

MAKING CONNECTIONS

NATIONAL EATING DISORDERS ASSOCIATION

An Olympic-Sized Issue?

Eating Disorders and Athletics:
What You Need to Know

PLUS

**Eating Disorders and
Older Women**

Dr. Cynthia Bulik

We Can Change the Media

Julia Bluhm

Overcoming Trauma

Caroline Rothstein

Recovery in College

Nancy Hemendinger



NEDA

Letter from the PFN Chair | BY Deborah Kreiger, Florida

Hello Everyone,

I want to begin by expressing my gratitude for your very positive feedback about the newsletter.

Many of you have shared with us

just how much the articles resonate in your personal lives while others have found opportunities to engage in activities and programs because they see a need and feel empowered to address it. Thank you for sharing your thoughts with us; your ideas and comments are always welcome, appreciated and most importantly, valued.

The date on the calendar reminds us that students are returning to school



all across the country. With classes come extracurricular activities, and the focus of this issue surrounds coaches and athletes. The information is timely, and I hope you find the articles both enlightening and helpful.

Did you know that we all have an opportunity to meet in person this fall? The Annual NEDA Conference, October 11-13, brings together top physicians, treatment professionals and advocates for the opportunity to learn from and support one another, and as family and friends, we are truly fortunate to be included in this opportunity. There are a couple of important additions to this year's conference and one is the NEDA Buddy Program; it is designed to help those of you who are attending for the first time and perhaps feeling a bit intimidated. By requesting to

participate in the Buddy Program (you can do this when registering for the conference) you will be matched with someone in advance, so you can begin communicating before you arrive in St. Pete. Additionally, be sure to mark your calendar for the Support and Recovery Roundtables that will take place throughout the day on Saturday. This will be a tremendous opportunity to interact with others who have similar experiences, personally or with a loved one, and to share experiences, discover new resources, discuss self-care and learn coping skills.

I look forward to seeing many familiar faces and welcoming new ones this October in St. Petersburg, Florida. Register now at www.myneda.org/conference, and be sure to stop by the PFN table and say hello! ■

PFN Steering Committee:

Deborah Kreiger, Florida (*Chair*)
Lorri Antosz-Benson, California
Jane Cawley, Maryland

Nancy Hemendinger, New York
Phoebe Megna, Connecticut
Mike Polan, New York

IN THIS ISSUE

- | | | | |
|----|--|----|--|
| 2 | Letter from the PFN Chair | 14 | Help is at Hand with New Mobile Application for Eating Disorders |
| 3 | Editor's Note | 15 | Continuing Recovery at College: Considerations for Parents |
| 3 | What Readers Are Saying | 16 | Congressional Caucus Recognizes Eating Disorders |
| 4 | Why Should You Attend the NEDA Conference? | 17 | We Can Change the Media! |
| 6 | Eating Disorder Behaviors and Weight Concerns are Common in Women Over 50 | 18 | Art Therapy Applied to Somatic Experiencing and Eating Disorder Work |
| 7 | Hope for Recovery for Chronic Sufferers | 19 | Overcoming Trauma in the Throes of an Eating Disorder |
| 8 | A Coaches Guide to Eating Disorders | 20 | Richard Hubbard's Moving Tribute to His Sister's Memory |
| 10 | The Role of Coaches: Balancing the Focus on Health, Fun, and Performance in Our Student Athletes | 21 | Insurance Tricks to Watch For |
| 11 | Pursuit of the Impossible: Perfection | 23 | Meet the NEDA Staff! |
| 12 | A Balanced Relationship to Exercise: A Daughter's Struggle, A Mother's Journey | 23 | NEDA Network Spotlight: Ophelia's Place |
| 13 | My Recovery: I Did Not Choose this Illness, but I Choose to Get Better Everyday | | |

Editor's Note | BY Susie Roman, *Director of Programs*

Dear Readers,

We are delighted to bring you another issue of the PFN Newsletter, which reflects the experiences, concerns and resiliency of a diverse Parent, Family and Friends Network (PFN). Each quarter, as we receive submissions from readers like you, I am struck by the insight, honesty, compassion and strength in your stories. And, I am grateful to the professionals that are willing to share their expertise with families, so that they can provide the best possible support for their loved one. Bringing families and professionals together to learn from one another is critical, and we are thrilled to be able to say that such collaboration is thriving in the pages of the PFN Newsletter.



Thanks to the many who take a few minutes to send their feedback, we know that readers appreciate hearing from others with similar experiences, and the articles provide practical tools, a sense of community and hope. Many personal connections have been made between readers and authors, and we encourage you to email us if you'd like to connect with one of the contributors.

Making Connections is a wonderful reminder that no matter where you are in your journey, you are not alone. There are many people out there who have been through it and are sharing the lessons they learned along the way to help guide others. So, email

pffnetwork@myneda.org and tell us what you would like to see in future issues. The PFN Newsletter is shaped by you, and we welcome your ideas, questions and contributions.

Thank you for reading *Making Connections*. We hope you enjoy it! ■

What Readers Are Saying

"I just read your quarterly newsletter and really enjoyed it! I've read several 'newsletters' but yours not only had great articles, but the layout was spectacular!" — A Dad

"Thank you both for writing about your sisters. I am so sorry for your losses – but it touched me and made me think maybe I shouldn't give up and maybe someone really will truly miss me if I'm no longer here." — A reader working towards recovery

"The Spring 2012 PFN Newsletter is really well done, and I liked that it focused on the sibling theme and extends a warm welcome to the Florida conference. Thanks for creating such an informative newsletter!" — A Mom

"I just finished reading your most recent PFN quarterly newsletter, Making Connections, and found it to be both an informative and emotional read. I'm writing because I found the article written by Elizabeth Sexton, 'A Sibling's Perspective,' to be extremely relatable. In it, she mentions wanting to start a support group specifically catered to siblings - which amazingly enough, is a project I am currently undertaking. I would love to get in touch with her to see if she would be interested in working together." — A Sibling

"Thank you so much for an outstanding print newsletter! It's an excellent publication about resources and education our community is so desperately needing. So, THANK YOU!" — A Treatment Professional

"It is a fantastic newsletter filled with great information!" — A Mom





NEDA CONFERENCE 2012

October 11–13, 2012
St. Petersburg, FL

What About Us?
*Diversity and Complexity
in Eating Disorders*



Why Should You Attend the NEDA Conference?

Because you'll walk away feeling more knowledgeable, skilled and inspired.

Those who've attended before tell us the NEDA Conference offers a unique and exciting opportunity to meet researchers, treatment professionals, individuals affected, family members, educators and activists alike. You'll learn a tremendous amount from the many exceptional and diverse Breakout and General Session speakers, and have the chance to chat with them over lunch or at one of the socials!

Whether you are personally affected, have a loved one struggling, are a dietitian, treatment provider or educator in your community, there's something here for you. **Don't take our word for it, take theirs:**

"Words cannot express how amazing this conference was. It was so encouraging to meet so many amazing professionals in the field that I had, prior to this, only read about. The topics for seminars were diverse and interesting, and I feel like I have a lot more information to share. I can't stop raving about this conference!"

— Individual in Recovery

"I would not trade my conference experience for anything at all, and I can honestly say that both conferences that I have attended have played essential parts in my own recovery."

— Individual in Recovery

"It provided attendees a global perspective about eating disorders. There is a place for everyone at the table."

— Family Member

"Loved, loved, loved the Keynote speakers! They gave me information I could use IMMEDIATELY in my practice."

— Treatment Professional

"I felt the conference was extremely informative. It opened my mind to new thoughts and concepts about eating disorders. It reminded me that even though I may think I know a lot about a topic, there is always still more to learn!"

— Individual in Recovery

"Being in recovery for only 1 year, it gave me the strength, motivation and determination to conquer this battle and to help others do the same. It was absolutely fantastic!"

— Individual in Recovery

"I enjoyed being around other people passionate about recovery and eating disorders education. I also enjoyed learning about the different treatment center options available and talking to the staff representing the organizations. The breakout sessions were informational and could be selected according to my interests and preferences."

— Educator

"I came home with excellent information that I could share with my daughter. I also met some amazing people that gave me such hope. I also feel that all the folks that work and are involved with NEDA are so approachable. Thank you for your hospitality. I never felt alone the entire weekend."

— A Mom



"I had the opportunity to eat dinner with presenters after the conference and connect on a personal level. Thanks to this experience I now have two really inspiring mentors."

— Individual in Recovery

"Being a parent of a daughter who is working on recovery, it helps to be with others who 'get it' and make connections on a personal level. The wealth of information I was able to get from this conference cannot be measured."

— A Mom

"So much information, so many brilliant people and smiling faces are brought to this conference - it is hard to stay away from it! Such a great atmosphere! It is also good to be reminded, as a woman in recovery, that I am not alone!"

— Individual in Recovery

"Amazing. I loved that it's not just clinicians, but clients and families. I love that authors, researchers, experts, and clinicians are all there and accessible. I valued the diversity AND aptitude/quality of the sessions and presenters. And, I met amazing people from all over the country."

— Treatment Professional

REGISTER NOW!

