

## Letting Go, Time For Me...

By Susan Maccia, Outgoing PFN Chair

When my daughter was diagnosed with anorexia in 2005 at the age of 13, my family's world began to revolve around her and her eating disorder. We researched the disease and treatment options, participated in on-line support bulletin boards, attended family support groups, fought with the insurance company, attended family therapy sessions, drove hours to the hospital and made numerous flights to a treatment center 2000 miles away. We continued to work full time jobs and did what we could to hold on to what little life we had left. When my daughter entered recovery in 2007 there was more time to breathe and my daughter and I began sharing our story on behalf of NEDA. Not long afterwards, Lynn Grefe, CEO of NEDA, approached me and asked if I would like to chair the Steering Committee for the Parent, Family and Friends Network. Knowing how important it is to provide information and support to families and

loved ones, I jumped on board and set about trying to make a difference.

My daughter relapsed during her transition from high school to college in the fall of 2010. I knew this would be a critical time for her and felt prepared for "come what may." The process of withdrawing her from school and moving her back into treatment was no less traumatic and exhausting for our family. When she threatened to sign herself out of treatment, my husband and I stood firm; "If you sign yourself out of treatment, we will no longer support you financially and will need to consider whether or not you are a member of our family." Harsh words and emotionally draining for sure but this action marked a turning point not only for my daughter but for me. My daughter got the message that working on recovery was the only acceptable option if she wanted the family's support. I learned it was time for me to let go of my



Outgoing Chair,  
Susan Maccia, NJ

daughter's eating disorder and to focus on me! My daughter began working her way back into recovery and I began the process of letting go.

My daughter is an adult now and learning to take responsibility for her health and well-being. She's

beginning to understand the value of independence from her parents and what that means in terms of her recovery. I'm not naïve enough to think the journey is over, but I am coming to the realization that making the "world of eating disorders" a smaller part of my world is what I need to do for me to fully recover my daughter's eating disorder. With this realization, I am passing the torch as Chair of the PFN Steering Committee to Deborah Kreiger,

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## A Note From Incoming Chair, Deborah Kreiger



New PFN Chair, Deborah Kreiger, FL

As I welcome you to our quarterly PNF newsletter I do so with

tremendous gratitude in my heart. I am the mother of a wonderful daughter who struggled with bulimia, and ultimately anorexia, for three-and-a-half years before she began her journey toward recovery. I remember all too well the seemingly endless days filled with anxiety, desperation and loneliness. My deepest gratitude is to NEDA for providing information, support and hope to our family; as we began the healing process our fears were gradually replaced with knowledge, understanding and compassion...it all began with NEDA.

This is a big part of the reason I accepted the position as Chair

**"All that we behold  
is full of blessings."**

**—William  
Wadsworth**

of the PFN Steering Committee. As an extension of NEDA, the Parent, Family & Friends Network serves as a beacon of light to help support you through your own chaos and darkness; we are a group of individuals who have spent a significant amount of time walking in your shoes, and wherever you are along your journey, you

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**The work NEDA does is so critical to the field of eating disorders, but we need your help to do it!**

## Letting Go, Time For Me... continued

a long-time dedicated NEDA volunteer and mother.

I've met some amazing family members and professionals dedicated to making a difference during my time as Chairperson of the PFN Steering Committee. PFN members are reaching out to families, friends and loved ones and helping them find eating disorder resources in their communities and support from a "trained friend" we call a NEDA Navigator. We provide information through our revamped

newsletter, work continues on programs to bring awareness to our education community and PFN members are making a real difference in our state legislatures through NEDA's Solutions Through Advocacy & Reform (STAR) Program.

The work NEDA does is so critical to the field of eating disorders, but we need your help to do it! I hope you become inspired to extend your gifts and talents to the PFN Steering Committee and the many other

programs NEDA offers. We continue searching for ways to increase awareness and support, bringing you information about the in-roads the scientific community is making in research and treatment and let you know what's happening at NEDA and NEDA Network members. Contact the PFN Steering Committee at [pffnetwork@myneda.org](mailto:pffnetwork@myneda.org) with your ideas and suggestions. The committee wants to hear from you!

To find out more about the PFN and its programs, click [here](#).

## A Note From Incoming Chair... continued

can turn to us for understanding, guidance, knowledge and strength. The PFN was created for you and I encourage you to reach out...you'll find us waiting.

The PFN is where it is today thanks to a dedicated steering committee guided by the strong leadership of Susan Maccia. Her passion is evident as she champi-

ons the fight against eating disorders through her determination, perseverance and unstoppable sense of purpose. For the past four years, Susan has helped to shape the PFN, and has been a backbone of support as well as an active voice to grow this most important dimension of NEDA. She will continue to be a contributor to the

newsletter, offering her expertise in handling insurance issues. To Susan, I say thank you. I am grateful to have your continued support and am humbled to be entrusted with the honor of carrying on this most important work of the PFN.

With deepest gratitude,  
Deborah Kreiger.

**The PFN was created for you and I encourage you to reach out... you'll find us waiting.**

## A FEW WAYS TO GET INVOLVED WITH THE PFN

### Book Reviews

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 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 are also launching a new resource to PFN members – monthly webinars!

The PFN will host free webinars with speakers on topics of interest to you. Navigators will be joining us to share their stories of recovery or caring for a loved one. Fellow PFN members will discuss self-care tools and strategies, the role of fathers in supporting recovery, fighting insurance claims, and much more. Professionals will be invited to speak on topics such as eating disorders among athletes and recent research in the field. PFN members who have hosted successful outreach events will join us to share their knowledge and planning tips with those who want to get involved in educating their community. We will plan the webinar series based on what you want to hear, so email us at [pffnetwork@myneda.org](mailto:pffnetwork@myneda.org) to make suggestions!

