

A Message from the PFN Chair | Deborah Kreiger, Florida



PFN Chair, Deborah Kreiger, FL

Hello Everyone!

This edition of the PFN Newsletter focuses on siblings, from the important role they have in the family dynamic to understanding the impact an eating disorder has on them as they travel the path alongside of a brother or sister who is struggling. We have included a variety of perspectives and we hope these articles serve to enlighten and guide you.

As a Floridian I look forward to welcoming you to the charming city of St. Petersburg for the Annual NEDA Conference, October 11-13, 2012. As parents, families and friends,

this conference offers us the opportunity to support and learn from each other, as well as from leading experts in the field. It will inform, inspire and energize us to continue to make an important difference as we move forward together. There are many special features of the NEDA Conference designed to connect and support families and individuals affected, such as the new Support and Recovery Roundtable Series, NEDA Buddy System, First-Time Attendee Orientation, and the Family & Friends Kick-Off Dinner!

For more information visit:

<http://www.myneda.org/conference> ■

Register Now for the 2012 NEDA Annual Conference!

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What About Us? Diversity and Complexity in Eating Disorders

NEDA's Annual Conference brings together people in recovery, their families, educators, researchers and treatment professionals. You are invited to join us to connect, learn, and belong.

Featured Speakers:

KEYNOTE ADDRESS

by Cynthia Bulik, PhD, FAED

Reflection of Reality: Eating Disorders in Diverse Populations and Across the Lifespan



The Intersections of Trauma and Eating Disorders: Broadening Our Understanding for Supporting a Loved One and Improving Treatment
Timothy Brewerton, MD, DFAPA, FAED, DFAACAP

Treatment of Binge Eating Disorder: Current Research and Clinical Implications
Terry Wilson, PhD

"I have been affected for over 25 years by another's eating disorder, and am so grateful now to have the information that it is not a lifestyle choice, but a serious disease. Knowledge has empowered my own recovery, and given me compassion and empathy. The NEDA Conference offers families and individual affected an opportunity to get the critical information they need, directly from the experts."



Ashley Judd, Honorary Chair

Family Panel: What About Me? Stories of Recovery from High-Risk and Underserved Populations

Moderated by Ovidio Bermudez, MD with special introductory comments by FALK, NEDA Ambassadors and Singer/Songwriters.

Panelists include Asha Brown, Denise Folcik, Yasemin Merwede, Anahi Ortega, Ryan Sallans and Christopher Skarinka.

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Register Now! 2012 NEDA Annual Conference *(continued)*

New Features to Support Families and Individuals Affected!

Request a NEDA Buddy

We know that many individuals, family members, and new professionals attending the NEDA Conference may not know their fellow attendees, and it can be overwhelming, especially for newcomers. So, when you register to attend, you can select to be matched with other attendees, so that you can exchange emails and make new friends prior to ever arriving! You'll get the chance to meet your "NEDA Buddies" and many other attendees at the Conference Orientation on Thursday evening, prior to the Welcome Social, Family & Friends Kick-Off Dinner, and all other conference events.

NationalEatingDisorders.org



NEDA
CONFERENCE
2012

October 11–13, 2012
St. Petersburg, FL

What About Us?
Diversity and Complexity
in Eating Disorders

Support and Recovery Roundtables

We hear from many attendees that the NEDA Conference is a wonderful opportunity to meet other people that have a similar experience with an eating disorder (either personally or in support of a loved one) to share strategies for coping, self-care, and finding helpful resources. To help you identify one another and offer forums for these important conversations, we are hosting roundtable discussions throughout

Saturday, October 13th. Roundtables will be held for individuals in recovery, dads, moms, siblings, partners, men, LGBTQ-identified attendees, and those who have experienced grief and loss.

"What's Up With That?"

A lively impromptu Q&A with four leading eating disorder experts, Carolyn Costin, MA, MEd, MFT, CEDS, FAED, Michael Levine, PhD, Michael Strober, PhD, and Anne Becker, MD, PhD, MS. ■



NEDA's Urging Pays Off! American Medical Association Releases New Course on Eating Disorders

First-of-its-Kind Curriculum Educates Physicians and Other Medical Professionals on Early Detection & Intervention

NEDA proudly announces the American Medical Association's (AMA) latest online course, *Screening and Managing Eating Disorders in Primary Practice*, which was developed to educate physicians about eating disorders, with the goal of earlier detection and intervention.

The course – the first of its kind – is a part of the AMA's Educating Physicians on Controversies and Challenges in Health (EPoCH) program and: provides a basic diagnostic overview of the range of eating disorders; reviews the screening and referral process; and briefly describes the role of the primary care physician in treating patients with eating disorders. The curriculum fills a much needed void, helping more patients receive care and perhaps preventing severe chronic eating disorders.

NEDA approached the AMA last year about creating the course and commends their initiative, drawing attention to the need for a greater understanding of eating disorders in the medical community and proactively working to educate physicians. The AMA has also made a commitment to aggressively promote the course's availability to the medical community.

"We are grateful to the AMA and thank them for listening to the concerns of our families about a need for education on eating disorders within the medical community itself and taking action," commented Lynn Grefe, president and CEO of NEDA. "This course has the potential to make serious inroads toward earlier interventions and consequently more successful outcomes for patients. It's a terrific step forward and we are grateful for this partnership.

"We are also grateful," Grefe adds, "to the NEDA professional members who are also members of the Academy for Eating Disorders for their time and input into the creation of this important course."

Said AMA President Peter W. Carmel, M.D., "In treating eating disorders, early intervention and communication has proven to be highly effective in combating these diseases. This resource will help primary care physicians learn how to better identify, treat and manage these serious mental illnesses."

Added Anne E. Becker, M.D., Ph.D., president of the AED, "The AED applauds

the AMA's effort to provide health professionals with training on the detection and management of eating disorders."

Approximately 24 million people suffer from anorexia nervosa, bulimia nervosa and binge eating disorder in the U.S., yet too many eating disorders are not caught until the illness is entrenched often to the point at which there has already been irreversible physical health damage done, making the illness much more difficult to treat. Studies have repeatedly shown that early intervention leads to better treatment outcomes.

If doctors are able to intervene more promptly and the illness is treated at an earlier stage, it helps alleviate the serious health consequences that accompany prolonged eating disorders; lessens emotional turmoil involved for the entire family; and reduces the financial burden of treatment significantly.

To access this course and learn more, see: <http://www.ama-assn.org/ama/pub/physician-resources/> ■

Art Can Change the World: Changing the Industry from the Inside Out | By Ellen Domingos, New York

I started performing professionally at the age of eight years old. Being on a stage and in the spotlight quickly became the main focus of my life. I grew up wanting to be a great theatrical artist and singer; to make it big on the New York stage! I was told and grew up believing that if I was going to be happy and successful in the arts I would need to look a certain way; skinny and beautiful. Buying into this idea of happiness and success led me into a long battle with an eating disorder that took many forms.



In my late twenties and early thirties, I had worked hard enough at my career

that I was finally able to make a living as an artist. I had performed on off-Broadway, in regional theater, touring companies, cruise-ships, voice-overs, commercials, television, and film. I had the good fortune to work with Broadway veterans, Helen Hayes and Tony award winners and nominees. I had worked for years as a model posing for clients such as Sears, Dockers and Levis and had appeared on book covers, catalogues, Marie Claire and Latina

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Research and Free Treatment for Teenage Girls with Bulimia Nervosa

By Rachel Marsh, PhD, Assistant Professor of Clinical Psychology (in Psychiatry) at Columbia University Medical Center

Bulimia Nervosa (BN) is a significant public health concern that has risen with increasing prevalence among female adolescents. As most readers of this newsletter know, BN is characterized by recurrent episodes of binge-eating followed by self-induced vomiting or another compensatory behavior to avoid weight gain. These episodes of binge-eating are associated with a severe sense of loss of control. For the past eight years, we—researchers at Columbia University—have been using magnetic resonance imaging (MRI) to study individuals with BN, with a particular focus on a neural system and brain activity involved in the ability to control or regulate behaviors. Our previous findings suggest that a failure to engage this specific neural system

may contribute to the loss of control over eating behaviors in women (Archives of General Psychiatry. 2009 Jan) and adolescents (American Journal of Psychiatry. 2011 June) with BN. However, we do not yet know how these neural disturbances arise or how they contribute to the development and persistence of BN over adolescence. Such knowledge will allow us to design better treatments and prevention strategies for this disorder that affects so many young girls.

