



Susan Maccia, NJ, PFN Chair

This summer the PFN is gearing up for the 2011 NEDA Conference, October 13–15 in Los Angeles, CA, where we will be welcoming many new PFN members, and reconnecting with old friends. To learn more about the NEDA Conference, see the article in this newsletter and visit the conference website at www.MyNEDA.org. We are looking forward to seeing you there! This issue is full of great information contributed by PFN members, such as considerations for sending an adult child to college, tips for self-care, understanding Health At Every Size (HAESSM), research, peer education opportunities, and more! We hope you enjoy it and will consider submitting an article of your own in the future. Be sure to check out the submission instructions at the end of the newsletter...we want to hear from you!

2011 NEDA Conference

NationalEatingDisorders.org



NEDA
CONFERENCE
2011

October 13–15, 2011
Los Angeles, CA

Reaching for the Stars!
Advancing the Prevention and Treatment of Eating Disorders



Join us October 13-15 at the Renaissance Hollywood Hotel & Spa in Los Angeles, CA, to learn from top experts in the field, make new connections and be inspired. The Early Bird rate ends July 31st, so be sure to [register today!](#)

the *International Journal of Eating Disorders*. Dr. Vitousek is the 2011 recipient of NEDA's Craig Johnson Award for Excellence in Clinical Practice and Training

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The NEDA Conference is designed to connect and meet the needs of families and individuals affected by an eating disorder, with a special Family & Friends Kick-Off Dinner, Family Basic track, and much more. The Family Track promises to be filled with the information PFN members need! Session topics include insurance coverage for treatment, self-care for carers, recovering at all ages, integrating families into higher levels of care for children and adolescents, and "The Recovery Roadmap." Check out the [Schedule-at-a-Glance](#) to see all sessions.

Is "Secondhand" Media Exposure a Risk Factor for Eating Disorders?: A cautionary tale from Fiji by President of the Academy for Eating Disorders, Anne Becker, MD, PhD



Reviving the Bio-Psycho-Social Approach: The implications of current theory and research for families and professionals by top experts Carolyn Costin, MA, MFT, Michael Levine, PhD and Michael Strober, PhD

CONFERENCE HIGHLIGHTS INCLUDE...
Clarity, Compassion, and Consensus: Finding better ways to understand eating disorders



Keynote Address by Kelly Vitousek, PhD, Associate Professor of Psychology at the University of Hawaii, Co-Director of the Center for Cognitive-Behavioral Therapy in Honolulu and Director of its Eating Disorder Program, and serves on the editorial board of



Carolyn Costin, MA, MFT



Michael Levine, PhD



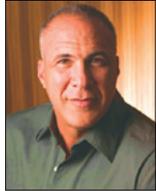
Michael Strober, PhD

Family Panel: A Kaleidoscope of Perspectives, Moderated by Ovidio Bermudez, with a special welcome from Bradley Bayou, Fashion Designer, Author, TV Personality and Father of a Daughter who suffered from an eating disorder. Featured

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2011 NEDA Conference *continued*

panelists include Vic & Lindsey Avon; Lynn Chen; Sunny Sea Gold & John Palvus; Rachael Stern, LMSW, LGSW; and Corazon Tierra.



Bradley Bayou



Sunny Sea Gold



Corazon Tierra

You'll gain insight from personal stories of recovery from bulimia, anorexia and binge eating disorder, featuring the ways diverse identities of ethnicity, class, sexuality and gender, can present unique challenges, relationship dynamics and barriers to help.

[Click here for more information and to register now!](#)

NEDA's First-Ever Teen Summit!

Making *Real* the New *Ideal*: Body image, self-esteem and media

Teens between the ages of 13 and 17 are invited to come discuss how you and your peers feel relating to self-esteem, body image, media and eating disorders. Your input will shape NEDA programs impacting teens across the country — and you'll gain the tools and skills you need to be a leader in your community!

Featured speakers include...