## Getting Back in the Game... of Life

By Kim Dennis, MD, Medical Director, Timberline Knolls Residential Treatment Center in Lemont, IL

Eating disorders are an epidemic in the United States today. One population increasingly at risk for developing anorexia or bulimia is athletes. Athletes are far more prone to eating disorders than non-athletes, especially for females. The risk increases significantly for those involved in sports that necessitate a certain body type or weight, when success tends to be more appearance-based than performance-based, and when the athlete is competing at an elite level. This includes sports such as ice skating, gymnastics, wrestling, diving, rowing, distance running, ballet, and other forms of dance.

Those taking part in judged sports are particularly at risk. Research indicates that female athletes in judged sports have a 13 percent prevalence of eating disorders, compared to just 3 percent in the general population. Factors that contribute to risk for developing an eating disorder include: endurance sports, sports with weight categories, individual sports and "lean" sports. Sports with revealing clothing are rapidly moving to the top of this list, as sports attire continues to shrink. With every passing year, players on the tennis circuit or professional volleyball teams are revealing far more skin than ever before.

Athletes struggling with eating disorders are not unlike non-athletes dealing with similar issues. Highly competitive, they rarely admit to having a problem, for fear of losing playing time or displeasing coaches, teammates or family members. They may incur more injuries and have declining health, as they restrict food intake and engage in rigorous exercise schedules. Often times, these dangerous behaviors go unrecognized by coaches, parents and teammates. In fact, these very behaviors are frequently encouraged by coaches and/or parents who believe that weight loss and extreme training will give their athlete a competitive edge. Tragically, the cost may be the young person's life, since anorexia and bulimia are potentially fatal illnesses.

What is important for parents, trainers and coaches to remember is that an ath-

lete who develops an eating disorder doesn't have to permanently relinquish his or her involvement in sport. Effective treatment is available and recovery is possible, especially if the individual is young and the eating disorder is relatively new. However, though weight may be restored and health regained, serious thought must be given to when or if the athlete will return to training or competition.

Attention must be paid to what is motivating the person to return. Is it internal or

**The good news is many of the same characteristics that make an athlete great make for a successful recovery from an eating disorder.**

external? Does the athlete want to return to competition due to a genuine love of the sport, or is pressure to return being applied by a coach, teammates or even family? Just because an individual is highly skilled in a particular area in no way means he/she "must" continue to participate, especially when first entering recovery.

If a comeback is decided upon, it is imperative for an outpatient team of professionals to be in place. At the very least, this team should include a primary care physician, a psychiatrist, an individual therapist, a family therapist and a dietitian. A representative from the team should also be included in the treatment plan. This support network will ensure the athlete is maintaining recovery as a top priority. Recovery behaviors

need to be clearly identified: taking in sufficient nutrition according to a meal plan prescribed by a sports nutritionist; sustaining a healthy weight and not exercising to excess; participating in individual, group and family therapy sessions; and attending 12 step or other community support groups. Parameters around weight ranges and recovery behaviors necessary for healthy participation in sport need to be developed and explicitly communicated to the athlete, parents and coaches. All parties involved need to support the treatment plan in order for it to work.

There are some instances where return to sport would be contraindicated. For instance, if an athlete has unstable vital signs, abnormal electrolyte levels, significant weight loss, or engages regularly in eating disorder behaviors, he/she should not return to sport. If an athlete has relapsed with eating disorder behaviors several times in the past upon returning to sport, that person may need to consider not returning until at least 1-2 years of recovery are achieved, if ever. It can be a devastating loss for the athlete and family to let go of the sport as well as the identity, meaning, and accolades that go with it. Grief work for the athlete and family can be an important piece of facilitating life-long recovery for those who cannot safely return to their sport. As tough as grief work is, it is much easier to help a patient and family work through the loss of sport, rather than the loss of their child's life.

The good news is many of the same characteristics that make an athlete great make for a successful recovery from an eating disorder. Athletes tend to have better treatment prognosis because they are used to being coached and taking direction. They also have a built-in support system to help monitor signs of improvement and slip-ups: coaches, trainers, teammates and family. Finally, because of their love of the sport, many athletes have a unique motivation for recovery. They know they need to get healthy to get back in the game, thus giving them the internal motivation needed to succeed in a healthy and long-lasting recovery.

# Reaching for the Stars: A Family's Reflection of Hope, Belonging and Gratitude

By Nancy, Emily, Ashtyn, and Jerry Hemendinger, NY

## Nancy

As I was boarding the plane for the National Eating Disorder Association's Annual Conference in Los Angeles, I found myself recalling how this journey originated with the first signs of my daughters' eating disorders. I checked my Facebook one last time before the plane departed. My daughter Emily had already posted her inventory of our family's journey:

*"mom, i can't believe how far our family has come. just think at the end of this month SIX YEARS AGO, Ashtyn and I were beginning treatment and this time SIX YEARS AGO, our family was being torn apart by a terrible illness...we couldn't go on vacations or trips together (let alone be in the same room)...BUT now look at us! SIX YEARS LATER we are all going TOGETHER, attending a conference about eating disorders. we're going as a FAMILY who has come so far and has made such great strides! i love you, daddy, Ashtyn and Joan."*

- Emily, October 11, 2011 at 8:39am

Our family's recovery from eating disorders was certainly not as direct as our 5 hour flight to the NEDA conference. Our journey has been continuous over a number of years and has been laden with turbulence, fears and frustrations. It was during my initial contact with our therapist, when I realized that our lives would be delayed, and diverted to a new destination. During these six years, she has supported us, taught us the importance of self-care and now encourages us to share our experiences to help others. It has been through her consistent and firm support and care that our family has been able to transform into new relationships with each other, and with the NEDA family.