Our organization recently received a five-year grant from the National Institute of Mental Health (NIMH) to fund a large research study of brain development in teenage girls (ages 12 to 18 years old) with BN. Participation in the study

involves completing interviews, games and puzzles, and an MRI scan. MRI does not involve any radiation exposure; it is an extremely safe and painless imaging modality. The scans, surveys and any other information provided will be kept strictly confidential. Girls who participate in our study can receive inpatient or outpatient treatment, free of charge, at the Columbia Center for Eating Disorders. Compensation (up to \$400) will also be provided for participation. The study takes place at the New York State Psychiatric Institute, 1051 Riverside Drive in Manhattan. For more information, please call the Eating Disorders Clinic at (212) 543-5739 or visit our website, <http://teenbulimiastudy.org>. ■

Art Can Change the World (continued)

magazines. I was considered skinny and beautiful. But, I was extremely unhappy. After years of secretly battling an eating disorder, I was losing the fight and it had taken over my life.

And it was my art that suffered the most. The art that I was passionate about, that had given me confidence and that I could rely on had been replaced by my eating disorder. It was now my eating disorder that I was passionate about, that seemingly gave me confidence and that I thought I could rely on. Through the difficult process of trying to make it as an artist in an industry that demands perfection, I had lost not only myself, but my art. Admittedly, I was not strong enough at that time to stand up to industry standards and expectations. I wasn't able to say what I wanted to say, which was, "Actually, I can't stay at this weight and remain a healthy, functioning individual." "I take responsibility for losing my voice in an industry that is saturated with "You need to be a little more this" or "You aren't enough that." But now, after therapy, attending an eating disorder treatment facility, nutrition

counseling, support groups, help from family and friends, years in recovery, I am strong enough. Finally, it is enough to just be me in an industry that seems to constantly be saying it isn't.

All artists deserve to feel that their talent and creativity is the key to success and not the exterior package the talent comes in. But, how do we do this?

It's the key question, and I don't have a definitive answer. However, I do know we can all do our part and many already have. Each artist can find their voice and stand up to extreme industry standards in however way they choose and feel comfortable with. Actors can support one another in health. Casting agents can look outside the box of perfection when casting their new project. Writers can write for everyone. Agents can look at the talent first, and accept the package it comes in, as it is. The fashion industry can recognize that the models wearing their clothes on the runway are 1 percent of the population that they are designing for, and then act accordingly. Dance companies can promote health

and wellness to their company members. What I am proposing is that we set realistic standards in an industry that seems to do the opposite and get rid of extremes that make us forget who we are as artists.

Today, I am 38 years old. I am not a great theatrical artist and singer. I am not a skinny ingénue of 25 years old. I am not rich or making a living exclusively as an artist. But, I am happy. I am an artist. I am trying to make a difference. And, I am eating disorder free. Life has taught me that she has her own plans for all of us, and we must make the very best of the ride we are given.

And, listen, I'm not completely out of touch. I understand that what I am asking for here would take a movement so strong that it changes our industry, our culture, our media, our current priorities to their very core. But, big changes happen. Art can change the world. Strength is in numbers. Faith and perseverance is the key. Join me. Do your part. Let's change it together. ■



IN FOCUS

The Impact of an Eating Disorder on Siblings

By Joel Jahraus, MD, Medical Director, Oliver-Pyatt Centers, Florida

When an eating disorder takes hold of a family, every member of the family is impacted in some way. The family dynamics prior to the onset of the illness, and the complexity of eating disorders, create a unique dynamic within families. The family dynamics prior to the onset of the eating disorder may shape the individual responses among family members yet the overall response remains remarkably similar from family to family.

The mental and physical health of each individual, and the family environment as a whole, impacts the family such that a “reorganization” of family life ensues, and each members’ life tends to become focused around the illness. Yet family remains the most important resource for recovery of a young person with an eating disorder. Siblings are not immune to the impact of the eating disorder and may have a variety of responses to the illness of their sibling.

The fact that eating disorders can cause serious and even life-threatening physical changes in the individual causes the anxiety of family members to focus on doing whatever they can to reduce the potential for disaster – the loss of their loved one. Unfortunately this may actually play a role in maintaining the problem. Negative ways of coping become more prominent, including taking control, anger and blaming, avoidance, denial or substance use. Time and attention from parents that would normally be available for a wider range of family activities is nonexistent. There may be concerns among siblings for the health of their parents as well. In general, family members may all feel as though they’ve lost control over their lives.

Meal times become particularly challenging for siblings as family meals become intense and filled with conflict. This may cause healthy siblings to avoid family meals altogether, preferring instead to eat elsewhere. A new routine is established often with family members feeling like they’re constantly at risk of causing a meltdown with the ill sibling, should they say something that triggers him or her. Unfortunately, this may lead to tolerance of the eating disorder behaviors, simply to avoid such occurrences. Resentment surrounding these illness-related changes to family life is common and in itself may lead to guilt feelings among siblings, particularly if they feel that they may have contributed to the eating disorder by something they said or did. In turn they may compensate by taking on more responsibility for caring for the individual although this in turn may lead to more behavioral issues of their own becoming oppositional or even outright defiant. They may have feelings of rejection by their siblings’ behavior toward them and they may begin to separate more and more from the sibling. Occasionally a previously well sibling will develop an eating disorder.

Given the lengthy treatment duration of an eating disorder, the impact on siblings is extended during a critical period of time in their own growth and development physically and emotionally. They are facing the challenges of school, peers and developing their own individual identity. And interestingly, their development can represent a reality check on the cost of the eating disorder to the ill sibling and may become part of a motivation to resist the eating disorder.

Depending on their own stage of development, a younger sibling may be less aware of the effects of the eating disorder and may not wish to see their older sibling as ill. They may attempt to care for their ill sister or brother by assisting them with everyday tasks or by providing companionship and emotional support. These siblings may express concerns and opinions but also give advice and even confront their sisters and brothers. They may be the ones that bring the illness to the attention of their parents.

The pre-illness factors that contribute to sibling responses to the eating disorder and ill sibling include age, gender, personalities of siblings, length of time the illness has been present, whether or not the sibling lives at home and the relationship of the siblings prior to the illness. Siblings may indeed be similarly at risk for some of the same behaviors as the individual with the illness. The intense stress on families and the strain on sibling relationships is often unavoidable. It is important to consider siblings as an integral part of all treatment methods including family and individual therapy. Ultimately the healthy sibling may become a model for healthier behaviors. ■

References:

- Jasper K, Boachie A. *Living with an Eating Disorder: What about brothers and sisters?* National Eating Disorder Information Centre; Toronto, ON; 2007
- Whitney, J, Eisler I. Theoretical and empirical models around caring for someone with an eating disorder: The reorganization of family life and inter-personal maintenance factors. *J of Mental Health*, Dec 2005;14(6):575-585



A Sibling's Perspective

By Elizabeth Sexton, New York

As the children of an Italian mother, my siblings and I always took for granted lavish home-cooked meals. We regularly came home to freshly baked pies and cookies, the smell luring us in from the yard. For every holiday and celebration, my mom made sure to include an array of food to suit everyone's taste and pleasure. On birthdays we ate creamy chocolate frosting, on the Fourth of July the grill sizzled with hot dogs, and on Christmas we devoured perfectly seasoned filet mignon. Some of my favorite memories are of Easter morning brunch and my mom's famous oven-baked French toast. Beyond being an essential part of our existence, food has always shaped our experience as a family.