Visit the NEDA Conference website at www.myneda.org/conference to check out the many topics being covered – including the new Support & Recovery Roundtable Series, information about Continuing Education Credit Hours for professionals, the NEDA Buddy program for new attendees, information about featured speakers, **Cynthia Bulik**, PhD, FAED (Keynote presenter), **Timothy Brewerton**, MD, DFAPA, FAED, DFAACAP, **Terry Wilson**, PhD, presenters on the Family Panel, and closing speaker, **Susan Fales-Hill**. We look forward to seeing you there! ■



Susan Fales-Hill, closing speaker



Eating Disorder Behaviors and Weight Concerns are Common in Women Over 50

BY Cynthia Bulik, PhD, FAED, Director of the University of North Carolina Eating Disorders Program, author of *The Woman in the Mirror*, and 2012 Annual NEDA Conference Keynote Speaker

A total of 1,849 women from across the USA participated in an on-line survey as part of the Gender and Body Image Study (GABI). The primary finding is that age is no barrier to disordered eating. In women aged 50 and over, 13% reported some current core eating disorder symptoms, 3.5% reported binge eating, nearly 8% reported purging in the past five years, and more than 70% were trying to lose weight. The study published in the *International Journal of Eating Disorders* ([http://onlinelibrary.wiley.com/journal/10.1002/\(ISSN\)1098-108X](http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1098-108X)) revealed that 62% of women claimed that their weight or shape negatively impacted their life.

Our study was designed to cast a wide net and to address various symptoms of eating disorders. The data confirms what many of us who run treatment programs have been witnessing as more and more women in midlife and beyond are seeking treatment. To many people who are still under the false impression that eating disorders are the province of adolescent and young adult women, these results are a real eye-opener. We absolutely have to eliminate these damaging stereotypes that hinder accurate detection and treatment of eating disorders across the lifespan.

Going beyond the study, many people wonder how eating disorders in midlife and beyond differ from eating disorders in younger individuals. The exact symptoms differ very little; however, the context can differ dramatically. When a 50 year old woman is struggling, it can effect her marriage or partnership, her children, her work, and even her parents if she is caring for them as they age. Another difference is related to treatment. Most



of our treatments have been developed for adolescent and young adult patients. Traditional family based therapy, although valuable for youth, may no longer be feasible or appropriate if you're 60 or if your parents have passed. So we may need to look to partners for support and participation in therapy such as our Uniting Couples in the treatment of Anorexia Nervosa (UCAN) approach.

We are also concerned about the health effects of eating disorders in older women. Eating disorders take a physical toll on the body, and our bodies become less resilient with age. Older bodies have more difficulty bouncing back from the effects of an eating disorder, so we are seeing more gastrointestinal (e.g., gastroesophageal reflux disease or GERD), cardiac, bone (e.g., osteoporosis), and even dental effects of eating disorders as women mature.

The most important take home message for clinicians is to keep eating disorders on their radar screen regardless of the age of the patient — this means anorexia nervosa, bulimia nervosa, binge eating disorder, as well as symptoms of these disorders if a person does not meet full diagnostic criteria. Eating disorders are stigmatized at any age, but many adult women are especially hesitant to bring up their eating disorder with their health care providers for fear of being told that they should have grown out of it, or that it is a young person's disorder. Clinicians need to be sensitive to this and to consider the possibility of eating disorders regardless of the age of the patient.

We would like to conduct a larger study with a more diverse population, so that we can determine the extent to which these patterns are seen in various racial

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Hope for Recovery for Chronic Sufferers

By June Alexander, Australia

We know that early intervention is critical for those struggling with an eating disorder, and research supports the use of Family-Based Treatment (FBT) as a front-line option for treatment of anorexia in children and adolescents. But what about when an eating disorder has a twenty-year head start before diagnosis? Is there any hope of recovery? Yes!



I developed anorexia at age eleven, transitioned into bulimia in mid-adolescence, and began recovery treatment when correctly diagnosed in my thirties. By that time, I really had no idea who I was; my thoughts and behaviours were entwined and entrenched with that of the eating disorder. My parents and sister had despaired at the 'loss' of their daughter and sister.

I despaired too, at the loss of my self. Thankfully, in my late 20s, love for my young children inspired me to find a way to seek recovery. This took many years. The learning and applying of coping skills was essential in regaining a sense of identity – and feeling safe, secure and stable.

Initially, my thoughts needed to be handled consciously. In my forties, a therapist encouraged me to identify the thoughts that belonged to the real me, and build on those. At the same time,

I needed to learn to catch, defuse and delete the eating disorder (ED) thoughts. Starving and bingeing was not the way to cope with feelings. "Focus on your feelings and the food will take care of itself," my therapist said. Learning to let entrenched behaviours go was scary, as they had to be replaced with new, safe behaviours. I had to become sufficiently self-aware to say to myself: "What's bothering me right now? What can I do to deal with this right now?" I learnt to listen to music, walk my dog, talk to God, call a friend and sort my thoughts while walking. Doctors insisted I say the mantra "I deserve to be treated with respect," over and over, until it gradually sunk in.

I had to stop counting calories and tell myself that "I don't need to binge today because I can eat tomorrow"; that "even if I do binge today, I must eat tomorrow." "I must always eat breakfast, and lunch and dinner." For years I had not eaten anything until six o'clock in the evening, fearing that if I started to eat, I wouldn't be able to stop. To leave the eating disorder behind, I had to eat normally and feed my brain regularly and with different foods. Many times I had despaired that I would never be able to look forward to a meal or eat three meals a day; that I wouldn't know when I was hungry or when I had eaten enough. But practice makes perfect. Since age 55, in 2006, regular meals and good nutrition have led to an amazing transformation in thought patterns. I take pleasure in feeling what my body wants, and what foods I would like to eat for my next meal. Being free of the rigidity of the

illness behaviours is a luxury for which I give daily thanks.

I experienced anxiety before and after my eating disorder, and medication had been a great help. However, now a far more pleasurable solution appeared – in the form of a new generation. Such is the power of love, that I have eaten three meals and three snacks every day since the birth of my first grandchild in September of 2006, and have required no anti-depressant or anxiety medication. Lucky me.

Looking back, I wish someone had been able to say to me before I married: "Look, that torment you feel is due to eating disorder thoughts and behaviours. This is why you're feeling this way; this is why you're acting this way. You have an illness and we can help you fight it. We can give you and your family skills. Those thoughts belong to the illness, and these thoughts are the real you; we're going to help you strengthen the real you." That would have been incredibly helpful.

I remain amazed and enthralled and horrified at the ability of an eating disorder to twist and turn words. Not only the spoken word, but also the silent words that for decades raced incessantly, like champion dodgem cars, around my mind. Say one word and my resident eating disorder would grab and magnify it to the point where confusion reigned and common sense was vanquished. One word could trigger a thousand irrational thoughts. Today I know that peace can be achieved, and the ED silenced. The struggle is worth it for life is beautiful, absolutely. ■

► Eating Disorder Behaviors and Weight Concerns in Women Over 50 *continued*

and ethnic groups and to determine the role that menopause has on the emergence of eating disorder symptoms. ■

If you want to link to websites <http://uneatingdisorders.org> and <http://womaninthemirrorbook.com>

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[June Alexander is the author of *Hope at Every Age: Developing an Appetite for Recovery*, her memoir, *A Girl Called Tim*, and co-editor of *A Collaborative Approach to Eating Disorders* and *My Kid is Back: Empowering Parents to Beat Anorexia Nervosa*]



IN FOCUS

COACHES and ATHLETES

A Coaches Guide to Eating Disorders

Adapted from NEDAwareness Week 2011 Coaches Guide | BY Roberta Trattner Sherman, PhD, FAED

Support participation can be a very positive experience for an individual in that it can aid in developing self-esteem, a sense of competence, and physical conditioning, in addition to providing opportunities for healthy competition. At the same time, there are aspects of the sport environment that can increase a person's risk for developing disordered eating. This concern, however, should not be misconstrued to mean that sport participation should be avoided. It is not sport or sport participation that needs to be avoided, but rather the risks often found in the environment.

Eating Disorders: What They Are and What They Are Not

Eating disorders are not simply "disorders of eating." Also, they are not simply a misguided attempt to be thin; nor are they simply a sport participant's means to reduce body weight or body fat in an effort to enhance sport performance. They are mental disorders that manifest themselves in a variety of eating and weight-related signs and symptoms. They are not caused by sports or coaches, although sports and coaches can increase the risk of developing such a disorder or exacerbate an existing disorder. Rather, they are potentially life-threatening disorders with multiple determinants and risk factors, including socio-cultural, familial, and personality factors, as well as genetics.

Identification Difficulties

Athletes are probably more at risk for developing eating disorders than non-athletes because they experience the same eating disorder risks as non-athletes, but also face additional risk factors within the sport environment. Because treatment cannot occur until the athlete has been

identified as symptomatic, a risk to athletes is that identification is more complicated in the sport environment. Several issues can make identification more difficult. One of these is the (mis)perception of eating disorder symptoms as "normal" or even desirable. For example, dieting, weight loss, and excessive exercise are



eating disorder symptoms. However, in the sport world, where leanness and hard training are desirable traits rewarded by many coaches, such symptomatic behaviors, along with perfectionism, are apt to be viewed as traits of a good athlete. Even physiological symptoms such as amenorrhea may be viewed as "normal." The aforementioned symptoms are even less likely to be viewed as symptoms when the athlete is performing well, because there is often a "presumption of health" with good sport performance.

Recommendations for Coaches

Coaches are in the ideal position to identify symptomatic athletes because they spend so much time with them. It is therefore important for coaches to be aware of the physical/medical and psychological/behavioral signs and symptoms of disordered eating. (See Table) Additionally, coaches have considerable influence with their athletes. Thus,

their comments about weight are very powerful. As tempting as it may be to focus on loss of body weight or body fat to enhance sport performance, athletes and coaches need to be aware of issues regarding not only sport performance but also health. Sport performance is like most human behaviors in that it is determined by multiple factors. Leanness for some athletes is probably one of them, but it is one that is likely to increase the risk of disordered eating. Focusing on the other factors such as mental preparation, confidence, and physical factors such as endurance, strength, etc. is less likely to increase the risk. Other than genetics, the factor that probably plays the greatest role in sport performance is (good) health, and other than genetics, probably the greatest contributor to good health is good nutrition.