As the conference was approaching, I was anxious. Some thought I was nervous about presenting my workshop on "Integrating Eating Disorder Awareness and Prevention into Comprehensive Health Education," however, presentations on public health topics are second

nature to me. My anxiety came from the overall conference topic-Eating Disorders. Why would I go into something that still stirs such a strong emotional response? For me, this topic comes with an array of personal and family experiences and the realization that so much more needs to be done to help those still suffering. It was Joan's six years of support that helped me push forward and learn to believe that I

**"I was proud that the NEDA organizers identified Hollywood as the conference site. I felt like I was going into the 'Heart of the Beast'..."**  
- Jerry Hemendinger

would emerge stronger and more focused. My trepidation seemed to dissipate as soon as we sat down at the opening PFN dinner with our extended NEDA family. I quickly realized that this conference was not about what the eating disorder had taken away from our family, but rather, it represented a coming together of people who want to bring hope and a solution to these overwhelming illnesses.

In Carolyn Costin's workshop, "The Bio-Psycho-Social Approach," she discussed several familial temperament styles that are found in those with eating disorders. She posed the question, "Is temperament a liability or asset?" I mentally checked off each of the temperament styles that my daughters and I shared with Carolyn's list. I preferred the manner in which she re-framed each of the temperament styles. Instead of being a perfectionist, I am tenacious. Instead of being compulsive, I am driven. I am not anxious or highly sensitive to rejection, but instead I have high energy

and I am blessed with above average radar. Carolyn also discussed healthier thought patterns for each of these temperament styles, which included learning to be good enough, letting things go, finding ways to calm down, and being aware that I have a tendency to pick up on others' emotions. I realized that these characteristics which at times have a tendency to hold me back are the same ones that have helped propel me through some very challenging situations.

Carolyn cited a quote by C. Bulik, "... although there is nothing they can do to alter the passing down of DNA, they can alter environments that influence the likelihood of genes being expressed." The importance of this was reinforced by Dr. Ann Becker's research project in Fiji. She discussed the effects of second hand media exposure on Fiji students. Once these students were exposed to the western media culture, there was a marked development of disordered eating pathology. As a health educator and a parent, my life has been dedicated to the development and advocacy of healthier environmental norms. Both workshops reinforced that my prevention and awareness work with young people is vital to changing the unhealthy body image norms of our culture.

## Emily

When I heard that my mom's presentation was chosen for the NEDA conference in LA, I was so proud of her. When I found out my whole family was going to the conference, I was even more proud of our family. The fact that my sister and I both received scholarships to attend this conference made this trip possible and I'm still counting my blessings for the opportunity.

In the days before the conference, I reflected back on mine and my family's journey. Being almost four years in

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## Reaching for the Stars... (continued)

recovery and a huge supporter of NEDA (I even have the recovery symbol tattooed on my right hip); I was excited to finally be going to a NEDA conference. My journey was a long and painful one, but with the support of my loving family, my home and college therapists, and my treatment team, I was able to reach the place I am today. I was extremely proud that my family was journeying together to this conference. A few years ago, we couldn't even go on family vacations, let alone barely be in the same room, because of the eating disorder. And now, we were traveling to the conference, in recovery, and in a much better place. The conference showed me how far my family has come. We can go to meals together, laugh, talk, and not be bothered by ED. We can function individually, and recognize our codependent behaviors, but also we can function together as a loving family unit.

The conference was exciting for me because I am a senior psychology major at Hartwick College. I am also the current president of my school's Fifty-Fifty Peer Helping staff (a group of student leaders who help our peers with their problems). I plan to continue on to graduate school and obtain my masters in counseling or mental health psychology. I want to be able to help people not only with eating disorders, but also other addictions and mental health issues. This conference helped me see what professionals have done in the field that I will be pursuing. I gathered a lot of information about eating disorders that I brought back to the Fifty-Fifty office and Health Center at my school. The workshops provided a wealth of knowledge which I shared with my sorority and other friends. I'm planning to organize an event for Eating Disorders Awareness Week in February and bring a speaker to my sorority to talk about positive body image. I will also be doing an internship with Robin Pisano, a counselor at Hartwick College, in which I will be working on a new treatment plan and system for students and administration to follow about eating disorders. The conference was an amazing experience and I hope to attend next year.

### Ashtyn

Initially, I was not sure how I would feel attending the NEDA Conference. I was concerned that I was going to be looked down upon because I am still working on my recovery. The last thing I wanted to do was go somewhere and feel badly because I was still struggling. However, I soon realized that I was not alone. There were people at the NEDA Conference who were at all stages of recovery. It was comforting to know that I wasn't the only one who was having a difficult time. I was so proud of my mom when I heard she was presenting. Looking back on where my family was 6 years ago, I am amazed at the progress we have made both individually and as a family. We have grown stronger and are now able to communicate effectively with one another.

I really enjoyed going to the Nutritional Augmentation for Depression workshop. I found it interesting to learn how certain foods can actually help to lessen depression. I also liked the panel on Saturday with the different family members and various organizations. It was inspiring to hear stories about others' recoveries as well as to see how this disease affects everyone. I have brought information back to my dietician at school who would like to use this material to educate college students about eating disorders.

### Jerry

Attending this year's NEDA conference provided me with a sense of belonging and a direction for helping others. Initially, I was reminded of the helplessness I had felt when my daughters were first diagnosed with anorexia. At that time, my energy was dedicated to securing their survival. Now, that part of my life seems like a blur.

I was proud that the NEDA organizers identified Hollywood as the conference site. I felt like I was going into the "Heart of the Beast" and was sending a message to the "Glitz & Glamour" of Hollywood, that enough is enough! I attended the STAR Training workshop presented by Lara Gregorio. As a result of this workshop, I have found a new sense of clarity and direction. Through the STAR program, I will have an outlet to advocate for eating disorder screenings in schools, ade-



Members of the Family Panel at the 2011 NEDA Conference

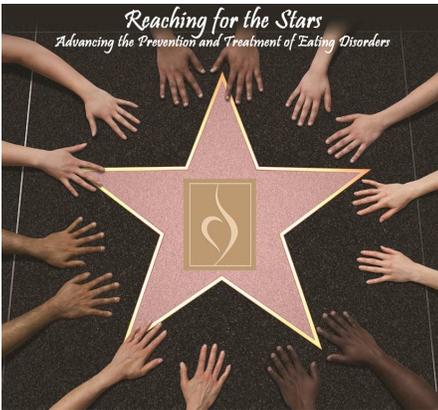
quate health insurance coverage for the treatment of eating disorders and raising awareness. The NEDA conference has energized me to use our family's journey to help others. I am thankful to the NEDA organizers for welcoming us into their family.