When my sister, Annie, received a diagnosis of anorexia nervosa in November 2007, our relationship with food and our relationships with each other were irrevocably altered. Five years, three high schools and six inpatient treatment stays later, I remain unable to understand how or why Annie treats her body the way she does. I am at turns incensed and heartbroken for the pain she causes and that which she endures.

At 18, Annie should be zipping from extracurricular activities to the mall to her part-time job, planning for her senior prom and applying to university. I should be celebrating her soon-to-be discovered independence and encouraging her rapidly developing interest in the world around her. Instead, she is a patient on the adult unit of an eating disorders treatment facility in a different time zone, and when I hear that she is alone at the mall on an afternoon "pass" I find myself having paranoid thoughts about whether she can manage and what will happen if no one is looking out for her.

Annie is the youngest in our family, and Greg is the middle child at 24. As the oldest at 29 and as a woman with incapable maternal instincts, I find myself torn between wanting to be Annie's friend and needing to be her caretaker. As she has maneuvered a roller coaster

My perspectives on family, food, women's health, mental health, and healthcare policy have changed dramatically as a result of her struggle.

of lies and failed to follow through on a myriad of promises – characteristics of the eating disorder being in control, not Annie – our relationship becomes increasingly distorted and strained. I want to protect her from this demonic illness but have no control. I want us to be close but find it difficult to respond to her words of advice about my life, which is so different from hers.

I often feel guilty when good things happen to me because I fear I am widening the gap Annie feels she must cross in order to be a "success." I know she keenly watches every achievement Greg and I attain: graduating from top-tier universities, obtaining promotions in well-known organizations in our respective fields, attending graduate school, getting engaged. It seems like a far leap before she will join us in adulthood because the eating disorder robs her of the ability to be fully engaged in creating the life she wants for herself. Though we tell her often, Anne never seems to hear that we

all have deep respect for her persistence and consider every stride she makes a triumph. She never seems to believe us that we think her an amazing, intelligent, artistic, compassionate person who would make it to the moon, if she could just set the eating disorder aside.

On the subway I find myself staring at girls I think are too thin and wishing I could do something to help them get healthy. I raise money for the NEDA walk and wish I could better describe my family's situation to my friends and colleagues. I overhear my teammate talk about her Weight Watchers program and wonder what the world would be like if all women accepted their bodies. I try to talk to my brother, Greg, about Annie's situation and face resistance and blanket optimism. I watch my parents slink further and further into the abyss of fear and blame, and I would do anything to help them.

The eating disorder, the OCD, the anxiety, and the depression do not only affect Annie. My perspectives on family, food, women's health, mental health, and healthcare policy have changed dramatically as a result of her struggle. I find myself wanting to educate others about eating disorders and can never identify just the right forum or entry point.

I continue to find support mostly from very close friends. Although I meet people who know a niece or a cousin who has struggled with anorexia, I have yet to find a structured sibling support group led by a therapist or social worker. I am presently trying to find time in my schedule to pursue professional help on my own.

I continue to learn about the importance of asserting my own needs. Last week I

(continues on next page)



Reach Out for Help: There Are People Ready to Support You

By Richard Hubbard, Connecticut

My sister was sick for 25 years, and lost her battle with an eating disorder this past January. We were very close, especially the last few years. I decided to speak out about her story because there are too many people losing their lives, and there are so many misconceptions about eating disorders out there. I'm still learning myself after all these years, but I want to help get the information to those who can use it in support of their loved ones. People asked so many inappropriate questions or commented to her that they wish they could have that much control. They treated it like a diet because they didn't understand it was an illness. There are so many similarities for those who suffer, but also every case is unique.

After my sister passed away, I signed up for NEDA's Loss Support Network (LSN) to help me cope with the loss. It was so helpful to talk with the LSN volunteers because I can't find anyone where I live that could ever relate to what my family has been going through. And it has really been comforting to know that people do recover, and I could be a part of helping to raise awareness about the seriousness of these illnesses in a way that honors my sister's memory. I design fonts, and because she 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. It is a nice way to remember her and help support others. It would make her feel important to know I've done this.

I find myself sharing my story in the PFN Newsletter because over the years, I've learned how misunderstood eating disorders are—and all the co-occurring issues, like depression. Anorexia often causes anger and control issues within the anorexic person's family. It's hard, but with time and education, it is possible to associate the anger with the illness, not the person suffering from it. I've learned so much from the NEDA Website, and I wish I had found it earlier. For me, it really helps to read the stories of other families in the Parent, Family & Friends Network Newsletter. And reading the Stories of Hope has been so helpful, because I never knew anyone else who struggled with an eating disorder and it is important to see that people do recover. There is support out there. Sometimes it just isn't geographically close.

The quality of care my sister had was really poor because there aren't any specialists here and she couldn't travel far. Unfortunately, from talking to others, I've learned that low quality of care is too common. I'd like to see that change, and speaking up

about the role of quality care for effectively treating eating disorders is something I can do to advocate for change.

My sister was very isolated here and I think it would have helped if she had known people who have recovered from anorexia. Now people can request a NEDA Navigator—either for themselves as a support person, or an individual struggling—for encouragement and guidance from someone who has been there, can empathize and provide real hope. So just know that you don't have to be alone; don't be afraid to reach out for help, because there are people ready to support you. ■

To request connection with a NEDA Navigator, email pffnetwork@myneda.org, or visit the NEDA Navigator homepage at www.MyNEDA.org.

**NEDA's free, confidential
Information &
Referral Helpline:
800-931-2237**

Thanks to all who have contacted the PFN to express interest in the topic of how siblings are impacted by an eating disorder in the family, this month's PFN Webinar Series, focused on siblings, featuring both those with personal experience and an eating disorder treatment specialist.

Visit the PFN homepage at MyNEDA.org to listen to the webinar recording.

A Sibling's Perspective *(continued)*

wrote my mom a card thanking her for being so involved in planning my wedding and admitting I felt a little sheepish for enjoying our one-on-one time as much as I have. She responded, "no one is too old to want attention from their mom." As independent as I am, I felt comforted knowing she understood what I meant.

As we continue on this journey I know we are in an odd way, quite lucky to have encountered a challenge that makes a family reconsider its values. As we develop our communication structures and find ways to support each other, we maintain our support for Annie. Knowing that the people she loves most believe she will overcome her challenges might make all the difference. ■



Lessons from My Family's Journey: Be Kind, Gentle and Patient with Yourself

By Kym Raines, California

My sister was 15 when her eating disorder took over and consumed her life. This March marks the 10th anniversary of her death. In the more than two decades of dealing with complicated and overwhelming emotions surrounding Kacy's eating disorder, I learned that there are glimmers of hope even in the most tragic stories. In most cases, that hope came from those in recovery. I believe, however, that my family's journey offers profound lessons for those who are suffering, as well as their families.

Driven by my own fear, I tried to take control of Kacy and "fix" her. I spent years making her disorder the primary focus of my life. I allowed it to invade all my passions, loves, dreams, friends, family and work. It was exceptionally unhealthy for me, not to mention for Kacy, my family, my friends and my marriage. Conversations about Kacy were often tense and argumentative. We had no boundaries with her, set no limits and

lived in shame that we could not end her suffering.