Keynote speaker and panel moderator **Jess Weiner** NEDA Ambassador, Dove's Global Ambassador for Self-Esteem, *Seventeen Magazine* Columnist, Founder of the *Actionist Network* and author

Panelists



Lisa Lee, Publisher of *Hyphen Magazine*, Co-Founder of Thick Dumpling Skins, the first online forum dedicated to body image issues and eating disorders within Asian-American communities

Emily-Anne Rigal, founder of WeStopHate.org, Lead Ruby Advisor for TheRubyBooks.org, Assistant Editor for AllyKatz.com and *Seventeen Magazine's* "Body Peace Breakthrough" winner



Troy Roness, NEDA Junior Board Member, legislative advocate in NEDA's STAR Program and eating disorders awareness activist

Activity Facilitators

Bridget Loves, workshop facilitator, eating disorder and body image educator and Executive Director, Fed Up Inc.



Morgan Prouse, Fed Up Inc. Junior Ambassador and body image peer educator



Closing Remarks

Bailey Monarch, 17 year-old recipient of The Robbie Munn Volunteer of the Year award

Chenese Lewis, President of Hollywood NOW, expert commentator, BEDA Ambassador, Fed Up Inc. Celebrity Ambassador



***\$10 registration fee, lunch provided. For financial assistance requests, email: sroman@myneda.org.**

More Information & Registration [click here.](#)

Download the [Teen Summit Flyer](#) and share it with your friends! Email it, print it, post it!



Continuing Recovery at College: Considerations for parents

By Nancy Hemendinger, PFN Steering Committee

You will need to be able to talk with health services, the housing staff and any other outside providers treating your child.

Senior year for your average high school student is focused on taking SATs, ACTs, applying for college, and by May, making what seems to be one of those major life decisions. Families that have been immersed in the battle of a child's eating disorder also partake in college preparation activities however, the primary concern is more likely to center on their child's healthcare needs. Unless your child's disordered eating miraculously disappears, the decision to attend college away from home can be daunting. Parents ask themselves: What will happen if the disordered eating behaviors return while our child is away? Who will support their recovery? Should we even consider sending them to college? How do we leave our child alone at school with the eating disorder? Entering college represents a major life change and can be especially challenging for those affected by an eating disorder. Identifying a therapist or support group can be helpful in navigating the change in roles you and your child will assume during transitions to college life.

An eating disorder that existed prior to high school graduation will not go away with college admission. However, accepting a college invitation can also provide a unique opportunity for your child to begin taking on more responsibility for their day to day recovery. For parents able to embrace recovery away from home, identifying resources and support before the beginning of the academic year is a sound strategy.

Being Proactive and Realistic

Families can proactively help their child secure strong supports, and encourage them to be diligent about establishing a plan for self-care. According to Robin Pisano, a therapist from Hartwick College in Oneonta, New York, "A big problem in the

college culture is that students' language with each other does not support someone with disordered eating. They critique themselves and others to impossible standards making comments about body types and about everyone else's eating habits. It's easy to be "romanced" back into the lifestyle when others normalize it. The college student will benefit by surrounding themselves with positive people, friendship groups, family and counseling staff to help contradict this negative language and to remain focused and grounded in recovery."

Parents must balance optimism with reality. College can be a positive experience. However, the eating disorder may continue to be a struggle for your child as they navigate this new life. Be honest with the college about the severity and the journey that the family has taken. What are your son or daughter's strengths and weaknesses? What are your concerns? By disclosing information, the school's counseling staff will be able to develop an individualized treatment plan for your child.

The Decision

As our family researched colleges, we each had our own set of priorities. Academics, campus activities, Greek Life were important to our twin daughters, Emily and Ashtyn. My husband was focused on information about tuition and financial aid. Our daughters had both been diagnosed with anorexia at 15, so I was intent on researching the availability of counseling and health services on college campuses. Our daughters' treatment teams recommended that they attend separate colleges and that we set a realistic limit as to how far away they could go. When May 1st arrived, academics, scholarship, tuition were considered in our college decision; however the type and level of health services were the

most important factors in determining where our daughters would attend school. Emily decided to attend Hartwick College in Oneonta, New York, and Ashtyn chose Carnegie Mellon University in Pittsburgh, Pennsylvania. Both schools provided suitable health and support services. Once the deposits were accepted, I contacted the student health services to secure a support team.

Dr. Anita Barkin, Director of University Health Services at Carnegie Mellon University (CMU) suggests that parents establish support care on campus or in the local community. If you need to use off-campus community specialists, try to select providers who have expertise in treatment of eating disorders, preferably in the college-age population. Dr. Barkin emphasizes the importance of providing new care providers with documentation of the history and treatment plans from current and past providers. This should be done before the new provider assumes care. CMU's Registered Dietitian, Paula Martin encourages families to discuss meal options with the school's registered dietitian or the on-campus food service provider. The registered dietitian may be able to help your child stay on course with their meal planning, weight and other vitals.