### The Family

Hope, Belonging and Gratitude...are three common themes that are apparent in all of our reflections. We can look back and realize that we have come from a place of pain and now we are able to move forward with an outlook of hope. The NEDA conference brought a sense of acceptance, belonging and as a result, a passion to change how eating disorders are viewed and treated. Finally, there were many people that helped us along our journey to the NEDA conference. It was those people that believed we could do impossible things. For that, we are thankful.

## CONFERENCE RECAP

**Thank you to all who attended our 2011 Annual NEDA Conference in Hollywood, California - *Reaching for the Stars! Advancing the Prevention and Treatment of Eating Disorders***



We also extend our thanks to the entire NEDA family – speakers, sponsors, exhibitors, families, individual, and contributors to the conference scholarship fund, and those who could not attend but told others about it.

Nearly 600 attendees made new friends, reconnected with old ones, learned from many top-notch speakers and were inspired to bring the knowledge they gained back to their families, colleagues and communities. As one attendee said in response to being asked if she was glad she had come, “I’m not glad...I’m overjoyed.”

Keynote speaker, Kelly Vitousek, PhD challenged families and professionals alike to be informed consumers of the latest research in the eating disorders field and to more clearly define these illnesses for improved understanding and treatment

outcomes.

Academy for Eating Disorders President Anne Becker, MD, PhD, presented new research that followed up her ground-breaking study on introducing western media to Fiji and the impact on body image and eating disorders among Fijian girls. Her new study demonstrated the potentially greater influence of second-hand media exposure on the development of eating pathology.

Additional highlights included presentations by Carolyn Costin, MA, MFT and Michael Strober, PhD, underscoring the complexity of eating disorders and the need for research and treatment that takes into account the intersections between the biological, psychological and social factors.

The *Family Panel: A Kaleidoscope of Perspectives*, began with opening remarks by fashion designer Bradley Bayou about the responsibility of the fashion industry, which was met with a standing ovation. Seven panelists – **Vic & Lindsey Avon; Lynn Chen; Sunny Sea Gold & John Pavlus; Rachael Stern, LMSW, LGSW; Corazon Tierra** – shared their personal struggles with anorexia, bulimia and binge eating disorder, offering insight into the many

ways one’s unique identity impacts the experience of an eating disorder.

Through their honest accounts of the road to recovery, they instilled hope and gave families practical tools for navigating the recovery process.



Next year’s Annual

NEDA Conference, *What About Us? Diversity and Complexity in Eating Disorders*, promises to be as inspiring, informative and exciting. We hope you will mark your calendar to join us, October 11-13, 2012 in St. Petersburg, FL at the Vinoy Renaissance Resort & Golf Club.



Also, please consider contributing to the [2012 Conference Scholarship Fund](#) so that a family member or recovered person in need can attend who would be otherwise unable to without your generosity.

## INAUGURAL TEEN SUMMIT SUMMARY

### **Making Real the New Ideal: Body Image, Self-Esteem and Media**

*Sponsored by Paige Premium Denim*

NEDA held its first annual Teen Summit on October 15, 2011, which was hosted by NEDA’s Junior Board and marked the launch of NEDA’s new interactive website for teens, Proud2Bme.org. After author and internationally recognized body image expert, Claire Mysko, gave opening remarks and introduced Proud2Bme and Eric Van Furth, PhD, the founder of the original Proud2Bme site in The Netherlands. Keynote Speaker Jessica Weiner—author, media consultant, and activist—led an engaging discussion on the mass media representations of eating disorders and other weight related issues. The teens at the Summit proved astute observers of pop culture, as they made keen insights into many contemporary media stories revolving around these issues—from Demi Lovato’s appearance on *Ellen* discussing her eating disorder to the runaway popularity of the television show “*Mike and Molly*,” in which the two main characters

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## Teen Summit... (continued)

met at an Overeaters Anonymous meeting.

Perhaps, most importantly, in keeping with the theme of the Summit, Ms. Weiner was successful at drawing out from the teens ways in which they believed they could actively work to change the standard “thinner is always better” dialogue surrounding weight in the media, and they collectively brainstormed ways that young people could use methods like social media, letter writing, and blogging to change the national conversation on this topic.

After an intermission for lunch, the Summit resumed with a panel of speakers and bloggers who are actively working to change the way eating disorders and body image are depicted in the mass media. Blogger and YouTube powerhouse, Emily-Anne Rigal, talked about the ways that her website WeStopHate.org works to raise teen self-esteem and empower youth to take a stand against bullying. Troy Roness offered a unique perspective on being a male with an eating disorder and why being an activist is important to his recovery. And, Lisa Lee, touched on the influence of racial stereotypes on body image issues, specifically within the Asian-American community. The diverse experience of the panelists shared a common thread, which was the im-



Musician and NEDA Ambassador Jenni Schaefer performs at the Teen Summit

portance of mentorship and finding your own voice. Ms. Weiner then helped the youth devise a plan for identifying and recruiting positive mentors in their own lives.

The final part of the day had the panelists working within a small group format—aided by NEDA Junior Board members—to have the youth develop specific action plans that could be taken back to their local communities or schools. Teens identified four key factors that influence their body image and self-esteem: Media, Friends & Family, Sports, and

Race & Ethnicity. Teens discussed their own personal connections to these factors and then worked together to develop their action plans. Some really exciting and impressive ideas came out of these roundtables, including an intramural sports club where the focus was on fun instead of competition (cleverly named “Play for Passion”) and a group aimed at increasing diversity acceptance in schools named the “4 A’s”—Anybody Anywhere is Always Accepted.