Kacy's illness spanned the mid-80s all the way to her death in 2002, before blogs, websites or online support. I was desperate to hear other siblings' stories. How did they handle their siblings' denial or that of their parents? Were they as frightened as I? Did they sometimes feel anger for coming second to the sibling's affliction? Did they feel their input was dismissed because they were not a parent? For me, there was no one I could turn to. I felt alone and ached to hear from someone who understood. Now there are NEDA Programs—like the NEDA Navigators, Annual NEDA Conference, and Parent, Family & Friends Network (PFN)—as well as other online or local resources for families and friends of those who struggle, so you don't have to go through a difficult journey alone.

Without outside support and therapy,

our family dysfunction became a powerful force, isolating us from one another and allowing the eating disorder to take over. But, my family has come a long way since my sister's journey, and I am thrilled to see family therapy become an important part of treatment. Along with therapy and online communities, support for families has grown with organizations like NEDA. I was honored to participate in this year's National Eating Disorders Awareness Week. I was actually quite moved as I was able to honor Kacy by celebrating the incredible growth around awareness, education, and advocacy. 25 years ago, I could not have imagined the social media campaigns, blogs, support groups, fundraisers or the Empire State building being lit for awareness. There is support and hope. Be gentle, kind, and patient with yourselves. You count too! I can't stress enough that families do their research and find resources, so that they can take care of themselves and better support their loved one. ■

The NEDA Navigators are individuals who have personal experience, either personally or through supporting a loved one, navigating the overwhelming systems and emotions involved with seeking treatment for an eating disorder. Trained volunteers are available to help you find treatment referrals, local support groups, resources tailored to your needs and be a listening ear through your journey. The range of experience among the Navigators is diverse, and when you request to be connected with a Navigator, we can be sure to match you with someone

who has been through a similar set of challenges to share their experiences in a helpful, responsible way. You can request to speak with someone who's dealt with co-occurring conditions such as depression, substance abuse or self-harm, or has the same relationship to the person struggling, such as a fellow dad, mom, partner, sibling or friend. Email us at pffnetwork@myneda.org and we'll get you connected. For more information about the NEDA Navigators, visit the Navigators homepage at www.myneda.org.

* 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.

NationalEatingDisorders.org



NAVIGATORS

NEDAwareness Week 25th Anniversary reached nearly 70 million people!

The success of the 25th Anniversary of National Eating Disorders Awareness Week, themed **Everybody Knows Somebody**, reminds us that education and awareness are critical to guiding people to

the help they need. National, regional and local press, outreach activities and events, and online activism resulted in a 50% increase in traffic to NEDA's Helpline, an all-time high in individuals served

through the Helpline; and a 150% increase in people reaching out for, and receiving support and guidance from, a NEDA Navigator. ■

Empire State Building Lights a Spark to Take Action

By Katie Rodriguez, New York
NEDA Helpline Volunteer

NEDA came into my life in a very grand way. My husband was walking to an appointment with his trainer one evening and sent me a text that read "Do you think the Empire State Building is lit up tonight for Leap Year Day?" Out of curiosity I hopped onto my computer and researched the Empire State Building's colors. I learned that the city was not in fact celebrating Leap Year Day but instead recognizing National Eating Disorders Awareness Week, which is a program of the National Eating Disorders Association. My thoughts immediately flashed back to a doctor's appointment I had a few weeks prior in which my doctor told me that I should use my experience and recovery from anorexia nervosa to help others. I immediately went onto NEDA's website and saw that they had a plethora of programs available for volunteers, and their Helpline specifically caught my attention. I of course applied right away and couldn't help but think that sometimes things fall into place so easily and are called to our attention so randomly for anything but random reasons. ■

"I get it Mom, I get it."

By Nichole Lewellyn, New York

A little under three quarters of a mile. That's the distance from Grand Central Station to the NEDA Office at 165 W 46th St. Three years ago I would have had trouble making that walk. I didn't even have the energy to throw the ball with my son. As we walked that 3/4 of a mile, I couldn't help but think about the little boy who could have lost his mom to an eating disorder, wondering if he at all "gets it."

No longer a little boy, I felt it was time that my son, Randall, see what NEDA is all about and take him to the NEDAwareness Week screening of the documentary film *Someday Melissa* in Manhattan. We arrived at the NEDA office around 3:30 pm and were greeted warmly. See-

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Austin NEDA Walk: Stigma Often Associated with Eating Disorders was Harder to Find than Waldo | By Jessica Meltzer, Texas

As you look through our NEDA Walk pictures, you may notice a recurring figure. Occasionally he is in the forefront, yet at other times he blends into the crowd. Although he stands out, he seems as if he is where he belongs. Who exactly is this man? No, it is not Ed; it is Waldo.

Yes, Waldo, the character from your childhood in a red-and-white striped shirt and thick-rimmed glasses. You may be surprised that Waldo was at our Walk—okay, maybe not *THAT* surprised if you have ever been to Austin (where the city's motto is "Keep Austin Weird")

—but the more important question is, why was he at our Walk? Let me start at the beginning.

My name is Jessica Meltzer, and I was a coordinator of the 2011 Austin NEDA Walk. Back in 2010, I was part of the team that organized the first NEDA Walk in Texas. We started small but found great support for the cause from those we knew and strangers alike. When 2011 came around, people in our community were eager to participate again, so we took what we had learned and began to plan an event that be-

came bigger than I could have imagined. Our goal was to fundraise for NEDA's programming and raise awareness in the Austin area. The theme was "It's Time to Talk About It," and talk about it we did. Our small walk more than tripled in size and raised more than double our fundraising goal.

As someone who is happy and healthy in recovery, NEDA is important to me on a personal level. After being diagnosed with an eating disorder, I was overwhelmed with what to do next. I
[\(continues on next page\)](#)

"I get it Mom, I get it." *(continued)*

ing both new and familiar faces, I felt at home. I was pleased to see that I caught Lynn Greffe, CEO, in time to introduce her to my son. She took us on a tour telling us of all the things that took place there and spoke of the schedule of that night's event. It was an incredible experience to show him just a piece of what goes on "behind the scenes" and how NEDA offers resources and support to so many in the grips of an eating disorder.

My son and I walked into the Schimmel Theater at Pace University together, and I saw more and more familiar faces from the NEDA events I have attended over the years - faces of those who I had lobbied with through NEDA's STAR Program and faces of those from the 2011 NEDA Conference. I then ran into Judy Avrin, the filmmaker, and had the opportunity to explain to my son how Judy has made it her mission to share her daughter Melissa's tragic story in the hopes of helping others who suffer from eating disorders. Watching Melissa's story with my son brought up different emotions than I experienced when I saw the film previously by myself. I watched his face change throughout the film wondering what he might have been thinking. As we left the theater, I asked him what he thought of the film. He said, "It's sad."



"Looking at the Empire State Building lit up with NEDA's Colors was like seeing God's Love shine down on the city."

—Randall Lewellyn

I left it at that.

We grabbed a cab to Little Italy for a late dinner. As we walked along the street trying to decide which restaurant to try, my son stopped to ask a question: "Mom, all those people that were at the

screening tonight, they weren't there just to watch the movie. Those were people that worked in the NEDA Office, and all those people you talked to that did all those volunteer things with you, they are all there to help people?" I shook my head yes. We started walking again when all of a sudden I felt Randall's hand on my arm. "Mom!" he said. I was puzzled as to why we stopped again. His eyes were looking toward the sky, "Look! There it is!" There stood the Empire State Building in all its glory, lit up in beautiful blue and green. We stood completely frozen in awe. Then my son put his arms around me, gave a big hug and said, "I get it Mom, I get it." ■



Mom and Ran

Austin NEDA Walk (continued)



Fast forward to November 19, the day of the Austin NEDA Walk. The turnout from the community was incredible. With almost 300 people in attendance, the park was filled with more people—and animals—than I could have imagined. (Seriously, there were two Great Danes and a miniature horse!) Though it sounds a bit chaotic, when it

had never personally known anyone with an eating disorder, let alone that there was an organization out there helping people navigate through the extensive information and life-changing decisions. Though the journey was tough, I was lucky enough to receive the treatment I needed and have a support network that never gave up on me. Along the way, I met a lot of amazing people who could not get the help they both needed and wanted, all because of a lack of resources. When I heard about the NEDA Walk, I knew that I wanted to get involved, to raise awareness, and to fight for my friends still struggling. And so it began.