Communication

Disclosure is extremely important. To facilitate communication with college personnel, our daughters signed medical releases. They understood that signing the disclosure forms was part of our agreement to let them live away from home. You will need to be able to talk with health services, the housing staff and any other outside providers treating your child. By disclosing information to the college and securing support,

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Continuing Recovery In College *continued*

you increase your child's success of a smooth transition not only during the first week, but the months and semesters to follow... and eventually into graduation. Initially we had daily conversations of encouragement with our daughters and routine contact with each school's health services team. In addition, we scheduled visits early in their semesters. The visits allowed us to see how they were doing physically and emotionally. We knew early on that we would be dedicating more time and financial resources into their college transitions. When exhausted by this long distance college plan, we focused on the eventual benefit of our daughters gaining autonomy, independence and recovery. As their health improved, our need for routine contact with them and with health services decreased.

There are no guarantees that a student will integrate into college life. For this reason, I encourage parents to purchase the tuition refund policy and make sure you understand how the policy works. The assurance of the tuition refund policy alleviates the added stress of losing a semester's worth of tuition in case your child needs to take a medical leave.

Advocacy

At times, advocating for your child's needs may be necessary. Prior to beginning their freshman years, we received our daughters' room assignments. Hartwick unknowingly assigned Emily a roommate who also had an eating disorder. The school was alerted to the situation, and the directors of counseling and housing had her room changed before she arrived. Carnegie Mellon University assigned Ashtyn to off-campus housing. Ashtyn's health needs were explained to the housing and the medical directors, and she was placed in a dorm right above health services. This was the very dorm I had envisioned for

her when visiting the school!

Bumps in the Road

Freshman year acclimation seemed to be going so well that my husband and I went on a short vacation. This was the first time we were away since the eating disorders overwhelmed our family. I would not recommend going too far the first year your child is at school. We were on our way home when we received a call from Emily. She was having a difficult time and she and the school thought she should return home. We went from a relaxed state into crisis mode. We arrived home and immediately drove the 4 hours to Hartwick. After several meetings with Emily, the therapist and doctors, we decided that Emily would stay until the end of the week and then the situation would be assessed. We all believed that as long as Emily was medically stable, she could stay. Our goal was to have her feel success by completing the semester. Daily communication was re-established between Emily, the school and us. She was encouraged to focus on taking care of herself, not her grades or honors classes. She completed the semester, focusing less on academic achievement and more on her well-being. We believe this was progress in her recovery.

Ashtyn is still learning how to manage her recovery, school work and activities. Her challenge has been to balance her drive between over-achieving and overextending herself, and taking care of her health. At times she has struggled with this challenge; however she recognizes when to ask for help and she is open to treatment recommendations. Ashtyn is staying at school this summer. She will take one class and work as a Head Orientation counselor for CMU. We met with health services staff and arranged a support system for Ashtyn. We will miss her, however

she is moving in the right direction... independent from her family, autonomous from her sister and distancing herself from her eating disorder.

College for our children was not about preparing for a career or focusing on grades. The eating disorder derailed that path. College was our daughters' opportunity to work on their individuation, learning to manage their health and having some fun. As they enter their senior years, I believe they have accomplished this and much more. Both are planning for graduate school. As the eating disorders slowly lose hold, our daughters have been able to begin defining a career path for themselves. Emily's junior year Facebook posting demonstrates that by being proactive and realistic, continued recovery is possible while away at school.

...sooo 3 years ago when i was very sick i used to want hot chocolate, but would only let myself get fat-free hot chocolate and i wouldn't let myself mix it with milk. i had to mix it with water...just a little while ago, i went downstairs and made myself a cup of regular hot chocolate. For a second i thought "hmmm... milk or water," but then i said to myself "milk, duh it tastes so much better," and then i thoroughly enjoyed my regular hot chocolate with milk...

thank you to you, daddy, ashtyn, Joan and everyone else who got me the help I needed ♥...Emily

This article is not meant to recommend or promote any particular school(s). They are only listed to illustrate how each person's individual needs must be considered.