Additional information is available through the [NEDA Coach & Trainer toolkit](#) located under Information and Resources on the NEDA website, www.myneda.org.



And from the *NCAA Coaches Handbook: Managing the Female Athlete Triad* (NCAA, 2005). To download the manual, go to: <http://www.ncaa.org/wps/ncaa?ContentID=1446>, then follow the link to Female Athlete Triad Prevention. *Eating Disorders in Sport* (Thompson & Sherman, 2010) provides a thorough discussion of the above topics.

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What should you do if you are concerned about an athlete? *From the NEDA Coach & Trainer Toolkit:*

Don't try to manage the situation alone! People and resources to involve:

Health Services at your school. (Ideally there is a designated physician or nurse who is educated in these matters.) They can help by:

- Connecting the athlete with a doctor for examination
- Monitoring an athlete for weight and vital signs
- Weighing in athletes for weight-restricted sports
- Giving a talk to your team

Mental Health Services. (Psychology/psychiatry/social work.) They can help by:

- Connecting the athlete with a therapist
- Talking to the team if there is a designated specialist
- Informing you of the school's policy on eating disorders

- Aid in handling athletes who refuse to seek treatment or address the problem

Nutritionists. They can help by:

- Giving an athlete a meal plan
- Talking to the team about healthy eating for performance

Trainers. They can help by:

- Having a good enough rapport with athletes to sit a player down and express concern
- Giving a talk on the importance of nutrition in strength and endurance building

Tips on How to Positively Intervene. *From the NEDA Coach & Athletic Trainer Toolkit:*

1. Approach your athlete sensitively and in private, while being as direct and straightforward as possible; cite the evidence you see for disordered eating, the impact of his or her behaviors on both individual and team performance, while also expressing your concern for the athlete's health and well-being.
2. Do not judge or criticize your athlete. The goal is to help the athlete tell his or her parent/caregiver about the disordered eating, if he or she has not already done so.
3. Seek help as soon as possible. Make a prompt and appropriate medical referral to a healthcare specialist familiar with treating eating disorders (e.g., physician, therapist, eating disorder specialist, or dietitian). Voice your concerns to a responsible family member or caregiver and to the school's student assistance program or health services. Early detection increases the likelihood of successful treatment, as well as decreases the likelihood of serious or long-term medical and psychological consequences; left untreated a problem that begins as disordered eating may progress to an eating disorder.
4. Encourage your athlete to seek treatment. Ideally, an athlete can stay involved in his or her sport while seeking treatment; however, when physical health is at risk, be prepared to encourage the athlete to abstain from participation until given a doctor's permission to return to sport participation. Consider the whole person when making decisions about an athlete's level of participation in sport: physical and emotional/ mental health.
5. If your athlete is noncompliant with treatment recommendations, consult with the treatment team about suspending participation until the athlete is willing to comply. This course of action may seem harsh. Tell the athlete that the suspension may feel like a punishment, but is actually a protective action to guard against possible physical and psychological harm. It is a communication that says that health is more important than sport. Even though this communication is a positive one, it still should be approached cautiously. Reassure the athlete that his position on the team will not be jeopardized by seeking treatment.
6. Be open and cooperative with the treatment team. The most effective treatment for an eating disorder is to utilize a collaborative treatment approach consisting of a team of health professionals (e.g., physician, therapist, dietician, etc.). As a coach, your support of, trust in, and cooperation with, the team's treatment plan will be critical to your athlete's successful recovery.
7. As a coach, your involvement and positive communications are very important for your athletes. Be a source of support. Try to maintain open lines of communication with athletes dealing with eating issues and support them in their recovery. Ask what they need, what might be helpful in their recovery. Be as sensitive and understanding as you can. With adolescent athletes, be alert to changes in self-esteem that can make their recovery effort more difficult. ■

References

National Collegiate Athletic Association. (2005). *NCAA coaches handbook: Managing the female athlete triad*. Indianapolis: The National Collegiate Athletic Association.

Thompson, R.A., & Sherman, R. T. (2010). *Eating disorders in sport*. New York: Routledge.

The Role of Coaches: Balancing the Focus on Health, Fun, and Performance in Our Student Athletes

By Mike Polan, *New York, NEDA Navigator*

Having coached 30 plus years, I never really took into consideration or felt the need to address the importance of nutrition and athletic performance with my athletes. I always assumed it was common knowledge. That is until my daughter was diagnosed with anorexia at the age of 10 years old. After the diagnosis, she struggled with this illness for 8 years and has been in recovery for the past 2.

There is extreme pressure on today's student athletes to do well academically, athletically (including travel teams) and socially. As seniors, there are additional pressures of college applications, AP classes and community service projects. With these kinds of schedules, I am surprised they have time to sleep.

I honestly believe that many coaches don't realize the schedule most of their athletes maintain, and are primarily concerned with performance on the athletic playing fields. With these rigorous schedules, something has to give. Talking to some of my players, and my own children, I was surprised that some students do not have time to have a lunch period scheduled into their school day. Therefore, they are eating on the run, or even worse, not eating at all. After school, they are off to practice without having eaten since breakfast and probably will not eat again until after practice at dinner.

As a coach, I believe it is my responsibility to be in tune with my students/athletes and take the time to discuss the importance of nutrition in their lives. Today, when I see my athletes tired and lethargic, the first thing I ask them is, "What did you have for lunch?" Most times, they will tell me they had next to nothing for lunch or they had their school lunch at 9:30 in the morning. I make it a point at the start of every season to discuss with my players the importance of nutrition. I tell my players it is essential to eat a healthy lunch, a healthy snack before practice and on days when we have away games, to pack a sandwich and a drink for after the game. I explain the importance

of having a balance between exercise and nutrition because lack of nutrition leads to poor performance, lack of energy, lack of focus, and a greater chance of injury.

Coaches and parents also need to be aware of the impact of what they say in regard to weight gain and nutrition. I have heard track coaches say to their athletes, "You need to lose 10 pounds to get your times down," or "The reason your times are slower is because of your weight gain since last season." Comments like these from coaches and parents (it happens more often than you think), who they respect and look to for guidance, can contribute to a player becoming preoccupied with weight. Unhealthy weight control behaviors such as laxative abuse, vomiting and fasting can lead to a full-blown eating disorder, which may eventually require the athlete to leave their sport altogether, losing their opportunity to participate in something they enjoy with their friends. Don't forget, your students are growing as they go through adolescence, and their bodies will change through the process. Supporting them to be healthy and active while having fun should be a top priority, and coaches can do so without focusing on the athlete's weight.

In addition to creating a team culture that supports athletes to take care of themselves, coaches should also be aware of athletes that may already be exhibiting some of the signs and symptoms of an eating disorder. Although the school doctor may clear them to participate, they may not be healthy at all. Coaches should be able to recognize a player with a potential eating disorder and report it to their athletic director and school nurse. Athletes who struggle with an eating disorder may not be skipping meals due to time constraints, and it is critical that coaches know additional signs to look out for and how to talk to someone they are concerned about. In the past, I have set up a meeting with the athlete's parents, school nurse, athletic director, and a guidance counselor to voice concerns in a supportive way, and hopefully get them the services they need. If you aren't



familiar with the signs and symptoms of an eating disorder, or how to talk to someone struggling, check out NEDA's [Coaches & Athletic Trainer Toolkit](#) (free to download or request a CD-ROM be sent to your school). And if you, an athlete or the athlete's family would like NEDA to provide information or treatment referrals, call [NEDA's Helpline](#) at 800-931-2237.

With the average onset of eating disorders occurring in teens and young adults, coaches and parents cannot ignore this potentially life threatening illness. I would recommend making it mandatory for all coaches to be trained in recognizing and addressing the problems of eating disorders and athletics. Like most illnesses, early detection is the key. The earlier the diagnosis, the faster they will be on the road to recovery! You are in a unique position to recognize the signs and direct the athlete and their family to treatment and support. If you know an athlete or parent that could benefit from connecting with someone who has experienced an eating disorder personally or within their family, direct them to the [NEDA Navigators](#) (pffnetwork@myneda.org). Navigators are trained to help others find treatment options, support groups, be a listening ear, and share their own story to provide insight and hope. We Navigators understand the challenges and are here to share our experience and knowledge. ■

Mike Polan is a NEDA Navigator and can be reached at: mikep@pfn.nationaleatingdisorders.org



**IN
FOCUS**

COACHES *and* ATHLETES

Pursuit of the Impossible: Perfection

By Alyssa Burns, New York

I remember the exact day it happened. It was a simple thought that turned into an action which ultimately changed my whole life. At 15, I sought perfection in everything I did, including my sport. I was a competitive level nine gymnast struggling to fulfill the incredible demands that gymnasts face every day. Between the ages of fourteen and fifteen, I began to work harder than I ever did at anything, to push myself to limits I never thought I could reach. As a result, I became very good at the sport, but of course with more skill came more pressure.