So where does Waldo fit into this story? I planned the walk with my co-coordinator and friend, Janessa Slatky. A professional photographer had volunteered her time, and while we were excited to document the walk, we were also a bit apprehensive. Ahead of time, a few people had expressed concern about being in pictures due to eating disorder-related issues, so Janessa and I were brainstorming ways to alleviate their fears while also maintaining our goal of normality. Enter Waldo. We were sitting in a bookstore, joking that it was too bad Waldo would not be there to steal some of the spotlight in pictures. After several delirious hours of planning, we decided, why not? Let's invite Waldo!

came time for the speakers, everyone was quiet and engaged. We were lucky enough to have Jenni Schaefer, Chair of NEDA's Ambassadors Council and author of *Life Without Ed* and *Goodbye Ed*, *Hello Me* both speak and perform at the walk. In the midst of it all was our friend in the striped shirt, posing for some pictures and "photobombing" others. While people loved Waldo, it turned out that we did not really need him after all. The stigma so often associated with eating disorders was harder to find than Waldo. Participants from all backgrounds

shared their hope and experience or reached out to ask for help of their own. We were a group of 300 strangers, yet people talked like we were a group of friends. With an illness proliferated by silence, speaking up is crucial. Hearing people talk about it was what this walk was all about.

Where is Waldo now? You will have to look closely. More importantly, where is the stigma? Thanks to NEDA, the public is becoming much more informed about eating disorders, which ultimately helps prevent eating disorders and allows more people get the treatment they need. I recently became Chair of the Austin Foundation for Eating Disorders, and we hope to become a NEDA Network member this year to help further their efforts. We don't need Waldo to come next year, and instead of trying to blend into the crowd, we hope walkers can smile proud for the cameras, knowing that they are making a real difference. NEDA envisions a world without eating disorders, and I envision empowered and informed communities in Austin and around the country to help work toward our shared goals of health and happiness. ■



Your Dentist, Your Friend

By: Robert Schlossberg, DDS and Deborah Klotz, DDS, Maryland

It has been said many times, that the eyes are the window to the soul. The same is true of the mouth. The oral cavity is the window into the body. Much can also be learned about someone's health and lifestyle by a thorough look into the mouth and at the teeth themselves. Those affected by an eating disorder often go to great lengths to hide their disorder from loved ones, who may not recognize that they are struggling. Dentists can help play a role in catching eating disorder behaviors before they progress to a more chronic state. The average person will visit the dentist two to three times more often than other health care providers, and for this reason, the dental office is a perfect environment for early detection, advice and care for eating disorder related concerns. A well-educated dental professional should be able to spot the warning signs and help point you in the right direction to get help.

Countless research articles have been written about the strong links between one's oral health and overall systemic health. This data links diabetes, heart disease and more recently infertility with poorly maintained oral health. Many medical and dental schools now include curriculum that address these links. One grouping of systemic disorders that is not only prevalent, but has significant oral ramifications is eating disorders. Bulimia, anorexia, binge eating disorder and other diagnosable varieties of eating disorders not only wreak havoc on the body, but can have more localized devastating effects in the mouth.

Eating Disorder (ED) Related Dental Complications:

- Without the proper nutrition, gums and other soft tissue inside your mouth may bleed easily. The glands that produce saliva may swell. Individuals may experience chronic dry mouth.
- Throwing up frequently can affect teeth, too. When strong stomach acid repeatedly flows over teeth, the tooth's outer covering (enamel) can be lost, and the teeth can change in color,

shape and length. The edges of teeth often become thin and break off easily. Eating hot or cold food or drink may become uncomfortable.

- People with anorexia oftentimes become deficient in nutrients that promote oral health, such as calcium, iron, and B vitamins. Insufficient calcium promotes tooth decay and gum disease; even if an anorexia patient does consume enough calcium, they also need enough vitamin D to help the body absorb it. Insufficient iron can foster the development of sores inside the mouth, and insufficient amounts of vitamin B3 (also known as niacin) can contribute to bad breath and the development of canker sores. Their gums can become red and swollen, almost glossy looking, which is often a sign of gingivitis. The mouth can also be extremely dry, due to dehydration.
- Another dental complication associated with ED's is degenerative arthritis within the temporo-mandibular joint in the jaw. This joint is found where the lower jaw hinges to the skull. When arthritis begins in this joint it may create pain in the joint area, chronic



Eating Disorders and Oral Health

headaches, and problems chewing and opening/closing the mouth.

- Another sign a dentist may see as a result of purging is redness, scratches and cuts inside the mouth, especially on the upper surface commonly referred to as the 'soft palate.' Such damage is a warning sign for dental professionals, because healthy daily behaviors rarely cause harm to this area. Soft palate damage is often accompanied by cuts or bruises on the knuckles as a result of an individual's teeth placing pressure on the skin while attempting to purge.
- Finally, a frequent binge and purge cycle can cause an enlargement of the salivary glands, a symptom which can be particularly bothersome for individuals with bulimia. Enlarged glands can be

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Treatment of the Oral Health Consequences of Eating Disorders

- Maintain meticulous oral health care related to tooth brushing and flossing, as well as frequent and appropriate communication and examination by your dentist. A confidential relationship should always be maintained between the dentist and patient, and therefore, the patient should feel that the dental office is a "safe" place to disclose their ED struggles and progress towards recovery.
- After purging patients should immediately rinse their mouth with water or use a sugar-free mouth rinse. Patients should swish only water around their mouth due to the high acidic content in the oral cavity. It has also been recommended that brushing be halted for an hour to avoid actually scrubbing the stomach acids deeper into the tooth enamel.
- A dry mouth, or xerostomia, may result from vomiting and/or poor overall nutrition. Xerostomia will also frequently lead to tooth decay. Moisturizing the mouth with water, or other specified products will help keep recurrent decay at a minimum.
- Consult with your dentist about your specific treatment needs. Fluoride rinses may be prescribed as well as desensitizing or re-mineralizing agents.
- See your dentist regularly.

Communication Strategies with Patients with Eating Disorders in the Dental Setting

By Shannon Albert, MS, Oregon

Dental providers are uniquely positioned to identify the signs and symptoms of an eating disorder; often before other health care providers. It is important to take warning signs of an eating disorder seriously. They are serious, potentially life-threatening disorders, and early intervention can significantly improve the recovery outcome.

Guidelines for Communication

Setting the Stage: Where possible, begin dialogue with the patient in a comfortable setting where there will not be interruptions. This might be in the dental chair, or in a separate consultation room. To help preserve confidentiality as well as respect the sensitive nature of this issue, ensure that the conversation will not be overheard by patients or staff nearby. Though challenging, try to plan enough time so your conversation will not be rushed.

Introduce the Issue with Care and Concern: Share your oral findings directly with patient coupled with your concern.

- “I have noticed some changes in your mouth (specify what changes you’ve identified)...”
- For example: “These changes include loss of enamel from your teeth and damage to the soft tissues of your mouth and throat.”
- “I am concerned about these findings, and your oral and overall health.”

Ask for More Information from the Patient: Express your curiosity about why these symptoms are present in a non-judgmental manner and be prepared to listen. Their response provides you with important information.

- “Are you aware of any reasons why these changes have occurred?”

Provide Information with Permission: If the patient is ready to listen, explain the possible reasons for why the oral damage you are seeing can occur.