What It Looks Like: Modeling self-care | By Robyn Cruze, NEDA Navigator

At dinner, she demurely pushes her food around her plate, then claims she “ate at Jill’s.” I know there’s something wrong, but I don’t know how to fix it.

Unfortunately, a parent alone cannot prevent an eating disorder in their child. They are biologically based illnesses with complex factors contributing to the onset. But, as a mother, I know we can help.

Having had an eating disorder for 18 years, I understand the tendency we have to go to any lengths to hide our illness from our loved ones. Though my mother saw through my secrecy immediately, it never stopped her fear or the suffering she felt watching me slowly kill myself as I related only to “It” — my disease. But by her recognizing the power of the eating disorder, it allowed her to stop blaming herself and separate the disorder into its own identity in order to fight it with me.

“Who is ‘It,’ Robby?” she would calmly inquire, as her insides screamed for her daughter to gain enough sanity to fight her eating disorder. “‘It’ is what is taking me over, Mom. ‘It’ tells me what to do,” I sobbed. She heard my sobs. She heard my powerlessness. And sometimes hearing me was all she could do...other than modeling self-care in her own life.

I know now, as a parent, how important looking after myself is for *myself*, as well as for my children. It sets an example for our children of what self-care is. It allows our children to actually see what it looks like to honor oneself. The memory of my mom’s self-care — even when I could not follow in her

footsteps — is what enables me to know what self-care looks like now. My own self-care routine of exercise, taking vitamins, having “Mommy time,” placing boundaries on Daddy when he says something not-so-nice, and meeting with support groups appears to be just a part of “what mommies do” to my girls. But it is so much more. It is this example that allows my children to know the difference between self-care and self-abuse. So maybe they can begin to question their actions sooner, if they start going down the path of destruction.

I can be careful not to look in the mirror and criticize myself or squish my tummy after having a meal. I can give thanks for all the food we get to eat and educate my girls on which foods make them grow big and strong, and which foods are “just for fun.” I do not comment on their eating, yet I encourage them to listen to their bodies. No food is forbidden in our home.

When it comes to mealtime, Ellyn Satter, an internationally recognized authority on eating and feeding, says that as parents, we can help our children by “supporting their normal pattern of development by doing an excellent job of feeding, parenting reliably and well, and letting kids grow up to get the body that is right for them.” We are responsible for “choosing and preparing the food, providing regular meals and snacks, making eating times pleasant, showing our children what they have to learn about food and mealtime behavior, and not letting children graze for food or beverages between meal and snack times,” in order to allow our kids to grow into their bodies as they are meant to.

Espra Andrus, my frequent co-author and a licensed clinical social worker (LCSW), provided me with her own list of ways to help establish a healthy lifestyle around food for your children and for yourself:

1. Create boundaries: Parents should praise children for being children, rather than allowing them to function as (or praising them for being) “little adults.”
2. Deal with your problems: Deal with your own weight issues with professionals or other supports rather than expressing guilt or shame to your child.
3. Don’t talk with your mouth full: Do not comment on your own eating.
4. Accentuate the positive: Point out things that you are grateful for about your body, and what it does, that have no relationship to size, shape or weight.

I cannot prevent my girls from experiencing life, just as my mother could not prevent my life-lessons. But I can be an example of self-care. I can put my “oxygen mask” on first... and then be ready to better serve my children.

[...]as parents, we can help our children by “supporting their normal pattern of development by doing an excellent job of feeding, parenting reliably and well, and letting kids grow up to get the body that is right for them.”



Self-Care Tips from Your Fellow PFN Members

“One of the best things I learned during recovery was to take nature walks. By that I mean stopping to look at everything and exploring all the life nature offers. It didn’t matter if it was a plant, flower, bug, etc. just watching other life gave me the will to live mine.”

— Maisen

“For me, one of the most important aspects of self-care during and post-recovery is talking about my feelings. As simple as it sounds, I lost this critical “skill” with my ED and kept everything inside. I had to re-learn how to share thoughts and feelings, and with whom. Over time I have developed a network of friends and family members I can call on to discuss anything, from the most trivial to the most intense issues.”

— Jennifer B.

