



February 2010 Newsletter

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Hello from the snowy North East!

I hope you all are getting ready to do **just one thing** with our many other PFN members across the country during National Eating Disorders Awareness Week. We offer a simple way for you to bring awareness to your community in this issue: Make a NEDA Educator Toolkit available to your local middle or high school as your “one thing”. It’s easy to do—all the information you need is in the NEDA awareness Week article.

Susan Maccia, PFN Chair

NEDA Invited to the White House

In March, the Obama administration announced the opening of their Office for Women and Girls. NEDA wrote to congratulate them and encouraged a meeting to help “enlighten” them about the severity of this illness that affects so many females. Lynn Grefe, our CEO, was invited and met with their leadership in May. In light of the First Lady’s efforts to combat childhood obesity, Lynn was invited back on February 5th, with 12 other organizational leaders representing children, to provide input and questions about the upcoming campaign. NEDA, as well as all the ED organizations, has been very concerned about the focus on diet and weight. Be assured that she had previously delivered a letter to the White House from the joint national organizations (NEDA, AED, EDC, IAEDP and BEDA) in addition to providing many thoughtful articles, statistics and AED Guidelines. Finally, at this February roundtable, Lynn spoke on behalf of our many families across the country that we speak to and hear from every day, encouraging that the administration “do no harm,” while trying to solve one problem, that they not worsen the landscape for eating disorders. She also spoke

of meeting with 6 different parents in the last two weeks who had lost their children to an eating disorder. They assured her that they are listening and encouraged our continued input into these issues moving forward. You can be sure we will.



It's Time To Talk About It!

Spread a message of hope: Help is available, recovery is possible and those affected are not alone in their struggle! If we all do something, we'll have a huge impact!

NEDAwareness Week 2010, the largest outreach effort on eating disorders in the nation, is just around the corner and **registration is free!** The PFN can be a powerful voice this year, and it only requires a few minutes of your time. [Register today](#) and find out the many ways to do **just one thing** to initiate awareness, education and discussion about eating disorders in your community.

An easy just one thing that all PFN members can do is to print and provide the free Educator Toolkit to local schools. If each PFN member provides the Educator Toolkit to at least one school, we will reach upwards of 3,000 schools nationally! NEDA is providing a pre-written letter for you to use in electronic format or hard copy to introduce the Educator Toolkit. All you have to do is fill out the free registration, then access the school letter (among many other free resources) from the NEDAwareness Week Resource Google Group (you will be granted access within 24 hours of registering). You can present the Toolkit either through an email with the download link, or provide a copy on a CD you create yourself, or you can print the file to present/mail it with the introduction letter.

Special thanks to our **NEDAwareness Week Partner Organizations**, 2010 participation has already drastically increased – more than tripled in total registrations - to be the biggest in NEDAwareness Week history. Find the growing list of Partners on the [NEDAwareness Week homepage](#).



PFN starts NEW national outreach: The NEDANavigators

Picture this:

A parent is frantic. Their child, away at college, is struggling with issues related to their eating disorder. They connect to another parent who listens calmly and offers suggestions for where to turn, what questions to ask and what to do. A sense of relief washes over that worried parent when practical assistance is offered from a caring person, someone who “gets it”, at a critical time.

This true story is from just one of the of many PFN members who've received preliminary training to begin a brand new outreach of the Parent, Family & Friends Network. This outreach is called the NEDA Navigators (NN). Training will open up to all PFN members soon. To be a NN you must have had first hand experience supporting a loved one with an eating disorder. You must be well into your own or a loved one's recovery and volunteer to be

trained in how to personally connect with others to offer encouragement and informal support. NN's are "educated" friends, not therapists.

Navigators will be trained to: (a) respond to families' and individual's initial questions and fears at a time when everything may be confusing for them (b) share their own story responsibly, (c) help people connect to available resources, information and options (d) help people learn what questions to ask as they seek help, and (e) build a healthy relationship of support.

Training sessions to be a NEDA Navigator will be offered via teleconference and webinar every other month. Doug Bunnell, PhD, former NEDA President and Board member, VP and Director of Outpatient Clinical Services of Renfrew Center is leading the trainings.

Upcoming training to become a NEDA Navigator will be announced via a special email from NEDA headquarters. Look for this to email arrive soon!

If you'd like more information about how to join PFN or NEDA Navigators specifically, contact Susan Maccia, PFN Chair slmaccia@gmail.com or Laurie Vanderboom, NEDA Director of Programs pffnetwork@myneda.org



Insurance Terms 101 - What is the DSM?

