and are extremely happy to help enhance their efficiency. We're already set up for sales and distribution, and this arrangement lets them focus their attention on activities that are more beneficial to the organization."

### **What does it mean for you, our constituents?**

Now you can shop *two online stores* in one visit! As you shop NEDA's online store for jewelry, posters and/or educational materials you will be able to add books from Gurze to your shopping cart and purchase everything including renewing your membership and even making a donation in honor of someone in one convenient visit.

### **In Closing**

I hope that you find this information useful. Once again, I ask that you contact me and share any ideas or requests that you may have to make this newsletter more beneficial to you. You may reach me at the e-mail address listed below.

In our next letter, I hope to have more information on the Worldwide Charter, a description of another NEDA partner program, and news from the May AED conference. I would like to remind you to look at the initial information about the annual NEDA conference that is now available at the [conference page](#).

We will have much more information regarding the conference as it draws nearer. NEDA's annual conference was one of the most useful tools I found to assist my daughter with her recovery and gain support for our family and myself. I hope you can save the date and join us for a caring, educational and supportive experience.

Keep networking,  
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P.S. Thank you to Jane Cawley for the beautiful new layout!

### **Join the PFN**



Please feel free to forward this newsletter to other parents, family and friends and invite them to join the network by signing up on NEDA's [PFN page](#).