I remember the exact thought that came to my mind when I was fifteen; “What else can I do to make myself a better gymnast?” My answer was that I would become thinner. I believed the thinner I was, the higher I would be able to fly and move through the air. So, I stopped eating. The first few days seemed deceptively fine. I thought that this was such a great idea, and wondered to myself why I didn’t think about this before. Then around the fourth day, I found myself exhausted at practice and unable to complete the skills I was required to. I didn’t know what to do. I felt so lost, and I didn’t want to tell anyone because this was my secret. I also didn’t think that this was a problem, asking myself: *I’m doing it for the sake of my gymnastics, right?*

Eventually, someone who I know cared a lot about me asked me what was wrong. I was very hesitant in telling her, but she finally got it out of me and forced me to tell my coach. At this point I was so early in the disorder that I had not yet started lying to hide it, and I couldn’t think of a good enough excuse as to why I was exhausted and unable to do anything at practice. My coach told me we were going to have a talk after practice, and just to hang tight for the time being. I

didn’t know this at the time, but reflecting back on it, I think initially talking with my coach greatly decreased the duration of my eating disorder in the long run. At first, I listened to her, and I went home and ate dinner, but soon enough, I was back to restricting. I spent endless nights looking up diet plans and looking at very dangerous “thinspiration” websites and videos. It was then that my eating disorder began to take over my life – obsessing over calories, being consumed by irrational thoughts, and practicing constantly, even when I was dizzy and not feeling well. The irrational thoughts



about my weight even led me to shave my legs every day because the idea that even .1 inches of hair might add to my weight and make gymnastics that much harder terrified me.

In my eating disorder, I kept pushing and pushing myself to the point where I didn’t even know who I was. Eventually my body couldn’t handle not eating, and I often found myself bingeing. The bingeing would then lead to purging, frequently in the form of over-exercise. The need to exercise was not about health, and the extent of my exercising only contributed to destroying my health. In retrospect, it blows my mind that I felt I had to exercise so excessively in order

to succeed in a sport that required the impossible: Perfection.

I lived with this painful cycle for years. Bingeing, exercising, starving, then repeating it. The eating disorder was controlling my life, and I started reading all the books on eating disorders that I could find, and saw all the movies. It was like I was looking for something I couldn’t find. Now I know that what I was looking for was help that would eventually lead to my recovery. It wasn’t an easy or short road, but today, I can proudly say that I do eat normally and no longer

feel the pressure to be a specific weight. This took years, and I credit a lot of my success to the help I received from an amazing nutritionist. I also could not have done it without the support of my friends and family. I had a teammate who cared so much about me that she would ask me every day how I was doing, and would constantly listen to me. She was there for me when I needed her the most, and to this day I don’t know what I would have done without her. I remember sitting in her car one day after attempting to eat dinner and she looked

at me and said, “Maybe someday you’ll help girls who struggle with exactly what you’re facing.” I looked back at her with a look on my face that shouted absolutely not! But now, four years after recovering and learning so much about both eating disorders and myself, I know that this is exactly what I was meant to dedicate my life to. I am currently attending college in hopes of becoming a clinical psychologist and registered dietician, with the ultimate goal of opening a rehabilitation center for the treatment of eating disorders. You can recover from an eating disorder. It’s taking those first few steps and believing in that light at the end of the tunnel that will change your life. ■

A Balanced Relationship to Exercise: A Daughter's Struggle, A Mother's Journey

BY Phoebe Megna, Connecticut, *NEDA Board, PFN Steering Committee, NEDA Navigator*



For many of us, getting out and doing something physical is energizing and just feels good. I had a blast playing in more than one tennis group for years. My

older daughter played on sports teams, and my husband has been an avid jogger since he was in his 30's. Our younger daughter grew up riding horses, biking and sailing in the summer, as well as being on school sports teams. Later in her early teenage years, her exercise seemed right in step with the country's race to the gym, and I was right with her on the treadmill. That her exercise was a crucial component of her developing an eating disorder and her drive for perfection was not on my radar screen at all fifteen years ago.

Today, I can look back on this time during my daughter's struggle and recognize that her over-exercising was not to gain energy or social connections, but instead was done solely to manipulate her appearance and compensate for her already highly restricted daily food intake. And although it now scares me to think she would start each day before dawn with a lengthy run outside in the dark and end each day with a vigorous session at the gym, at the time, I never noticed that her exercise routine was extreme. To understand (and not judge) my lack of understanding about the role exercise played in her eating disorder, it has been important for me to examine my own relationships with food, exercise and my body, and recognize that eating disorders have a genetic component, and they run in my family. As a child, I internalized many values about exercise and body image that derived from my mother who suffered from an eating disorder herself. Of course, being so young, all I could see was that my mother acted and spoke in ways that made it clear food was to be avoided. It took my daughter's struggle to drive me to educate myself about eating disorders and actually hearing a speaker at the NEDA Conference to help me identify my mother's illness as a serious eating disorder. Now, I know that my mother




NationalEatingDisorders.org

NAVIGATORS

Need support in the process of seeking treatment and caring for a loved one struggling with an eating disorder? The NEDA Navigators are here for you! Email pffn@myineda.org to be connected to a Navigator.

* Navigators are not mental health professionals or treatment providers. They are PFN volunteers who have been through an eating disorder themselves or with a loved one and are now in strong recovery.

Navigators are trained to help you identify resources, treatment options and be a source of support in your journey.

would have benefitted from professional help, and I would have benefitted from understanding her focus on my own body's thinness as part of her struggle.

As my daughter, and consequently our family, took off on the rocky journey of recovering from an eating disorder, we were given the opportunity to examine our own mindset on food, exercise and body image. In kindness to myself and others, I know that we all hold beliefs and values that are part of a culture that perpetually tells us that thin equals healthy, thin equals attractive, and thin equals better, particularly if you are female. Sometimes we have to actively re-program our own thoughts and beliefs because those we are raised with can be so strong. Prior to learning she had an eating disorder, I saw my daughter's exercise routine as being disciplined and diligent; one to admire. So when my daughter seemed dedicated to working out, I saw nothing wrong. I was completely blindsided by wishing that I, too, had such a lean body. I could not see the extreme thinness of my daughter because she was everything that I had learned to want. Thinner and thinner my daughter became until her older sister nearly had to tackle me to open my eyes to the situation and really LOOK. This was an emotional day and a turning point for us all toward recovery.

Recovery from an eating disorder and extreme exercise is possible. The fear of being fat was so strong for my daughter that it took years for her to have a balanced relationship with exercise. But, today, she does. Therapy and a desire

to get better helped her achieve this. Regular sessions with a therapist specializing in eating disorders was key not only for my daughter's recovery, but for my own understanding as well. My advice to moms and dads alike is to talk to your son or daughter at a VERY early age about balanced eating and exercise and then set the example yourself by highlighting that you exercise to be healthy, energized, or just for fun. If you have a two-parent household, talk about the ways you can compliment one another and your kids on non-appearance-related attributes to actively cultivate an environment in which all are valued for their diverse and unique strengths. Be cognizant of your own attitudes and behaviors about your appearance, and separate your desires for your own body from your son's or daughter's. Educate yourself on what the triggers are for eating disorders and how to prevent them or intervene when you are concerned. And importantly, care both for your loved one AND for yourself. The NEDA Parent Toolkit (available online at NationalEatingDisorders.org) is an excellent resource for anyone who wants to understand more about how to support a family member or friend affected by an eating disorder. The NEDA Navigators program is also a wonderful support system of PFN volunteers who can provide comfort and help for you and your loved one.

I know I did not cause my daughter to have an eating disorder, as they are triggered by a complex interplay of factors, which includes a genetic predisposition. However, it's important for me to realize that I did not help by treating food as the

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My Recovery: I Did Not Choose this Illness, but I Choose to Get Better Everyday | BY Molly Moran, Arizona

Right now, as I sit back in my chair fully satisfied and able to concentrate, I am overwhelmed with gratitude. This gratitude extends towards most of my family, my friends, my treatment team, any person who has helped me eat a “forbidden food” or given me a reality check, but mostly for having a second chance at life. I can now celebrate myself for the beautiful human being that I am. I can now partake in this once foreign concept known as “a social life.” I can have fun and be myself. All of this is possible because almost one year ago today I made the best decision of my life- I chose to enter (and stay!) in inpatient treatment. Since that fateful day in July 2011, I have had many tears, depression, even fits of anger, but it has been worth it. I am no longer a drone doomed to a life of people pleasing and meeting expectations; a lifeless ghost slowly walking a path of never ending hopelessness and desperation; a prisoner in my own mind. Now, I walk with confidence and grace; I have the energy to chase my dreams; I express myself shamelessly and fully. I am Molly Moran, and I am a recovering anorexic.

There are a few things about me that have always been certain: I love to play sports, I have always loved the idea of adventures, and I am very smart and funny. Beyond my true passions, I had many expectations that I felt obligated to overly succeed in, and those would come to dominate my life at the expense of expressing my real self. For as long as I can remember, my definition of self has been a blurred mystery. Until 7 months ago, I didn't have a favorite color because my favorite color was always someone else's favorite color. I was very

well versed in people pleasing and being a chameleon. In addition, my home life was challenging, as my mother was ill and my father was so busy with work that he was often absent. I felt that I was falling short of pleasing my parents and often sought emotional support, attention, and nurture through a string of abusive boyfriends, questionable promiscuity, alcohol, and a terrible former best friend: Anorexia. I was not happy in my childhood and adolescence; shame and anger dominated my life.



My illness began my freshman year of high school. I was politely forced to attend my three sisters' alma mater, a very expensive, exclusive prep school in Phoenix, Arizona. Although I met a handful of quality people that I still love and talk to today, for the most part it was a toxic environment for me. No matter what I did, I never felt “good enough.” I often wished I had that girl's hair or her smile or her abs or her grades. I became obsessed with fitting in and being popular. Honoring myself was not important

education and awareness, my daughter and I can stop the inheritability and cycle of eating disorders and move forward truly claiming our own lives.