Remember that it is not your responsibility to diagnose, but to provide information designed to protect your patient’s oral and systemic health.

- “My hope is to open up a conversation with you about the changes I am seeing in your mouth. Would that be okay? I view my role as assisting you with your oral health, and am not going to judge or try to change you.”
- With permission, explain your oral findings: “The types of changes I am noticing in your mouth appear to be from the presence of acidic substances repeatedly coming into contact with your teeth. Sometimes this can occur from things like heavy consumption of soft drinks and juices or extensive sucking on sour candies, or can occur from stomach acids coming up after episodes of vomiting or gastric reflux...”

If the patient says they don’t want to discuss the issue, or indicates this is

not a concern of theirs, offer a handout they can read at a later time. (Visit the National Eating Disorders Association website at www.myneda.org for free downloadable and printable handouts.)

Connect your oral findings to an eating disorder and explore the patient’s relationship with food and their body:

If the patient gives an indication that they are, or may be, struggling with an eating disorder, provide information in a way that demonstrates compassion and understanding. Then, begin to explore how their eating disordered behaviors impact their dental and overall health.

- “In my experience, people often have a complicated relationship with food and their body, and may make changes in their eating habits in an attempt to alter their appearance or cope with challenging situations. Sometimes these changes can become extreme, and may lead to

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Your Dentist, Your Friend (continued)

painful and are often visible to others, a situation which may prove to be emotionally disturbing for individuals with eating disorders who may already be self-conscious about their appearance

Unfortunately, unlike hair and nails that typically suffer reversible damage from the ED, the teeth and mouth may have lingering and even permanent damage. When armed with the right information, and the appropriate guidance from your oral health professional, this damage can be tempered.

Early detection of eating disorders may ensure a smoother and successful recovery period for the body and the teeth. It is common for oral healthcare practitioners to be familiar with many of the signs and symptoms associated with eating disorders. However, not all of them have the experience needed when treating patients that are directly

affected by an eating disorder and should educate themselves to ensure the best care possible. If you, or your child, have struggled with an eating disorder, make sure you ask questions about your dental provider’s qualifications, their experience, the kinds of cases they have treated and their treatment philosophies. It is important that like all of your relationships with healthcare providers, your relationship with your oral healthcare provider be candid and honest. They can only provide as much help as you allow them to provide.

Dr’s Schlossberg and Klotz are partners in life and professionally. They own Bethesda Sedation Dentistry; a dental practice in Bethesda, Maryland that cares for the complex needs of high fear, high anxiety dental patients. They have tremendous amounts of experience caring for the emotional and physical needs of those with eating disorders. ■



Talking to My Dentist | By Yasemin Merwede, New York

I had already been in recovery from bulimia for 12 years when I visited a new dentist my friend

had referred me to. From our first meeting, I could tell this new dentist was very friendly and approachable. While doing an initial exam of my teeth and noticing that I needed a few root canals, he casually joked, asking if I was chewing rocks. He meant the comment to be comedic, and I appreciated his humor. I decided to reveal to him that I had battled bulimia for two years as a teenager. I was relieved at his reaction to my revelation – he acknowledged what I told him without judgment. After mentioning how great it was that I was in recovery,

he turned his attention to helping me solve the problems I developed with my teeth. He maintained a professional yet friendly demeanor as he continued his exam, pausing to ask questions about my bulimia. He was so kind, I felt very comfortable in sharing my story with him.

I could see realization dawn on his face while I watched him examine my back teeth. He was noticing the acid erosion on my molars, connecting what I was telling him with what he was seeing. I was forthcoming about how I felt defeated because of the damage I had done to my teeth, but he was nothing but encouraging and optimistic about saving the teeth that had been badly damaged. He mentioned that he was very glad I was able to confide

in him, because with this knowledge he was able to look past my back molars and notice decay on other teeth I was unaware of – dental problems even my previous dentist had overlooked.

Since our meeting, he has mentioned that because I was able to confide in him, he is now aware of what signs to look for in other patients that could signal an eating disorder. He told me that he is now encouraged to approach patients and begin a dialogue when the suspected cause of dental erosion is an eating disorder. I feel content that not only was I able to trust him with the story of my recovery from an eating disorder, I was able to sensitize and educate him to be able to identify it in others now. ■

Communication Strategies with Patients (continued)

an eating disorder. This is often a difficult issue to discuss, but is not something to be ashamed of. Eating disorders are an illness, not something you chose to have, and they impact over 10 million people in the United States alone. Would it be okay to ask you some direct questions about your eating behaviors?"

With permission, ask what eating disordered behaviors they engage in, how long these have been going on, how frequent their behaviors are, and if they have ever sought help for their illness from a professional or team of professionals.

Provide referrals to eating disorder treatment specialists: Because eating disorders are serious, and potentially life-threatening conditions that impact one's physical, nutritional, mental, and oral health, it is very important to obtain professional help from eating disorder specialists. Relay to your patient the importance of seeking professional help coupled with the message that recovery is possible. You can suggest that your patient contact the National Eating Disorders Association Helpline at 800-931-2237 for eating disorders information and referrals to eating disorder specialists across the nation, or visit their website at www.myneda.org.

Provide eating disorder specific dental care instruction: Some of the damage to the oral cavity incurred from an eating disorder, particularly erosion to the enamel of the teeth, cannot be reversed. Thus, providing oral instruction to reduce or slow the progression of deterioration is important (e.g. not brushing immediately after vomiting, using a fluoride mouthwash, etc.).

Coordinate care with the patient's treatment team: Explain the benefits of coordinated care to the patient (e.g. improved treatment quality, increased patient satisfaction with treatment, and patient empowerment) and obtain written authorization to release personal health information to their specific providers.

- *"My goal is to provide you with the best care possible, and it is often valuable for me to be able to communicate with your other eating disorder treatment providers so that we can work together in addressing your needs. Would you be willing to provide me with permission to contact them and discuss your treatment?"*

Remember, your efforts to have this conversation may make the difference in whether your patient receives life-saving

treatment for their eating disorder. Even if the patient is not ready to acknowledge a problem, or you do not see an immediate change, you have done your part to provide information and express concern. This is like the planting of a seed that may later result in help seeking behavior.

The Academy of General Dentistry (AGD), another leading international dental organization has made numerous recommendations and coordinated statements over recent years that coincide with those of the American Dental Association and the Mayo Clinic's department of oral health. Unfortunately, because ED's are often left off on the sideline, rather than being brought into the spotlight where they will receive the attention they deserve, there is not a distinctly agreeable protocol among institutions, organizations and practitioners when it comes to caring for the oral manifestations of these diseases. Therefore, the oral care as it relates to ED's, is typically more of a symptomatic rather than systematic approach.

Shannon Albert, M.S., is a clinical psychology doctoral candidate at Pacific University in Oregon. She has a special interest in enhancing the role of dental practitioners in the assessment, early intervention, and care of patients with eating disorders and has devoted her dissertation research to this area. Shannon is a huge NEDA supporter and past NEDA Helpline Supervisor and PFN liaison. ■

Loss Support Network: Personal Connections to Foster Healing

By Marybeth Saunders, Indiana, and Pearl Mattenson, New Jersey

Marybeth

Sitting...I get up and pet the cat. Put in a load of laundry. Go back to the computer and stare; get up and eat chips, sit down again at the computer and look at a photo of my sister, Rebecca, taken seven months prior to her death. She was living with my husband and me, and wanted to create a Facebook account, but hated how she looked so it never happened.

I get up, go back to the kitchen and grab a handful of deep purple grapes and head back to the computer. I take a deep breath; eat a grape hoping it will magically give me courage and clarity. It doesn't. So I sit and stare again at the computer screen.

How can I possibly write about this? What can I write that will be of help to anyone else?