One participant also spoke honestly about how her experience of weight-related discrimination at her job triggered her disordered eating, a story that inspired a discussion about how teens can speak up and use their voices to bring attention to companies who are perpetuating unhealthy ideas about weight and beauty.

Rounding out the day was a performance by musician and NEDA Ambassador Jenni Schaefer, a call to action by NEDA’s 2011 Robbie Munn Volunteer of the Year Award winner, 17-year-old Bailey Monarch, and an excellent synthesis of the Teen Summit’s key takeaways by Binge Eating Disorder Association Ambassador and Hollywood NOW president Chenese Lewis. Panelists and attendees created

Proud2Bme videos, which will be highlighted on Proud2Bme.org.

It was an informative, action-oriented, and empowering event for teens with so much opportunity for future growth. Participants took away a for-teens-by-teens “Teen Summit Activist Guide” to continue working toward change in their own communities. The ideas and insights from the Summit do not end there...they will be put into action, informing and improving NEDA programs and resources. And the impact of the teen summit went far beyond those in attendance, with live and wrap-up tweets and Facebook posts from the teen summit reaching over 10,000! NEDA looks forward to continued collab-



Panelist Lynn Chen, Keynote Speaker Jessica Weiner, and Panelist Lisa Lee

oration with youth at this annual Teen Summit, which will be held next year during October in St. Petersburg, Florida!

### Press, Blogs & Social Media Coverage

[LA Times coverage of Proud2Bme, launched at the Teen Summit](#)

[Imbee, a leading social networking site for kids](#)

[Thick Dumpling Skin \(founded by Teen Summit Panelist Lisa Lee and NEDA Conference Family Panel speaker and actress Lynn Chen\)](#)

[The Actors Diet \(By Lynn Chen\)](#)



## Breaking the Mold

By Vic Avon, NEDA Navigator, NJ

Sometimes one size really doesn't fit all. All too often people come into this world feeling the pressures to fit into a certain mold, but are unable to do so for one reason or another. I was one of them. There were several molds that I was supposed to conform to throughout my life. The internal and external pressure to meet those standards helped to push me towards a dark world and into the arms of my eating disorder.

I grew up in a family that had clearly defined standards of what a man should be, like many families. Having a very tough and physically imposing father and four



Lindsey and Vic Avon

uncles, the message was sent to me that I HAD to be like them. I had to be tough. I had to beat people up. I had to be insensitive. I had to be a "man." Unfortunately, I wasn't. I was everything that I wasn't supposed to be. I was quiet, shy, and insecure, and I could never be the person my father expected me to be no matter how hard I tried. While most kids are focused on watching cartoons and making friends, I

was living with the feelings of not being good enough, of being broken, and of being defective. My self confidence was in the gutter, and I was constantly ashamed of who I was. The only comfort I could find was in the food that my grandmother put on my plate. It made me feel better, but things would soon change.

I began gaining a good deal of weight, and soon became the target of bullies. I was an easy target. My body was different, the accent I talked with was different, the music I listened to was different...I was just different. I've never felt so utterly helpless in my life, and I absolutely hated every second of it. I tried to turn to family members for help, but was made to feel even worse about myself. I couldn't be a "man" like my dad wanted me to be. I couldn't be like him and I was completely ashamed and destroyed by it. I felt broken on the inside and the outside. I kept turning to food for comfort more and more, but hated myself for the weight I was putting on my body.

I wasn't fitting anybody's standards. I didn't have the body I was "supposed to have." I didn't have the toughness I was "supposed to have." I wasn't the man I was "supposed to be." As a result I retreated within myself. I slipped away from everybody and built walls around myself. I pushed the world away and tried to lock all emotion out. I detested everything about myself. Why was everything about me so wrong? Why couldn't I just be normal? I began creating a friend that I thought would protect me, that would love me, and that would accept me for who I was. That friend was my eating disorder. I lived with my friend from

sunrise until the time I went to sleep every day for six long years. It was an abusive, yet comforting, relationship. My friend would be there to comfort me

*I grew up in a family that had clearly defined standards of what a man should be... I had to be tough.*

while screaming at me. It would protect me while telling me I wasn't good enough. It would hug me while strangling me. It found its fuel within every memory, emotion, and insecurity I ever felt and then used them against me. It gave me an identity for the first time in my life, and made me feel as though I was forever attached to it. It intensified everything I ever felt and forced me to believe that it was the only thing that would ever protect me from the world.

As time went by and I was officially diagnosed with my disorder I grew to feel more and more broken. I was a man with an eating disorder. The two terms are not synonymous with each other. The diagnosis crushed me because now I felt as if I was as far away from the mold as I could ever get. I never turned to anybody for support because I had been tormented for my differences my entire life. I grew up feeling broken and defective and the eating disorder verified this in my eyes. I suffered in silence because it was easier to live in my

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## Breaking the Mold... (continued)

own private hell instead of living in a public one.

Three years have now passed since I checked myself into a hospital and dedicated myself to recovery, and I can say that I am a different person than I once was. I had to face every fear, insecurity, memory, emotion, etc. and challenge them all one-by-one. I've learned to not run from and hide my differences from the world, but rather have embraced them and allowed myself to become ME. We are all different and unique. There is only one of us in history. To think that we should all magically fit into one mold can only lead to insecurities, self hate, bullying, etc. Accepting others and accepting ourselves for being different allows all of us to grow and blossom into the people we are meant to be. Accepting ourselves gives us the confidence to grow stronger, to recover, to do anything we want. Don't be afraid of who you are. Be different. There is no script in life. I had to accept that I am my own person. I had to take a chance and prove to everybody (and to myself) that I don't need to fit a certain mold or set of standards to thrive in this world. I am not going to let people put me down anymore. I am not going to call myself broken ever again. I am going to thrive and leave a mark on this world that none of the bullies of my past could ever leave. I'm not the person my dad or uncles wanted me to be. I'm the person that was tormented for being a little different. I'm the man that battled an eating disorder. I am proud to be me. This whole recovery process has shown me that if you don't fit the mold then the best thing to do is to shatter it, and show the world how bright you can shine.