It's “hard stuff” to look at yourself squarely when in the midst of such confusion and turmoil, but my advice is to DO IT! Do it with a no-blame attitude. Do it with love. ■



during this phase of my life; instead, I focused on what I thought everyone else thought was appropriate. I relied heavily on other people's esteem. Despite the overwhelming insecurities, my trembling family life, and desperation for escape, the anorexic voice was merely a lingering whisper in high school. The anorexia started with self hate, body comparisons, popularity comparisons, and then food restrictions. It did not fully rear its ugly head until college.

I have been an athlete since I was nine years old. I worked very hard and earned a full ride scholarship to play volleyball at a junior college. It was a dream come true. Not only did it make my true self happy, but it also pleased my parents. Unfortunately, it also very much pleased my eating disorder. The common insecurities that scarred my life became spotlighted during my freshman year of college. It was the beginning of the dark ages.

Sophomore year, I began to take on several roles of responsibility: Captain of the volleyball team, girlfriend, Honor Society Member, Student Government President. I was finally that girl that I had always wanted to be in high school. People envied me. It looked like I was the happiest person alive, but on the inside, I was crumbling. My anxiety and fear of failure skyrocketed. Perfectionism and self-hatred were clenching their fists. I began to starve and over-exercise in order to gain control and escape. I thought that this was the answer to all my problems. I thought wrong. My eating disorder took away everything from me and gave me nothing. It took away my ambition, natural intelligence, muscle, ability to think, energy, passion, my scholarship, most friendships, and most importantly, my personality. I went from being a competitive college athlete to a frail zombie who could not even jump off the ground. I lived to starve and nothing more. I remember crying in my bed convinced that I had to live like this because being a certain number on the

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▶ A Daughter's Struggle, A Mother's Journey *continued*

enemy and exercise as a means to work off calories that I consumed and considered a fault. I learned that I could think and behave in ways that supported her recovery and were part of the solution, which in turn would be better for both of us. It's also important to recognize that although I developed certain values and learned specific behaviors from my own mother, it too was not her fault. And with

► My Recovery *continued*

scale determined if people loved me. I felt doomed to a life of misery with no way out. Thankfully, I was only at my worst for a short period of time. I got very sick very quick. Despite its short length, that time in hell was enough for me to hit rock bottom and to realize that if I did not change, death was a real possibility. On July 13th, I called the NEDA helpline and whispered, “I need help. I think I have an eating disorder.”

After a couple long days in the hospital, I made the decision to enter inpatient treatment. This was and still is the best decision I have ever made because I cannot do this alone. I have found that there is no shame with recovery and that it is possible, but I needed that support and guiding hand. I needed the nurture. I needed a person to talk to. I needed to learn new coping skills. Over the past year, I have made a significant transformation, and I owe it all to my treatment team and my dedication to get my life back, anorexia-free.

When I reflect upon the past year, I have made an amazing, beautiful transformation. Now, I am not ashamed of who I am nor am I ashamed to be recovering from anorexia. I did not choose this illness, but I have been choosing to get better everyday by making my recovery my top priority. With the help of a dietitian and

my support team, I have been trying new foods, eating out, being more social, challenging my disease, learning what normal eating is, and partaking in life — even when it involves food! I make memories now, instead of losing my memory. I also found, and fully embrace, my voice and willpower. Instead of succumbing to others wishes, I do and say what I want. And it feels good. I also am honest and raw with my relationships. I no longer hide. I have formed real, true friendships over the past year simply by being honest and myself. Talking about the anorexia and surrounding myself with recovery-focused people has been an essential part of my success.

I have found my adventurous side again; in fact, last April I traveled to New York City completely by myself, simply because I was healthy and wanted to. I have been sticking to my meal plan everyday because I know that I am destined to do amazing and fun things in my life, but I cannot do them when I am malnourished. Therefore, I fuel the fun and it feels so amazing! I can wake up, honor my body throughout the day, and it allows me to live fully. Last year, impulsion and adventure were not an option. Although I still struggle with body image issues, I know that my shape does not make me beautiful. It is my smile, my ambition, my intelligence, my humor, and my personal-

ity. When I was sick, none of these were present. I may have thought that I was physically beautiful but my sparkle had dimmed. Now, I celebrate myself and have found that the more I feed myself and focus on the intrinsic qualities, the more confident I become and the less the body starts to matter. I would rather be strong and healthy with a bursting personality, than a shell of a human. I am finally finding who I am, and I love it. I really am “good enough” after all! Through recovery, I have also re-kindled my passions. I recently accepted a position coaching at my old college. I am now able to enjoy the sport that I love in a healthy way. That right there is proof that dreams do come true! I accomplished a tremendous amount of things when I was sick. I can only imagine the good that is to come now that I am healthy!

When I wake up every morning, I am excited to face the day. I know that if I struggle, I have my coping skills, support and love from many people, and my meal plan. I no longer live in fear. I can do anything I want, as long as I am healthy. My best friend, who is in recovery from an eating disorder, once told me the phrase, “born free.” I wasn’t born sick. I was born free. And I will die free. Full recovery does exist and that is why I choose recovery everyday. I am worth it, and I can do this! ■

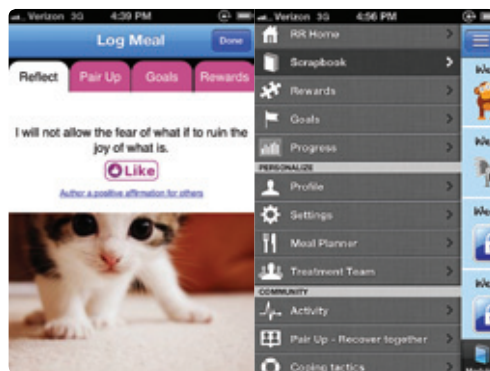
Help is at Hand with New Mobile Application for Eating Disorders

By Jenna Tregarthen, California, *Summer Institute for Entrepreneurship program at Stanford University*

Clinicians, parents and other trusted supporters go to great lengths to aid the self-monitoring (therapy homework) quest. Colorful notepads, Google Calendar alerts, and text message reminders are some of the tools adapted to increase completion.

This begs the question; why are so many going to these great lengths?

Systematic self-monitoring is the cornerstone of effective Cognitive Behavioral Therapy (CBT) for eating disorders. But, for many patients, the current pen-and-paper approach to recording can be anxiety provoking, easy to forget, embarrassing, and isolating. As a result,



monitoring is often a great source of angst and frustration for all involved.

Indeed, I have personally experienced the frustration surrounding pen-and-paper homework. I watched my best friend

struggle with bulimia nervosa for over ten years without adequate meal-to-meal support. As a psychologist in training, I lacked the high-quality patient data required for clinical decision making, and as a Clinical Psychology PhD Candidate, I grew increasingly aware of the gap that often exists between what we “know” (research) and what we “do” (translation).

In direct response to this need, in July 2011, I joined forces with the Stanford University Eating Disorder Research team (<http://edresearch.stanford.edu/>) to begin conceptualizing what is now Recovery Record (www.recoveryrecord.com).

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► Mobile Application for Eating Disorders *continued*

So, what is Recovery Record? Recovery Record replaces the pen-and-paper self-monitoring component of CBT with an engaging and rewarding iPhone or Android App. For clinical treatment teams, there is a web dashboard that (with patient consent) presents real-time patient data in the familiar CBT format for review in session, in addition to materials to help patients and therapists chart progress and identify problem areas.

So far it appears that such an application may be helpful. Since the mobile App and clinician dashboard became publically available six months ago, over 12,000 people living with eating disorders and 400 clinicians have begun using the free service.

One twenty-three year old who is using the iPhone App said: *“I have been waiting for something like this for years. This app is clearly designed with love and with our wellness in mind. It is full of joyful surprises and really helps me to stay on track with my eating... I’ve learned that, if I’m given the choice and made to feel like I am in control, I can make it work.”*

Recovery Record has been met with overwhelmingly positive reviews – 90% of the 500 reviews received have been five star. Users report particularly appreciating how discrete and rewarding the App is, and that it provides accountability and 24-hour support. Feedback from clinicians is that Recovery Record

enables them to make timely and well-informed decisions about the direction of treatment, and highlight trends and triggers that might be maintaining the disorder.

While many users report using the App in conjunction with a treatment team, half of users report that they are not currently seeing a clinician. This is perhaps unsurprising, given that only one in ten people living with an eating disorder reportedly receive treatment. One potential future development of Recovery Record may be to help bridge the treatment gap. Another intriguing, yet to be explored but potential use of this tool, is to conduct research about eating disorders. ■



If you are interested in using or sharing this free service with a loved-one, you can direct them to the Recovery Record website (www.recoveryrecord.com) or to the iTunes (www.recoveryrecord.com/iphone) or Android store (www.recoveryrecord.com/android) to download the App.

If you have questions or are interested in collaborating with Recovery Record, please don't hesitate to email jenna@recoveryrecord.com.

Continuing Recovery at College: Considerations for Parents

By Nancy Hemendinger, New York, *PFN Steering Committee Member*

College can be a positive experience; however, if your child has struggled with an eating disorder, it is important to balance optimism with reality. The eating disorder may continue to be a struggle for your child as they navigate this new life in which there are many stressors. Be honest with the college about the severity and the journey that the family has taken. What are your son or daughter's strengths and weaknesses? What are your concerns?

Being proactive can help your child secure strong supports, and encourage them to be diligent about establishing a plan for self-care. Research the availability of counseling and health services on college campuses to be sure that the school selected will provide the kind of care and support your child needs. If you need to use off-campus community specialists, try to select providers who have expertise in treatment of eating disorders, preferably in the college-age population. You'll want to be sure to provide the new health care team with the history and treatment plans from current and past providers.