“I recognize now the need to take time to care for myself. I’m always interacting with people in my work, but I am not an extrovert by nature! So I have specific ways to unwind: I keep a journal and I go for walks on the trails near our home. I play my piano and intentionally find new tunes to learn. Music has always been calming to me. I love to read, and I’ve discovered I enjoy knitting. All of these things keep me level-headed, able to identify my

own emotions. The eating disorder caused me to become detached from my feelings; ongoing recovery means that I keep searching my own mind and heart.”

— Suzanna P.

“One of my favorite activities to do is yoga. Just plain, regular, focus on your breathing, allow moments for meditation, feel your body move and stretch yoga. I discovered the true practice of yoga last year when I was recovering from severe depression and disordered eating. I love how yoga can be done as little as once a week to feel the benefits in your body. I love that yoga does not focus on the size and shape of one’s body, but rather on the movement and freedom and power that your body has in moving through poses. I love that yoga focuses so much on the breath, and that in breathing, you visibly see your abdomen move in and out as you fill your lungs with positive energy. Finally, I love that yoga can create a community of people, that it has been shown in studies to aid recovery from any number of mental and physical illnesses, including eating disorders. I encourage you to find a class, many are free, and experience for yourself the wonderful effects of yoga practice.”

— Anna T.

What is Health at Every Size (HAESSM)? | By Dr. Deah Schwartz

There has been a great deal of discussion lately about the Health at Every SizeSM philosophy and how it can interface with the field of eating disorders. Some of the conversations have been quite heated with concerns that this approach grants permission to eat uncontrollably thus giving up any investment in obesity control. Others cite current research that challenges the assumption that being fat equates with being unhealthy. People with eating disorders explain their resistance to adopting a HAESSM approach for fear that they will never be thin; and others have tried to transform HAESSM into a new weight loss technique, which goes against everything that health at every size is about. With such a diverse range of reactions among people in the field of eating disorders, I was curious to learn more.

There are many players on the team battling eating disorders. First and foremost, of course, are the people diagnosed with, or at risk of developing, an ED. Then there are the clinicians and professionals from a variety of disciplines who are working with the clients, e.g. therapists, medical and mental health doctors, nutritionists, dieticians, alternative health practitioners, weight management and fitness coaches, all of whom assert that their goals are to eradicate eating disorders and help people overcome their problems. Sounds like a cohesive team doesn’t it? And it would be except for the fact that while all eating disorders have to do with food, not all fat people have eating disorders. This may not seem to be a dividing factor but if you add societal factors into

the mix, the scenario becomes more complex.

There is an array of reasons why people may be fatter than the societal norm that have no association with disordered eating and may not even result in poor health. These etiological differences may go unnoticed however, because of a cultural bias against fat people. The common assumption is that if someone is fat, they are out of control. Falsely accused of being lazy, ugly, and undisciplined, this negativity often leads to futile attempts at dieting, using diet pills and undergoing unnecessary surgery (such as liposuction), in an attempt to conform to a more culturally accepted standard of beauty. The result of these tactics is frequently weight gain and disordered eating patterns that previously didn’t exist. Conversely,

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What is Health at Every Size *continued*

a person with Anorexia or BED (Binge Eating Disorder) may go undiagnosed because their body conforms to the societal expectation of thinness. A person who is thin from restrictive eating is not subject to the same negative societal stigmatization. Quite the opposite, their behavior patterns are positively reinforced until the tipping point of “too thin” is reached and their health compromised. In both cases if the focus stays on the person’s health rather than their weight, the likelihood of a more positive outcome increases.

As I familiarized myself with HAESSM, I kept in mind the wide spectrum of clients with eating disorders that I have worked with during my years as a therapist and what the role of HAESSM could be. My conclusion: incorporating HAESSM is both a pro-active and sustainable therapeutic approach for those struggling with a diagnosed eating disorder, sub-threshold disordered eating, or body dysmorphia. The basic premise of health at every size, as written in Linda Bacon’s Book, *Health at Every Size: The surprising truth about your weight*, is that “Health at Every Size” (HAES) acknowledges that well-being and healthy habits are more important than any number on the scale. Participating is simple:

1. Accept your size. Love and appreciate the body you have. Self-acceptance empowers you to move on and make positive changes.
2. Trust yourself. We all have internal systems designed to keep us healthy—and at a healthy weight. Support your body in naturally finding its appropriate weight by honoring its signals of hunger, fullness, and appetite.
3. Adopt healthy lifestyle habits. Develop and nurture connections with others and look for purpose and meaning in your life. Fulfilling your social, emotional, and spiritual needs restores food to its rightful

place as a source of nourishment and pleasure.