## Research Summary

### Why Men Should Be Included In Research On Binge Eating: Results From A Comparison Of Psychosocial Impairment In Men And Women

*(International Journal of Eating Disorders, Sept., 2011)*

This new study published in the International Journal of Eating Disorders, by Striegel, Bedrosian, Wang & Schwartz, looks at how men are affected by binge eating using a variety of health and psychological measures. Binge eating has been shown to effect health in a variety of ways, including hypertension, dyslipidemia and Type 2 diabetes. The disorder has also been shown to cause psychological distress and impairment in the individual. Although the prevalence of binge eating is the similar among men and women, the number of studies that include men is far fewer and the number of men who receive treatment is well below the number of women who get treatment. This led the researchers to study the question: To what extent do men who binge eat experience impairment and how does it compare to women who binge eat?

The study looked at the data of 46,351 participants who completed an online self-assessment questionnaire about health issues and measures of impairment over the past year. The main areas they studied were: Experience of mental health issues, health problems, and worksite productivity. Specifically, they assessed depression, anxiety, sleep problems, dyslipidemia (e.g. poor cholesterol levels), hypertension, Type 2 diabetes, missed work days and work productivity.

The results of the study show that binge eating (at least one episode per month) was reported by 7.5% of males and 11.1% of females. They also found that on all points measured both men and women with binge eating episodes fared worse to a statistically significant degree than those who did not binge eat. For example, 8.7% of men who did binge eat reported Type 2 diabetes, compared to 5% of men who did not binge eat. 37.1% of men who did binge eat experienced depression compared to only 12.6% of men who did not binge. In addition, the data showed that the more frequently binges occurred, the higher the prevalence of depression, stress, lack of sleep and work impairment.

The next question addressed was: How are male binge-eaters different from female binge-eaters? There were small but statistically significant differences between men and women who binge eat, showing that men were affected less than women on measures of distress and impairment, but not by much. For example, 37.1% of men who binged experienced depression, compared to 47.3% of women. The authors noted that these differences probably reflect the fact that women are more likely to suffer from some of these issues in general than men, whether or not they experience binge eating.

The researchers conclude that men who experience binge eating are significantly affected by the disorder and should receive adequate screening and intervention to treat the issue. Based on the data, the authors recommend that public efforts be increased to raise awareness of binge eating disorder among men, decrease misconceptions about eating disorders especially among males and increase access to treatment.

## Insurance 201: Single Case Agreements

By Susan Maccia, Outgoing PFN Chair, NJ



Throughout this journey of recovery from an eating disorder, I've become pretty aggressive about

fighting for insurance benefits for my daughter's treatment and have spent hours searching the internet for information so I can better understand the insurance process. My "intensity" paid off when we received full reimbursement for my daughter's residential treatment. Since that time I have attended several NEDA Conferences being sure to attend the presentations on insurance where I always learn some new bit of information I can use. This year's NEDA Conference presentation on insurance was no different. The presentation was outstanding and introduced me to something I had never heard of before: Single Case Agreements.

The following is the most common definition of a Single Case Agreement:

*"If the services to meet an identified clinical need are not available within the contracted network, necessary services are provided in a timely manner through an out-of-network provider. A single case agreement is a contractual agreement developed for an enrolled person (insured) based on that person's behavioral health needs and for a predetermined period of time."*

Insurance companies are responsible for making sure you have access to adequate care by properly trained professionals. To meet this responsibility and to control costs, insurance companies "contract" with treatment providers. These contracts include agreed upon reimbursement rates for treatment, among other things. Additionally, most insurance contracts have rules about how far the company can require you to travel for treatment.

The problem many families run into is finding in-network providers close to home who "specialize" in treating eating disorders. There are currently no specific educational credentials a behavioral or medical health provider (LCSW, RD, MSW, MD, etc.) can obtain to "document" a specialty in treating eating disorders. Most providers become specialists in eating disorders based on the number of years they have been treating patients with eating disorders, the training they may have received outside of their formal education or licens-

**When dealing with an insurance company, no matter what issue you may come across, be willing to move up the proverbial "insurance food chain if you feel you aren't getting the service you deserve or qualified, intelligent answers to your questions.**

ing or if they treat eating disorders exclusively (with or without a co-occurring condition such as OCD, bi-polar disorder, etc.) That does not mean a provider isn't qualified, there are many wonderful, outstanding, fully qualified eating disorder treatment providers! It just means there are no educational or professional credentials a provider can use to identify specialization in the treatment of eating disorders.

The scenarios below exemplify when a Single Case Agreement might be helpful:

*Karen needs to find a therapist for her son whose pediatrician feels may be suffering from anorexia nervosa. The pediatrician provided a referral to a therapist who has his MSW and*

*LCSW but the therapist is out-of-network. Knowing that going to an out-of-network therapist will cost quite a bit more than a therapist in-network, she decides to check her insurance company's in-network provider directory. When on the company's web site, she is asked where she lives and what type of provider she's looking for (hospital, physician, group, etc.). Karen selects physician (since therapist is not one of the options) and is then asked to select a specialty. She can find lots of specialties for medical issues such as rheumatology, gastroenterology, obstetrics and gynecology but cannot find a specialty for eating disorders. The best she can find is a specialty in psychology or psychiatry so she selects psychology and is presented with a list of 100 in-network providers in psychology. Unable to determine if any of these providers specialize in eating disorders. Karen calls the insurance company and is told there is no specialty for eating disorders and if she decides to use a provider who is not in-network, she will have to go out-of-network.*

*Joann's daughter Hannah is 13 years old and suffers from anorexia. After several hospitalizations, Hannah's treatment team and the doctors at the hospital feel Hannah needs a higher level of care and recommend residential treatment. There are no in-network residential treatment centers (RTCs) close to home and Joann identifies a highly recommended RTC several states away but the RTC is out-of-network.*

In Karen's circumstance, the insurance company was unable to give her the name of a behavioral health provider specializing in the treatment of eating disorders. In Joann's case, there are no in-network providers in her state and the insurance rules

*(Continues on next page)*

## Insurance 201... continued

under her contract say she cannot be made to travel to an in-network provider farther than 60 miles away from her home.