To remain a part of the treatment and recovery process, have your child sign a medical release so you will be able to talk with health services, the housing staff and any other outside providers treating your child. It will be very helpful to establish a routine schedule with school medical staff to discuss your child's health, and discuss meal options with the school's registered dietitian or the on-campus food service provider. The registered dietitian may be able to help your child stay on course with meal planning.

And of course, let your child know when you will be having these communications.

Your child's transition can be scary for you as a parent, so I recommend that you identify a therapist or support group for yourself to help navigate the change in roles you and your child will assume during transition to college life. Being mindful of your own self-care is critical during a time that you'll have to be prepared to dedicate additional time and financial resources during the transition. You may

want to consider purchasing the college's tuition refund plan. This could alleviate the added stress of losing a semester's tuition in case your child needs to take a medical leave.

And finally, plan to visit your child at college. This will give you the opportunity to keep the lines of communication open between you and your child and check in to see progress. Encourage your child to focus on self-care and continued recovery, not grades or honors classes. I know from experience that all the effort put into the transition to college can be exhausting. When you're feeling exhausted by this college plan, it's helpful to focus on the eventual benefit of your child gaining autonomy, independence and recovery. If you'd like to read more about how my husband and I implemented these tips when our children transitioned to college, check out the 2011 Summer Issue* of the PFN newsletter! ■

* http://www.nationaleatingdisorders.org/uploads/file/PFN%20July%202011%20newsletter_FINAL.pdf#page=3

Congressional Caucus Recognizes Eating Disorders

By Lara Gregorio, LCSW, *NEDA STAR Program Manager*

Your help is needed to build the size and strength of our Congressional presence.

As you have probably now heard, NEDA's first year of federal advocacy paid off with the February 2012 creation of the first ever National Eating Disorders Awareness Caucus in the U.S. Congress!

Chaired by Congresswoman **Nan Hayworth** (R-NY-19) and co-chaired by Congresswoman **Nita Lowey** (D-NY-18), the Caucus aims to increase national awareness about eating disorders and support those who suffer by seeking to enhance prevention, facilitate therapeutic advances and improve access to treatment.

This is a very exciting step, as eating disorders now have a voice in Congress and a growing group of legislators who are publicly taking a stand against eating disorders. An established and recognized foundation of support like this can be instrumental in passing legislation which can make a difference in the lives of those currently suffering, and may help prevent future eating disorders.

While the establishment of the Caucus is a start, the work is not over; your help is needed to ensure that the Caucus will grow. The larger the Caucus membership, the greater our voice to influence change. Please help the growth of eating disorder support in Congress by inviting your representatives to join the caucus!

Visit NEDA's *new* Action Center on the NEDA website: NationalEatingDisorders.org — under the "Get Involved," then "Take Action" tabs — to learn how just 2 minutes of your time *can* make a difference! And,

get involved by learning more about NEDA's STAR (Solutions Through Advocacy and Reform) Program, which was established to fight for awareness, education, early intervention and prevention programs, funding for research, and improved access to treatment of eating disorders by speaking with legislators, mobilizing members, and forging alliances with other groups who share our vision. ■



We are so thankful to the Caucus Chairs and to the members of Congress who are leading the way in promoting health and well-being by being the first to join the National Eating Disorders Awareness Caucus. Please join us in recognizing and thanking these committed legislators.

Nan Hayworth (R-NY-19), Caucus Chair
Nita Lowey (D-NY-18), Caucus Co-Chair

Members:

Jason Altmire (D-PA-04)
Ann Marie Buerkle (R-NY-25)
Ted Deutch (D-FL-19)

Richard Hanna (R-NY – 24)
Alcee Hastings (D-FL-23)
Lynn Jenkins (R-KS-2)
Brad Miller (D-NC-13)
Carolyn McCarthy (D-NY -04)
Laura Richardson (D-CA-37)
Henry Waxman (D-CA-30)



Submit a Book Review

Have you read a book recently that offered you insights, tools or helpful information? Write a review for the newsletter!

All you have to do is submit a 1-page article to pffnetwork@myneda.org that includes:

- Your name and contact information
- Title of book, author, publisher and copyright date
- A brief summary of the content of the book
- What you gained from the book: Hope, tools for recovery, strategies for self-care, encouragement, educational information, etc.

*Book reviews are provided by individual PFN members to share with others what they have gained from reading a book that served as a resource to the reviewer. NEDA does not endorse any specific books or authors. NEDA reserves the right to edit book review submissions prior to publication. If your review is edited, you will be asked to approve the final version before use.

We Can Change the Media!

Taking on Photoshop and Petitioning Seventeen Magazine

By Julia Bluhm, Maine

It's no secret that the girls of today are unhappy with their bodies. Girls of a younger and younger age are struggling to measure up to the impossible ideal of beauty that we see all over the media every day. After blogging for SPARK Summit for a year, it became clear to me that computer editing programs such as Photoshop are a culprit. People are misusing these programs, to digitally alter girls' bodies. That's why in magazines and ads, you always see models that are unrealistically thin, and ultimately blemish-free. It's really common for girls and teens to compare themselves to these "perfect" images, and to want to look like them. Girls often try to change themselves, to achieve this perfect appearance that's actually unachievable without a computer. These altered, unrealistic images are what made me want to do something about the use of Photoshop in the media, especially in teen magazines. Girls fall into the trap of longing to look like a model in a magazine without even knowing that they're Photoshopped.



After discussing the topic in a meeting at SPARK Summit, I wrote a petition targeting Seventeen Magazine. I asked them to include in their magazine at least one unaltered photo spread a month. About two months and 85,000 signatures later, Seventeen Magazine used a whole page of their magazine to address the issue of Photoshop, and make a public promise that they will never "alter girls' bodies or face shapes." I think this is a significant moment. Not only did we get one of the most popular magazines to take us seriously, but we raised substantial awareness about the issue, and inspired another petition (targeting Teen Vogue) to be started. That petition now has over 35,000 signatures and is still growing. The Seventeen Petition was only the first step in the right direction.

What started as just a petition has grown into a movement.

Some people say that Photoshop is the norm now, and we can't change it. I think it's only the norm if we let it be the norm. Are you going to let it? Join me and other teens advocating for diverse and real images in the media at the **Proud2Bme Summit, We Are the Media: Tune Out Body Hate, Turn Up the Confidence!** on October 13th, where I'll be presenting the keynote address! It's free to register, and you won't want to miss hearing from all the awesome industry-insiders that will be talking about how we can create change and have fun doing it. Check out www.Proud2Bme.org for details and to register. ■



Become a Media Watchdog!



The Media Watchdog program empowers consumers to advocate for positive media messages. This means recognizing and celebrating advertisements that send healthy body image messages, as well as taking the time to express our concerns about advertisements that send negative body image messages or promote unrealistic ideals. When we act together, we have a stronger voice to hold advertisers and entertainment media accountable for the impacts of their media messages. Visit the Media

Watchdog homepage to alert NEDA about a praise-worthy or protest-worthy advertisement/media message, download how-to instructions on deconstructing an advertisement, check for current Media Watchdog Action Alerts and more information on becoming a media activist! ■

Art Therapy Applied to Somatic Experiencing and Eating Disorder Work

By Ann Kreindler-Siegel, LCSW, SEP

Art therapy and somatic experiencing are wonderful adjunct therapies, which also complement each other, in the treatment of eating disorders. For eating disorder clients, emotions are both difficult to identify and very overwhelming. I believe art therapy and somatic experiencing together provide the distance and perspective necessary to experience these feelings in a healthy way.

Eating disorder work has been my specialty for thirty four years, and I have been a Somatic Experiencing practitioner since 2010. The model of Somatic Experiencing, (SE), as developed by Peter Levine, is an important model that I believe can be integral to fully addressing recovery from an eating disorder. SE brings in the use of the body sensations in the therapeutic process. The “felt sense” component, (how we experience aspects of our life in our bodily sensations), is part of everyday life, and is important in reaching recovery from issues that we struggle with.

Art therapy can be used in somatic work as a tool that allows access to the body through an alternate therapeutic mode. Through the techniques of art therapy the client creates images of the sensations felt in the body through color, shape and abstract right brain concepts. The intention is to allow some distance from the sensations. When a person can draw representations of feelings, they can observe from a distance rather than feeling it in the body and being overwhelmed by it. I’ll explain with an example.

Often clients who present with an eating disorder describe their feeling as emptiness. I interpret their behaviors then as either filling this void with food or fearing feeding themselves; for fear that the emptiness is a bottomless pit. In my experience, people with anorexia will tell me they are afraid to eat because if they do they will never be able to have enough food to fill the emptiness they are feeling. People with bulimia and binge eating disorder often say the food is used to fill the emptiness that binge eaters feel; the

purge is a response to the overwhelming anxiety or fear that just gets to be too much to handle. In such cases, food serves the purpose of filling an emptiness that is not at all related to hunger.

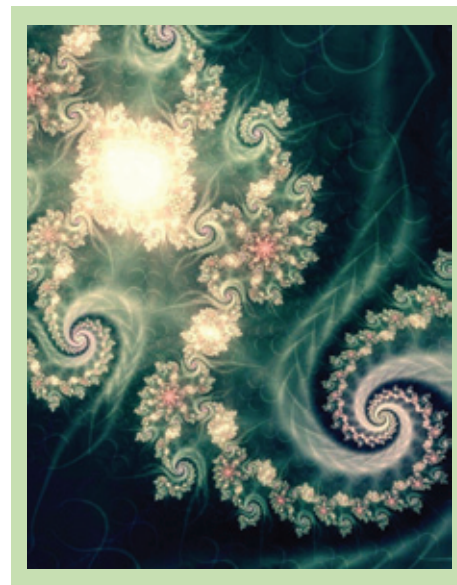
When a client can draw this feeling of emptiness and look at it in front of them, they can see it instead of experiencing it in the body. With the art piece I can ask them, “Now that the feeling is in front of you, how does it feel to see it instead of just feel it inside?” This can help them verbalize what it is like to feel it, see it, and experience it. Many times this opens up the dialogue about when they feel the emptiness, what it might really be about. Similarly, this technique can be used for the experience of the sensation of tightness when fear or anger are present. A client can then experience the feeling without feeling “stuck” in the feeling or overwhelmed by it.