By Susan Maccia - PFN parent

Living with a family member or friend with an eating disorder is an emotional roller coaster. The ride is compounded by the confusing world of medical insurance. While my daughter was in residential treatment, I made a conscious effort to learn all I could about insurance terminology. This knowledge gave me power to interact with the insurance company on a relatively equal playing field. It gave me the self-confidence I needed to fight for the coverage to which I felt we were entitled under our insurance plan. It allowed me to "check" on the accuracy of my daughter's diagnosis and whether my daughter's mental and physical status at any point in time "fit" the criteria of the diagnosis.

The two most important pieces of information you need when fighting for insurance are 1) the specific diagnosis made by a treatment provider and 2) the criteria used by the insurance company to determine if your loved one's diagnosis is covered under your insurance plan.

The DSM or Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association (APA), contains a description of mental illnesses and the criteria used by most treatment providers to make a diagnosis of that illness. The DSM assigns codes to each mental illness for the purpose of medical record keeping. It is this all important code assigned by treatment providers and used by most insurance companies when making a decision on a claim. For example: if your loved one is diagnosed with an eating disorder, you should be able to obtain the corresponding DSM code assigned to your loved one's case (say 307.1 for anorexia nervosa or 307.51 for bulimia nervosa). It's important to make sure the code is correct. A claim denial often occurs simply from use of the wrong code. Read the DSM diagnosis criteria for the code to make sure your loved one's illness falls into the criteria described in the DSM.



The most recent version of the DSM currently available is the DSM-IV-TR or Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. You can usually find a copy in your local library, you can purchase



a copy or do an internet search. The APA is scheduled to release an updated DSM (DSM V) in February 2010.

If your insurance company does not use the DSM-IV-TR, ask the provider what criteria is used and request a copy of the criteria in writing. Insurance providers may use the Milliman Care Guidelines or some other guidelines prepared outside of the APA.

For more information on navigating insurance and a glossary of terms, visit the NEDA website at www.myneda.org and utilize the Parent Toolkit. Knowledge is power!

Change the Future of Eating Disorders in Your State!



Join the STAR Program to advocate for improved access to treatment or early intervention programs. All across the country volunteers just like you are engaged in grass roots organizing, and working with policy makers, to make a difference. Visit the STAR page of the NEDA website to read about some of the exciting initiatives.



We have many states already engaged in efforts—you can join the team that is active in your state, or get a movement started. No experience is necessary—we provide the training—all you need is the commitment, dedication, and passion to see change. For more information, contact star@myneda.org.

NEDA Network Feature Organization

By Jane Cawley - PFN parent



NEDA Network member, the Eating Disorder Network of Maryland (EDN) in Towson is a terrific resource information and recovery support. I dropped in recently to visit with EDN's Director, Sharon Peterson, LCSW, an energetic and passionate advocate for people with eating disorders and their families. The warm and welcoming headquarters offer various meeting spaces and a drop-in resource room.

One of EDN first goals was to develop a comprehensive referral resource. "There are people from all over the state; some in smaller towns with few resources," Sharon explains, "What we're trying to do is organize everything that's available in Maryland." The website lists a broad range of resources. EDN reaches out to public through a monthly newsletter. Sharon also often speaks on eating disorders at community events.

Free support group meetings are offered. ANAD of Baltimore coordinates with EDN to offer weekly meetings. Every second and fourth Tuesday, Supporting Each Other, a group open to parents, spouses, and friends gets together. Sharon says, "It's very low-key there's no agenda, we want people to be able to just come and talk about whatever. Events include movie nights.

Each year, EDN brings together professionals, people in recovery, and family members to celebrate National Eating Disorder Awareness Week with a free event with guest lecturer. The 4th annual program, to be held on March 7 at Towson University, will feature Chevese Turner of BEDA and Amy Pershing of Bodywise.

EDN also serves eating disorder professionals, hosting quarterly professional workshops. The low cost brown bag lunch series offers an opportunity to update skills, network, and learn about new eating disorder resources, while earning continuing education credits.

EDN has accomplished a great deal in its first few years and shows no signs of slowing down. Sharon will soon restructure office space to create a larger room for movie nights and other events. In addition, plans are in the works for EDN's first-ever NEDA Walk this spring.

To learn more, visit the ednmaryland.org website or call EDN at (410)339-3474. Connect on the web: Follow EDN on twitter [here](#) and become a fan on facebook [here](#).

You Can Help Support NEDA during NEDAwareness Week

NEDA is featured as the Charity of the Day on Goodsearch, February 23rd during NEDAwareness Week. When you use Goodsearch, www.goodsearch.com as your search engine that day, 1 cent per search goes to the cause!

NationalEatingDisorders.org



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