Getting a SCA is not as simple as asking for one and your treatment provider must be on board. Some treatment providers will obtain the SCA on your behalf if they have the staff and time, but many individual providers aren't able to be as involved – they are busy treating patients! If you plan on requesting the SCA, be willing and able to evidence the lack of in-network providers specializing in eating disorders who are currently available and within a reasonable distance from your home. Be able to evidence that your choice of a treatment provider “specializes” or has “qualified experience” treating eating disorders. Evidence should include number of years treating patients with eating disorders, number of patients currently being treated, and any specialized eating disorder courses or training the provider has attended. Don't be shy about asking the treatment provider for his/her assistance in putting together your case for a SCA. An experienced treatment provider will have some nuggets of wisdom to strengthen your case. In the case of a larger group practice, hospital or residential treatment center, ask the facility's staff if they will pursue a SCA on your behalf.

When dealing with an insurance company, no matter what issue you may come across, be willing to move up the proverbial “insurance food chain” if you feel you aren't getting the service you deserve or qualified, intelligent answers to your questions. Be vigilant in documenting all conversations with the insurance company including the name of the person you spoke to, the time you called, and the end result of the conversation. Follow-up every conversation in writing with a letter to the insurance company re-capping the conversation and include the details such as names, dates and times. Always mail your letter to the insurance company return receipt requested with a copy for your files.

## PROGRAM SPOTLIGHT: NEDA NAVIGATORS

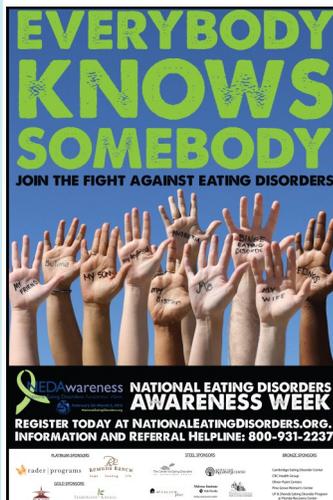


**The Parent, Family & Friends Network is here to support you. The NEDA Navigators are available to help!**

If you could benefit from connecting with a parent, family member, friend, or someone in recovery themselves to help you navigate insurance issues, find support groups or treatment options, find addition resources like books and websites, and support you as you deal with overwhelming emotions that accompany caring for a loved one, contact us at [pffnetwork@myneda.org](mailto:pffnetwork@myneda.org) and we'll connect you with a Navigator that fits your needs.

*\* 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.*

## WAYS TO GET INVOLVED: NEDAWARENESS WEEK



Everybody Knows Somebody...so everyone can join us in the fight against eating disorders during the 25<sup>th</sup> anniversary of National Eating Disorders Awareness Week this February 26 – March 3, 2012! Registration is free, and there are tons of free resources available to make participating easy and fun. Make a difference in your community by committing to do one of the following PFN activities:

1. Connect community members with compassionate support: Let your local schools, health care professionals, PTAs and youth service providers know that NEDA Navigators are available. Navigators support those caring for a person struggling with an eating disorder by providing direction to treatment, support groups, information and resources, and provide a sense of hope and understanding. NEDA Navigator flyers are available to registered participants to spread throughout their community. A sample script is available to introduce the program.
2. Distribute the free *NEDA Toolkits CD-ROM*: Fill out the free online CD-ROM request form on the PFN homepage and NEDA will send a copy, with a letter of introduction, to a local educational institution on your behalf.
3. Raise awareness in your workplace, school or other community setting. The discounted NEDAwareness Week Kits – including posters, pamphlets, NEDA pens, signs & symptoms bookmarks, and much more - will be available soon in the online NEDA Store!

**Register at [myneda.org](http://myneda.org)!**

# A Unique Kind of Support, for a Unique Kind of Grief

By Kathy Benn, Loss Support Network Volunteer, PA

The death of a loved one is always difficult, but when eating disorders are the cause of death, survivors are left to manage loss and grief that is unique. Because eating disorders are still misunderstood by much of the lay and even medical community, it is unlikely that a knowledgeable and effective support community is in place to meet your needs.

Instead of being embraced by our loved ones during your grief, you may find yourself responding to their wrath and judgment. Many in your community may not understand why you just didn't make your loved one eat. Their ignorance is not intended to be hurtful, but that doesn't reduce the pain of these comments during this period of extreme vulnerability. Others may interpret the death of your loved

one as a commentary on the strength and quality of your relationship to the deceased. They may even become suspicious of abuse within the family. Yet another might perceive that your loved one attempted to victimize and manipulate you by slowly starving to death before your eyes.

Any of these responses will compound the pain of your loss. These responses serve no purpose but to increase the sense of shame and guilt you probably already harbor; a sense that if only you would have done more, you could have saved your loved one. Assuming the burden of responsibility for your loved one's death is corrosive and will impact your own health and the other relationships in your life. The truth is that eating disorders are multifaceted, extremely complicated illnesses impact-

ed by psychological, interpersonal, social, and biological factors. Coming to grips with, and understanding these facts will serve you and fortify you, better than unfounded guilt and shame.

The volunteers at NEDA's Loss Support Network have lived this tragedy before you. They are available to listen, relate, and console. As survivors, they offer you a connection to others who truly understand your exhaustion, frustration, sadness, grief, and the vastness of the hole left in your life. We hope that if you have lost someone you will reach out to NEDA's Loss Support Network and take a step toward your own recovery.