With eating disordered clients, when there is an ability to “step away” from the sensations, this work can assist them in embracing their bodies as their home. It is the only home we all get that stays with us for our lifetime. Unlike our vehicles, we cannot trade in our bodies when they get old. They will similarly break down if we wait until they are empty to fuel them and they do need regular maintenance. We cannot, however, get a replacement “home” for our lives. When the body can be viewed as a vehicle to live our lives, oftentimes intense hatred of the body will cease or at the minimum, decrease. When this happens, we have a stronger chance of healing with these clients through an embrace of their true being.

I also use art therapy to identify where in the body clients experience sensations. Again, the “felt sense” can often be depicted through color and art expression that is often less threatening than feeling it internally. An outline of a gingerbread person can be drawn by the client, and they can be asked to color areas that feel tight and then areas that feel looser. Their use of color is often indicative, as is the images they draw to express different feelings. Eating

disorders are often experienced as a jail type trap, and clients can draw this as well. They often had not thought of it this way until the suggestion to draw the trap of their eating disorder is used in session. Clients can then use the experience as an entry point for further talking about the eating disorder issues in treatment.

Art therapy and somatic experiencing can be wonderful therapeutic modes of working with clients, in combination with evidence-based treatments that fit the needs of the individual. They are vehicles to allow for creativity, perspective and strengthening one’s mind-body connection to process feelings and sensations without experiencing them as overwhelm. ■



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Overcoming Trauma in the Throes of an Eating Disorder

By Caroline Rothstein

Trauma and abuse make us equivocally doubt ourselves. The way someone or something manipulates our mind, body, and heart to believe we are powerless can be a most dangerous weapon. When breaking down the basic and fundamental components of eating disorders, sexual abuse, and other traumas, the correlation seems almost unavoidable — that those of us who have been abused would turn shame and loss onto ourselves through starvation, or bingeing, or purging, or alcohol and drug abuse, or self-harm seems terrifyingly justifiable. However, it is possible to recover — in full — from both.

already several years into the throes of starvation, bingeing, and purging when I was first touched against my will. But to say the molestation, rape, and loss exacerbated, prolonged, and perpetuated the eating disorder is an understatement. In the same vein, overcoming and surviving the pain of being sexual abused, as well as working through the grief and loss surrounding my brother's death, was profoundly integral to my ultimate recovery from a decade-long eating disorder.

An eating disorder is dissociation from the body. It is a manifestation of what occurs when we separate from our authen-

It is tremendously challenging to recover from an eating disorder, and equally difficult to survive sexual abuse or loss. However, when we compartmentalize the traumas and examine the ways in which they feed one another, it becomes more manageable to reconnect with our authentic selves and desires, rediscovering our bodies as worthy, magnificent, and loved.

Throughout the 10 years I had an eating disorder, I relentlessly attempted to recover. I tried to remove the symptoms without efficiently delving into the sources and causes of the illness. The multi-layered nature and chronology of my traumas were confusing. The eating disorder predated the worst things that ever happened to me. How could I figure out the root cause of the illness when I was barely surviving my brother's death, being date raped by a stranger, and being molested by an alleged friend?

I realized I had to conquer these traumas in steps. First, I dealt with my brother's death. I joined a grief and loss group on my college campus, and started seeing another therapist, in addition to the one I'd been seeing since high school. I confronted the reality of his death, choosing to live honoring his life, rather than suffocated by his death.

Next, I combated the sexual abuse and date rape. I became celibate for a year and a half. I didn't date anyone. I didn't hook up with anyone. I didn't sleep with anyone. I realized I had to allow myself to let my sexuality exist independently from the other facets of my life. It was like healing a wound. I gave the pain and trauma space to breath. I let my abusers' power over my body evaporate. I regained control.

Lastly, I worked on recovering from the decade-long eating disorder. With the other traumas under control and well-supervised, I could peel the eating disorder behaviors away from my daily life, layer by layer until I found the depths of myself, and love for who I was, who I had been, and who I would become.

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Caroline Rothstein in "faith," written and performed by Caroline Rothstein, directed by Alex Mallory, lighting by Brad Peterson, Women Center Stage 2012 Festival, Co-presented by Poetic Theater Productions & Culture Project.

Photo by Hunter Canning

The first time I was sexually abused at 14-years old, I had already had an eating disorder for three years. The abuse lasted for a year and a half, through the middle of my sophomore year of high school. Years later, a month into my freshman year of college, I was date raped by a stranger on my dorm living room floor. A week later, my younger brother was hit by a car and killed.

To say the sexual abuse, date rape, and loss caused my decade-long eating disorder is of course inaccurate — I was

tic bodies, authentic selves, authentic thoughts, needs, desires, wants, hungers, and thirsts. Similarly, sexual abuse is a violation of our authority over our bodies, selves, thoughts, desires, and wants. Traumatic loss, like the death of a loved one, is a violation of our homeostasis, our mortality, and our control. For me, because the eating disorder already existed during the multiple occasions when I was further traumatized, the incidents further validated the self-hate and insecurity I was already viciously inflicting upon myself.

► **Overcoming Trauma in the Throes of an Eating Disorders** *continued*

One of the most challenging correlations between sexual abuse and eating disorders is shame. There is so much shame rooted in both of these traumas. It is in confronting the shame, in recognizing that we do not need to root our identities in these shames, these traumas, and these pains, that we are able to release ourselves from their hold and flourish as the magnificent bodies, minds, and spirits we are, have always been, and will always be. ■

[**Caroline Rothstein** is a New York City-based writer, performer, and eating disorder recovery advocate, who specializes in spoken word poetry, theater, creative nonfiction, journalism, and performance art. She hosts the widely viewed YouTube video-blog "Body Empowerment," sharing her own recovery story as a means to promote positive body image worldwide. Her new one-woman play "faith" about her experience with and recovery from an eating disorder debuted as part of Culture Project's Women Center Stage 2012 Festival and received an award for Outstanding Overall Production of a Solo Show. Caroline was recently honored with the Planet Activist Award for her awareness work as well as raising money for NEDA during a June 2012 benefit performance of "faith" in the Planet Connections Theater Festivity in New York City.]

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Interested In Learning More About the Relationship Between Trauma and Eating Disorders?



Don't miss featured speaker Timothy Brewerton, MD, DFAPA, FAED, DFAACAP presenting *The Intersections of Trauma and Eating Disorders: Broadening Our Understanding for Supporting a Loved One and Improving Treatment* at the 2012 Annual NEDA Conference in St.

Petersburg, Florida, October 11-13! Register today at www.myneda.org/conference.

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Richard Hubbard's Moving Tribute to His Sister's Memory

Richard Hubbard's sister, Anne Hubbard, tragically lost her battle with an eating disorder this past January. Richard wrote about his experience as a sibling of an eating disorder sufferer in the most recent edition of this newsletter. Richard designs fonts and in the article wrote that, "because my sister loved to write letters and had said she wanted me to design one for her, I'm working on a font that would be sold to help raise money for the cause."

Richard has recently completed his font of Anne's handwriting and will be donating all proceeds from its sale to NEDA to support programs and services like the **NEDA**

Navigators and **Loss Support Network** — programs that Richard believes in and are helping him through a difficult time. As Richard says, "It is a nice way to remember her and help support others. It would make her feel important to know that I have done this."

NEDA extends a sincere thank you to Richard for his touching tribute. Please support Richard's cause by purchasing his font and use it on your next blog post, invitation, or flyer. <http://www.myfonts.com/fonts/national-eating-disorders-assn/annes-hand/>



Loss Support Network

The Loss Support Network offers those who have lost a loved one to an eating disorder a way to connect with others by:

1. Volunteering to support those new to a loss
2. Requesting support from a volunteer in the network
3. Connecting with fellow volunteers.

If you have lost a loved one and would like to become a Loss Support Network volunteer or would like to request connection with a volunteer, visit the Parent, Family & Friends Network homepage of the NEDA website (www.myneda.org) and click on Loss Support Network (<http://www.nationaleatingdisorders.org/programs-events/grief-registry.php>).



Insurance Tricks to Watch For

FROM the *Insurance Issues* segment of the PFN Webinar Series, presented by David Christian, PhD, and Stacey Brown, RN of Avalon Hills and Lisa Kantor, JD of Kantor & Kantor, LLP

Clinicians, family members and patients face multiple challenges in defeating an eating disorder. For many, in addition to dealing with the personal struggles these disorders breed, disputes with insurance companies can make the battle feel even more overwhelming. Without professional training or an in-depth understanding of your or your patient's insurance plan, it is likely that you will find yourself frustrated and wondering what you can do to get the necessary coverage. The following has been adapted from the archived *Insurance Issues* webinar (located on the PFN homepage of NEDA's website), in which David Christian, PhD, Stacey Brown, RN and Lisa Kantor, JD outlined a few of the games that insurance companies play to deny care to holders and provide suggestions on how to prepare yourself to handle them.

THE CONFLICT OF INTEREST (AKA The Two-Headed Snake)

‣ **Definition:** An insurance company is acting as both the prosecution and the judge.