Before I could answer those questions, I needed to help myself. Over the last year I stopped self-medicating with alcohol, received counseling to help me face the crushing grief, guilt, resentment, and sadness I'd stored over a lifetime. Lastly, I realized how helpful it would be to connect with someone else who had lost a sibling.

I emailed NEDA's Loss Support Network. Within days I received a brief, warm email from a woman named Pearl who invited me to write back if I wanted to. I liked her name and her open, no pressure invitation, so I wrote back and we scheduled a time to speak on the phone. The following day, I spoke, cried, and cursed while Pearl patiently listened. During that first phone call we learned that our sisters had struggled with the disease of anorexia nervosa since early childhood; their lives and our families lives were consumed by the disease for over 30 years. Most breathtaking and poignant was learning that our sisters died within three days of each other, Rebecca on June 16, 2010 and Karen, June 13, 2010.

Pearl

I attended the NEDA conference in Brooklyn, NY a month after Karen died. I sat at the first ever roundtable on Grief and Loss with mothers and fathers of girls who died in their teens and 20's. I felt at once relieved to hear stories that I recognized and a little out of place. I was a sister- not a parent. And Karen was in her 40's when she died. My connection to NEDA opened a door I didn't know existed. My relationship with Marybeth is the embrace of family beckoning me in for a healing hug.

*"May a river of mercy
flow through me
May any legacy of
harm be released
We have traveled a
lifetime together
May our song of Love
be embraced."*

*—from Marybeth's
CD, Medicine Voice:
Simple Songs & Chants*

Rebecca and Karen were unique human beings with dreams and hopes of their own. And yet as Marybeth and I talked, there was much that we recognized in each other's stories. We share a selective set of childhood memories: "snapshots" of joy and laughter and love; imaginary adventures and real explorations. Short-lived moments interspersed with long periods of sadness, frustration, fear and trying to pretend we didn't have a sister who was so different, who was suffering, and who we couldn't figure out how to fix. And all this lived side by side with our wonder that Rebecca and Karen, were the

beautiful ones. They were the brains.

It is shocking from this vantage point to realize we envied them at some level. If only they could have seen themselves as we saw them.

Marybeth

Over the past year, I think Pearl and I have become sisters. We have lived with and told our strikingly similar, bitter-sweet histories. Thanks to therapeutic support and the services NEDA so graciously offers, I am coming full circle to the present. A large part of my "second half of life" purpose has chosen me.

I have begun working with doctors and administrators at the hospital that – through their ignorance and apathy – harmed Rebecca. Together, we are planning educational events for the healthcare community. My vision is for this hospital to – within five years – offer solid holistic care to those suffering from eating disorders. Currently, this town with five institutions of higher learning has just one eating disorders therapist for the entire city, and not one primary care doctor nor pediatrician who specializes in eating disorders.

I'm excited to work with community members to produce a NEDA walk in the fall here in South Bend, IN and, most delightfully, I will be attending the October NEDA Conference and am bursting at the seams to share a room with my sis, Pearl.

I hope she won't kill me for snagging some of her cool clothes to wear.

Pearl

I am so inspired by Marybeth's work. She has taught me that it is never too late. And there are others to be helped.

In my own way, I am coming out of the closet. I have written publicly about my sister's struggle in various venues.

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NEDA
NETWORK



Meet NEDA Network Member: The Missouri Eating Disorders Association

By Judy Clifford, Missouri

It has been a busy spring for The Dahlia Partnership. First, this is the last time you will see that name. We are becoming The **Missouri Eating Disorders Association**. We will use the acronym MOEDA. Our new link and information will be available on the NEDA website very soon. The name change was part of a grant application process that resulted in a \$25,000 award from the Youthbridge Social Enterprise and Innovation Competition (YSEIC). The YSEIC is sponsored by the Olin School of Business at Washington University in St. Louis. We will be using the grant money to set up infrastructure that will support our outreach program of workshops for school counselors, coaches, and nurses. We have already done several pilot presentations and have received very positive feedback. We have even been invited to present our workshop format at the NEDA Conference in October!

Other things keeping us busy are plans for the 4th annual St. Louis NEDA Walk in September, a fundraising event

featuring author and orthorexia expert Ralph Carson, PhD, RD and our ongoing efforts to pass an insurance mandate in the Missouri Legislature. We have made significant progress in the legislature this year. The insurance committee has funded an actuarial study of the bill, a step that means they are very serious about voting on the bill. Also, the Missouri Eating Disorders Council, established by legislation we were successful in passing in 2010, has survived the notoriously severe Missouri budget cuts, and continues to move forward with plans. Members of our board will be included in the council.

Other plans include adding staff, thanks to the YSEIC award, and setting up regular membership and fundraising drives, along with an electronic newsletter. We are currently working with a consultant to make all these plans happen so that we can expand our fight against eating disorders in the Missouri-Illinois area. Stayed tuned for more exciting developments! ■

Loss Support Network: Personal Connections *(continued)*

I have contributed to the creation of NEDA's Loss Support Network and am a volunteer to support those who have experienced this unique kind of loss.

I joined NEDA's STAR (Solutions Through Advocacy and Reform) program in New York to lobby for a bill mandating physician education about early signs and symptoms of eating disorders.

And Marybeth and I hope to meet face to face in October at NEDA's Annual Conference in St. Petersburg, Florida,

October 11-13, 2012, to cement our bond and strengthen our resolve to make a difference.

May Rebecca and Karen's lives become memories that help and heal.

If you or someone you know has lost a loved one to an eating disorder, please consider visiting the Loss Support Network under the PFN homepage section of the NEDA website, www.myneda.org. ■

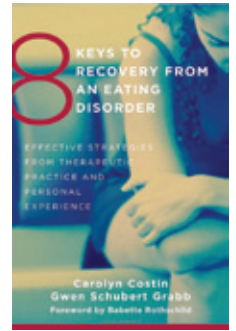
Book Review:

8 Keys to Recovery from an Eating Disorder: Effective Strategies from Therapeutic Practice and Personal Experience

Authors: Carolyn Costin, MA, Med, MFCC and Gwen Schubert Grabb, MFT

Copies available for purchase through Gürze Books at www.gurze.com

Review submitted by: Mike Polan, New York



**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.*

Whether you suffer from an eating disorder yourself, have a loved one who is suffering, or know someone who is suffering, *8 Keys to Recovery From an Eating Disorder* is a must-read for critical information and strategies to help you through the process of recovery (yourself or in support of a loved one). This book does not use overwhelming medical terms, but offers accessible, easy to follow explanations for serious eating disorder related issues.

The authors offer their own personal accounts of recovery as well as interviews from clients they treated in their practices, giving readers insight into the illness and recovery process. They also offer strategies on how to cope with and avoid destructive feelings and behaviors that occur as a result of having an eating disorder. In addition, the book provides assignments at the end of each chapter to give readers an opportunity to work on specific areas they are struggling with, as well as activities they can do to prevent acting on their eating disorder thoughts. Specific coping strategies and activities are helpful to those personally affected, and also give carers important tools for encouraging their loved one.

As a father who has been through it, I believe a key strategy cited in the book for carers is be there to support, not fix or judge. The book recommends the motto "Truth without Judgment." Costin and Schubert Grabb effectively explain how this idea can help open up the lines of communication, an important component for being able to provide support and encouragement. Your loved one will be more likely to open up to you if you approach them with patience and empathy.

The book offers another strategy that I found very helpful: Treat an eating disorder like any other serious disease. The authors explain the complexity of eating disorders in a way that helps to dispel much of the misinformation that is out there, and stresses: Get the best help possible – just like you would get the best doctor possible – and trust and believe in the treatment team while being a proactive part of the process.