## MORE ON THE LOSS SUPPORT NETWORK

**A new support system is available to those who have lost a loved one to an eating disorder: The Loss Support Network.**



NEDA held the first Grief & Loss Roundtable at our NEDA Conference in 2010 and learned that those who have lost a loved one wanted a way to find others for support and connection. There are three main ways for PFN members to use the Loss Support Network:

- 1) Volunteer to support others: Add your name to the network list, which signs you up as a volunteer to support others who have suffered a similar loss.
- 2) Request support from someone who has also suffered the loss of a loved one to an eating disorder: You can request to have NEDA send you a list of volunteers in your area, or request that NEDA send your contact information to a volunteer who will reach out to you directly.
- 3) Connect with other volunteers in your area: If you are already a Network volunteer, you can request a list of other volunteers near you.

To learn more about the Loss Support Network or register to participate in one of the three ways outlined above, select the [Loss Support Network](#) under the Parent, Family and Friends Network homepage located in the Programs and Events section of the NEDA website, [www.myneda.org](http://www.myneda.org).

### Did you know?

NEDA's Loss Support Network was developed under the direction of a clinical advisor: Illene Fishman, LCSW, NEDA Founder.

Fishman says, "NEDA understands the challenges facing those who have lost a loved one with an eating disorder. We are committed to creating an ongoing support system to help people with this unique grief."

## JOIN US IN THANKING HARBOR FITNESS IN BROOKLYN, NY



*Harbor Fitness ad in Brooklyn, NY that will be taken down after complaints from the Media Watchdog program.*

Good news, Watchdogs! Please join NEDA in thanking Harbor Fitness in Brooklyn, New York for their prompt response to a recent Watchdog concern that was emailed to us about a dangerous advertising message for the gym, "Indulge in a Healthy Obsession." President Christopher Ganim is currently working on getting the advertisement removed from the side of a building, stating, "We will immediately look into this ad in question and will work on changing it. We had no intention to insult or cause harm, and instead, if we can be helpful to anyone, as they approach a healthy attitude toward exercise, we are there for them."

***"We had no intention to insult or cause harm, and instead, if we can be helpful to anyone, as they approach a healthy attitude toward exercise, we are there for them."***

We trust that Harbor Fitness will have the ad removed and continue to be an ally in our cause. They have demonstrated their desire to support healthy relationships to fitness and regularly give back to their community by hosting events such as a Zumbathon to raise money for breast cancer and free self-defense classes for women.

To express your appreciation for taking this issue seriously, you can send an email to [info@harborfitness.com](mailto:info@harborfitness.com).

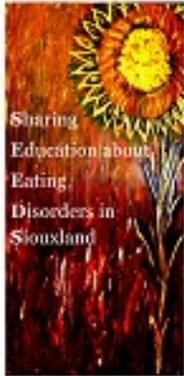
Thanks Media Watchdogs! When you growl, you make a difference!

## MEET THE NEDA STAFF



### **Elizabeth Saviteer, Program Coordinator**

Elizabeth joined the NEDA staff this summer after five years as a Helpline volunteer. After graduating in June with a master's degree in Nutrition and Clinical Health Psychology, she worked with NEDA to train the new team of Helpline Volunteers during the transition to New York. As a volunteer and now as a staff member, Elizabeth is passionate about preventing eating disorders as well as helping families and sufferers find the help and resources they need. In her "off" time, she enjoys traveling, experimenting in the kitchen and exploring the Big Apple.



## MEET NEDA NETWORK MEMBER: SEEDS

La Maison, Inc., a nonprofit educational and charitable organization, formed in 2002 in Sioux City, Iowa, was created to open a supportive transitional residential living facility for women who struggle with eating disorders. After years of fundraising, La Maison purchased a home. But, in 2009, after funding became unavailable, the house was sold.

In 2010, La Maison took its same beliefs and passions and began a new mission under a new name, Sharing Education about Eating Disorders in Siouxland (SEEDS).

Sioux City, situated on the boarder of Iowa, Nebraska and South Dakota (known as Siouxland), is an underserved area for both education and treatment for eating disorders. Made up of concerned citizens, families, friends, and persons in recovery, SEEDS, is a non-profit organization dedicated to bringing education, awareness and prevention of eating disorders to the Siouxland area.

SEEDS works on several fronts throughout the year to spread eating disorder awareness and prevention as well as be a resource for those struggling. Our website, ([werseeds.com](http://werseeds.com)) offers links for worthwhile information, and board members offer the community constant support. If a community member has a question or concern, anyone at SEEDS is happy to find an answer, or will lend an ear or shoulder. Because there are no local eating disorder sup-

port groups, SEEDS is working to start one. For National Eating Disorders Awareness Week, we hold fundraising events such as "I (heart) My Body" t-shirt sales and board member and artist Amy Thompson donates the profits from her eating disorder recovery inspired abstract painting sales. We host awareness events such as a candlelight vigil and a speaker, and we are always expanding events year round.

Our most popular program is SEEDS' educational talks. President Lisa Wrenn, whose daughter survived Anorexia, and Secretary Tina Benton, who survived Anorexia, are asked to speak by high school teachers and guidance counselors to give educational, awareness talks to high school classes. We are hoping to expand prevention talks into middle schools next year.

One of our biggest hopes as an organization is to be able to give scholarships to someone who cannot afford or whose insurance will not pay for treatment.

In just two short years, Siouxland has lost two young women to eating disorders. In a community where eating disorders are not discussed, SEEDS' goal is to make our community aware, to educate and to prevent any more deaths.

If you'd like more information about SEEDS, please contact us at [info@werseeds.com](mailto:info@werseeds.com).

### 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 [pffnet-work@myneda.org](mailto:pffnet-work@myneda.org). Be sure to include your full name, email address, and daytime phone number so we can contact you. The PFN Newsletter is by parents, family, and friends for parents, family and friends!



### National Eating Disorders Association

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