‣ **Example:** Insurance companies not only write their policies, but they also act as interpreters. Additionally, some insurance companies will allow for an external appeal but may hire their own appeal reviewer.

‣ **What can you do?** Confront inconstant interpretations of the policy. To do so, you'll need to have a copy of the policy to really understand what is going on. If you've read through your or your patient's copy and find that the insurers are changing their interpretation of the policy to get out of covering care, you can bring this to attention.

Also, make sure that external appeals are independent. You can do this by checking to see if the reviewer is on the payroll of your insurance company. If they are, the external appeal is not truly external and you are within your rights to request an independent reviewer.

THE RUBBER RULER (AKA The Bad Standard)

‣ **Definition:** An insurance company is using poor measures for what recovery is (i.e. not following American Psychiatric Association [APA] standards).

‣ **Example:** An insurance company argues that a patient does not meet their specific standards for residential care.

‣ **What can you do?** Compare their standards with best practice, such as APA standards and suggestions for best care, and outline inconsistencies. As Dr. Christian puts it, "Just because

they're not willing to use the best standard, it doesn't mean that you cannot hold them to that standard."

STRAW MAN ARGUMENT

‣ **Definition:** An insurance company emphasizes an irrelevant issue to ignore more pertinent matters.

‣ **Example:** The insurance company argues that because the patient's weight is in an ideal range, the patient no longer needs some or all of the care they were receiving.

‣ **What can you do?** Look at the APA standards. They follow the understanding that true recovery is holistic and takes into account psychological, social, and environmental factors.

FALSE AUTHORITY

‣ **Definition:** An insurance company is appealing to false authority.

‣ **Example:** Your insurance company tells you that a doctor they have consulted with says that you or your family member no longer need certain care, even though the doctor is not an expert in eating disorders.

‣ **What can you do?** Find out if that doctor has the right credentials. Ask them if they have experience, training, or specialized credentials and look into their past decisions to see if they have any known biases. Don't be afraid to ask them to justify why they can make their decision and why they qualify as an expert — you have the right to request an opinion from a professional with proper credentials.

RED HERRING

‣ **Definition:** An insurance company brings up an irrelevant issue to distract you from a more important issue.

‣ **Example:** Your or your patient's insurance company is making a fuss over a clinically insignificant matter (e.g., authorization was not obtained fast enough) to distract from their obligation to provide care.

‣ **What can you do?** Point out the clinical insignificance of their issue and bring back attention to the ethical and clinical issues of your or your patient's care.

NON-SEQUITUR (AKA Circular Reasoning)

‣ **Definition:** An insurance company's reasoning does not follow their hypothesis.

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♦ **Example:** An insurance company points out that you or your patient is not improving, and they decide that treatment should be stepped down.

♦ **What can you do?** Try reversing the reasoning to see if the opposite conclusion would make just as much sense. In this example, you could argue that because you or your patient is not improving, treatment should be stepped up.

THE DOUBLE STANDARD (AKA Hypocrisy)

♦ **Definition:** An insurance company is applying one standard to you and another to themselves.

♦ **Example:** The medical director of your insurance company denies your residential treatment because it includes telephonic family therapy, and the director does not believe that phone therapy is as good as live therapy. However, they come to this conclusion after reviewing telephonically obtained data.

♦ **What can you do?** Point out the inconsistency in their logic.

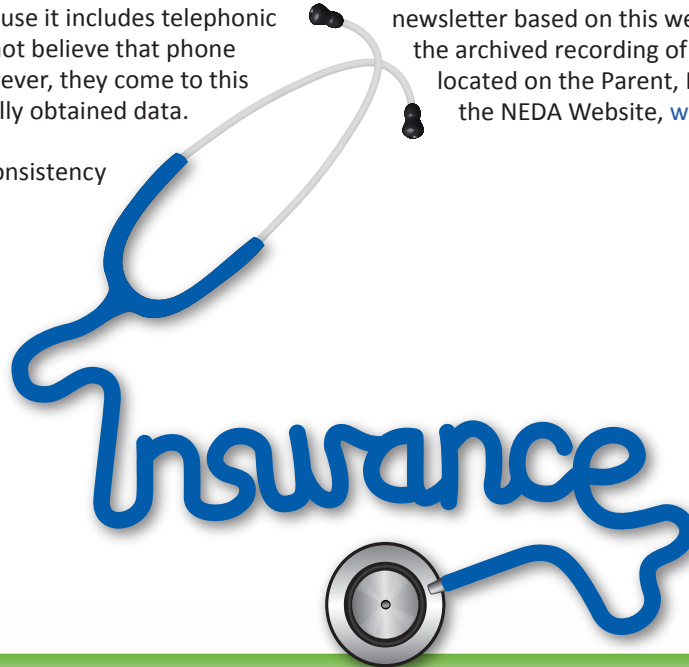
POST HOC FALLACY

♦ **Definition:** An insurance company claims that, because event A occurred after event B, event B was the cause of event A.

♦ **Example:** Your patient's insurance company claims that because your patient relapsed after treatment, the treatment was inadequate.

♦ **What can you do?** Point out that correlation does not mean causation and that there are other plausible causes for your patient's relapse.

This article is the first of a series to be published in this newsletter based on this webinar. You may also listen to the archived recording of the *Insurance Issues* webinar located on the Parent, Family & Friends homepage of the NEDA Website, www.myneda.org. ■



Good To Know: Insurance Tips

- ☛ Know what your policy says: request a copy and read through it.
- ☛ Whether you are a patient, clinician, or family member, always document your contact with insurance companies. Send everything to your insurance company in writing and request a return receipt.
- ☛ You are entitled to a copy of your claim file from your insurance company when you request it, free of charge. Your claim file includes any document, record, or other information that was used to make the decision of denying treatment.
- ☛ If you have ERISA (provided by non-government or employers not associated with religious entities), you are entitled to “higher-than-marketplace quality standards” as well as a “full and fair review” of claim denials.
- ☛ Be assertive, but also patient. As Lisa Kantor, JD says, “This is a marathon, not a sprint.”



Staff and Network Spotlight

Meet the NEDA Staff! | Beverly Blake, JD, *Director of Development*

Beverly Blake is an attorney and corporate executive who applies her expertise to the intricate demands of non-profit management and development. She has over twelve years' experience creating and implementing fundraising campaigns for organizations dedicated to improving the health and well-being of marginalized groups including those living with HIV/AIDS, those living in low-income communities and homeless people.



As a generalist, she has raised millions of dollars from foundation and corporate giving, direct mail, public support and special events. She has raised more than \$10 million in public and private funds for a variety of organizations, including Harlem United Community AIDS Center where she helped to

double the number of people it served and triple its budget from \$4 million to \$12 million within three years. At the Doe Fund, her department raised \$2 million annually in foundation and corporate giving and supported million dollar gifts from major donors. She has developed effective fundraising strategies and shaped innovative communications programs as well as successfully cultivated and maintained meaningful relationships with community stakeholders.

Since her interest lies in the field of behavioral health, she has found a home at the National Eating Disorders Association, and lives in New York City. Beverly holds a BS in Engineering Chemistry from the State University of New York at Stony Brook, and a Juris Doctorate from the University of Iowa, College of Law. She loves music, art and theatre and has been known to sing here and there in the city. ■

NEDA Network Spotlight: **Ophelia's Place**

Since Ophelia's Place, located in Liverpool, New York, first opened its doors in 2002, I can see the many opportunities for growth and change we experienced. Out of this journey has come our present model, which incorporates three important components; support, treatment and community.

Ophelia's Place continues to offer support for individuals who struggle with eating disorders and their friends and families in the form of groups, workshops and outreach to schools and providers.



Recognizing the need for collaborative support and treatment, Ophelia's Place formed a relationship with the Nutrition Clinic allowing clients to receive information and guidance regarding treatment options. We now house an intensive outpatient program and outpatient nutritional services managed by the Nutrition Clinic, who also provides case management services that follow clients through the full continuum of care.

In 2009, Ophelia's Place opened Café at 407, a full service café that transformed our building from one that was entered solely when an individual or family identified as being eating disordered to one where everyone is welcomed and recovery is visible, audibly supported and encouraged by the community as a whole. You only have to watch our group participants stay after support group ends to enjoy the music and their favorite coffee drink in the café to see that they feel embraced and accepted.

This year has brought changes to Ophelia's Place including a new Executive Director, Jodie Wilson

-Dougherty, to continue the wonderful programming developed under the leadership Mary Ellen Clausen. New programs include our Coffee Talks, bringing community and local experts together for conversations around topics such as media literacy and body image that impact many diverse groups within our society. In the fall, we will present a workshop that will partner our community and treatment components as we present nutritional education and creative ways to heal our relationship with food, utilizing locally grown produce from our community garden. ■

National Eating Disorders Association

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The PFN Newsletter offers a place for our members to share their personal experiences and insights to support others. While we value these contributions, please note that the views, beliefs and perspectives expressed do not necessarily represent those of the organization.

Share Your Thoughts

If you have an idea for an article, a question you'd like us to research, or would simply like to share your story — we'd love to have you participate in our newsletter! Email us at pffnetwork@myneda.org.

Be sure to include your full name, email address, and daytime phone numbers so we can contact you.

Making Connections is by parents, family, and friends for parents, family, and friends!

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SILVER: Rogers Memorial Hospital

STEEL: Center for Eating Disorders at Sheppard Pratt, Eating Recovery Center, Melrose Institute, The Renfrew Center, Timberline Knolls

BRONZE: Cambridge Eating Disorder Center, Center for Change, CRC Health Group, Eating Recovery Center at the University of Florida & Shands, McCallum Place, Oliver-Pyatt Centers, Pine Grove Women's Center