Having a daughter that has battled an eating disorder for 10 plus years, I know firsthand how confusing, frustrating, and difficult this disease can be to understand. This is a book I wish I had early on in my daughter's illness. The authors help you understand the thought processes that go on in your loved one's head. They also give strategies that we, as parents or loved ones, can use to help support them on their road to recovery. In order to truly understand what your loved one is going through, you must realize that there is an internal battle between their healthy self and their eating disordered self. This is like the old cartoon that shows an angel on one shoulder and a devil on the other, each one trying to get them to come over to their side. It can be like a constant tug of war! In the midst of an eating disorder, when a loved one's weight is too low and/or their body is not being fueled with the nutrition it needs, they are not thinking clearly and the eating disorder is in control. Understanding how difficult and stressful this scenario is will help you better understand their behaviors, preventing unnecessary anger on your part. It's not their fault; it's the eating disorder winning the battle. But the eating disorder does not have to win; with treatment and your support, they can fully recover. ■

Mike Polan is a NEDA Navigator in New York, and can be reached at mikep@pfn.nationaleatingdisorders.org.

** 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.*

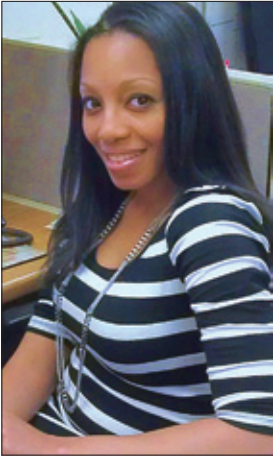
For more information about the NEDA Navigators, visit the Navigators homepage at www.myneda.org.

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.



Meet the NEDA Staff | Ashley James, Data Entry Assistant

Ashley James joined NEDA in September of 2011 as a Data Entry Assistant for the Development team. She graduated from Iona College with a bachelor's degree in Business Administration, where she majored in Accounting. Following graduation she also earned her certificate in Forensic Accounting. Ashley is very passionate about helping others and volunteers her time at soup kitchens and assisting in internal audits at her local church.

During her younger years, she trained to sing professionally as a member of the Highbridge Voices choir. This experience offered the opportunity to learn songs in different languages and to perform in places such as the Waldorf Astoria Hotel, Lincoln Center and Madison Square Garden where she sang with Celine Dion for her song "Let's Talk About Love." ■

National Eating Disorders Association Applauds Appeals Court Decision in Harlick vs. Blue Shield of California

Ruling Expected to Have Significant Impact Across the Country

Panel Judge Calls It a 'Common Sense' Decision

The National Eating Disorders Association (NEDA) applauds the United States Court of Appeals for the Ninth Circuit for upholding its August 2011 appeals decision in Harlick vs. Blue Shield of California. Under that ruling – which one of the panel judges referred to as a "common sense" decision in its review – insurers in California must pay for residential treatment for eating disorders and other serious mental illnesses under the state's mental health parity law.

The case hinged on application of California's 1999 mental health parity law. A federal mental health parity law was passed in 2008. However, many insurance companies continue to deny coverage for residential treatment of eating disorders or other mental or emotional conditions, which can reach costs of more than \$1,000 per day. Most professionals in the field feel there is "no question" that residential treatment can be a life-saving option for some patients who are battling eating disorders such as anorexia.

In the Monday (June 5) ruling, the court confirmed its original decision that the California Mental Health Parity Act requires health plans to provide coverage of "all medically necessary

treatment" for "severe mental illnesses" under "the same financial terms as those applied to physical illnesses." In the latest decision, the court held that health plans in California are obligated to pay for residential treatment for people with eating disorders even if the policy excludes residential treatment.

Commented Lynn Greffe, president and CEO of NEDA, "The Harlick ruling is a significant victory in the battle against eating disorders that we hope will have repercussions throughout the health insurance industries. Having a loved one struggling with an eating disorder is difficult enough without needing to go to war with your insurance company. Patients have been discriminated against by insurers through the years, so we hope this ruling will help turn the tide. Eating disorders can be deadly, but with appropriate treatment, recovery is possible. Insurance coverage for treatment is vital to that recovery."

The California case revolved around Jeanene Harlick, an anorexia sufferer who received lifesaving treatment several years ago at a residential facility in St. Louis. Harlick had battled anorexia for more than 20 years. When her condition

worsened in 2006 – despite intensive outpatient therapy – she checked into the Castlewood Treatment Center, where a feeding tube was required to sufficiently increase her caloric intake. Blue Shield of California refused to pay for Harlick's nine-month stay, likening it to assisted living care, which her policy did not cover. Harlick filed a complaint in federal district court in 2008 – with her lawyers arguing that undergoing residential treatment for anorexia is more comparable to receiving care at a skilled nursing facility, something that was covered by her policy – but the court sided with Blue Shield. Harlick appealed the decision and was victorious.

Commented Lisa Kantor, of Los Angeles-based law firm Kantor & Kantor, who represented the plaintiff, "We appreciate that the court not only denied Blue Shield's request for rehearing and rehearing en banc but also issued a new opinion with added clarity about the broad scope of California's Mental Health Parity Act. The majority opinion takes a common sense approach in interpreting the act and accomplishes the legislative purpose of mandating full coverage for severe mental illnesses." ■

Memo to the Fashion Industry: Using Diverse Models Increases Your Sales

Featured on Proud2Bme.org

By Claire Mysko

Ultra-thin models make us want to spend our money because we aspire to look like them—and they make good clothes hangers, right? Turns out those tired old excuses are wrong.

Designers have used that clothes hanger line forever and advertisers have long operated under the assumption that consumers spend money when we feel bad about ourselves. Hence the constant use of thin, light-skinned, “flawless” (thanks to Photoshop) models. We rarely see ourselves reflected in ads and fashion spreads, an intentional exclusion we’ve been told is all about turning a profit. But new research conducted by a fashion industry insider shows that diversity actually drives sales.

Ben Barry runs a modeling agency representing models of all sizes and ethnicities. He built his business on the belief that diversity in fashion is a good thing, and he set out to prove it in his doctoral thesis at Cambridge. The results of his study are published in the June issue of Elle Canada. Barry surveyed and conducted focus groups with more than 2,500 women, from ages 14-65, sizes 0-18, and representing a range of ethnicities. He created a mock ad featuring women of different sizes and ethnicities wearing the same Diane von Furstenberg wrap dress. Here’s how women responded to the ad:

Women increased their purchase intentions by more than 200 percent when the models in the mock ads were



Proud2Bme.org is NEDA's new website for young people offering a fun and interactive safe space to talk about the issues that matter to them. Log on and join the Proud2Bme Nation to participate in discussion forums, share your story, read the latest news, check out art and music that inspires your fellow Proud2Bme members, share your own art, learn about ways you can be an activist and more!

their size. Consumers increased their purchase intentions by over 175 percent when they saw models who reflected their age; in particular, women over the age of 35 increased their purchase intentions by 200 percent when they saw older models. When models didn't

reflect their age, consumers decreased their purchase intentions by 64 percent. Black consumers were 1.5 times more likely to purchase a product advertised by a black model.

In focus groups, women said they could better picture themselves wearing the dress when they saw it on someone who looked them: “I’d buy the dress in an instant because [the model] looks like me. I can see how this dress will hug my curves in all the right spots,” said a woman in one group. Well, that makes a whole lot of sense.

Barry envisions a change in the industry that would take his research to heart:

“Imagine this: You open a fashion magazine. It is filled with stunning glossy ads from the top fashion and beauty brands. You see gorgeous clothes, dramatic hair and makeup and breathtaking photography. Starring in these ads—showcasing fashion’s glamour, artistry and creativity—are models who reflect the full panorama of women’s beauty. So, brands, I ask you this: Will you continue to use an outdated marketing model or adapt to the new consumer mindset and reap the rewards?” ■



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

The PFN Newsletter is by parents, family, and friends for parents, family, and friends!

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