- Find the joy in moving your body and becoming more physically vital in your everyday life.
- Eat when you’re hungry, stop when you’re full, and seek out pleasurable and satisfying foods.
- Tailor your tastes so that you enjoy more nutritious foods, staying mindful that there is plenty of room for less nutritious choices in the context of an overall healthy diet and lifestyle.

4. Embrace size diversity. Humans come in a variety of sizes and shapes. Open to the beauty found across the spectrum and support others in recognizing their unique attractiveness.

These are strategies and mindsets that are applicable to all people struggling with body dissatisfaction and eating disorders. True, there may still be disagreements among the multi-disciplined clinicians as to what additional interventions are efficacious for specific treatment goals and objectives, after all each person is unique and this field above most others should be reticent to adopt any “One Size Fits All” approach. But I am hard pressed to imagine a situation where encouraging clients to focus on health and self acceptance would be excluded in anyone’s treatment plan. If our primary goal is improving one’s quality of life this means battling the societal and psychological factors that have created the disordered eating patterns and not labeling fat, in and of itself, as the enemy. It is acknowledging that the road to health is an incremental process that takes renewed commitment and success-oriented approaches. There is no quick fix and no miraculous intervention. One specific “how-to” provided in Dr. Bacon’s book is the following contract:

- ☞ Today, I will try to feed myself when I am hungry.
- ☞ Today, I will try to be attentive to how foods taste and make me feel.
- ☞ Today, I will try to choose foods that I like and that make me feel good.
- ☞ Today, I will try to honor my body’s signals of fullness.
- ☞ Today, I will try to find an enjoyable way to move my body.
- ☞ Today, I will try to look kindly at my body and to treat it with love and respect.

Signature: _____

Date: _____

Within the framework outlined, this approach does not focus on weight loss as the sole indicator of health or encourage self-destructive abandon in one’s eating. What I see is a weight-neutral approach and an opportunity to explore a more intuitive relationship with food, engaging in pleasant physical activity, and self-size acceptance. It couldn’t hurt!

Dr. Deah Schwartz has more than 20 years of clinical and supervisory experience in Expressive Arts Therapy programs in psychiatric hospitals, schools, and treatment programs in the Bay Area. Dr. Schwartz’s academic background includes: a Doctorate in Education, an MS in Therapeutic Recreation, an MA in Creative Arts Education, and a BA in Theater. She is co-author and performer in the NAAFA award winning Off-Broadway Show, Leftovers, the Ups and Downs of a Compulsive Eater.



Why I Navigate: Giving back and supporting others for recovery

By Robyn Cruze, NEDA Navigator

If you have ever asked yourself how you can help those you love and care for who suffer (as I have) from an eating disorder, then this article is for you.

Eating disorder awareness has been growing stronger over the past ten years, with many giving voices to the crippling impact that eating disorders have on lives. But still millions are suffering and dying from this predominantly misunderstood disease. Its devastating effects create the highest mortality rate of any mental illness. Those suffering are stuck in a world of disturbance that not only consumes them, but greatly impacts the lives of those around them.

“I was grateful to see the 2011 NEDA awareness week theme, ‘It’s Time to Talk About It!’ to increase awareness of the need to break the silence surrounding eating disorders. Often there is a chronic sense of isolation experienced by those suffering with this illness. Almost all of us know or know of someone who may suffer with some type of eating disorder. We may want to say something but we are afraid of being intrusive, offensive, saying the wrong thing in the wrong way, embarrassing someone or alienating them. So the fear keeps the rest of us silent as well. And so the eating disorder goes, silent, invisible, isolating and deadly.”
— Espra Andrus, LCSW

One of the tools Espra Andrus, LCSW, and I are currently writing about is speaking out. NEDA Navigator participation provides us with another opportunity to bring awareness, help others, and to say NO to the eating disorder on a community level. It has been said that those who are impacted by an illness, or have directly experienced an illness within their lives, are those best-suited to offer

NationalEatingDisorders.org



NAVIGATORS

help to others with the same illness. Being a volunteer in the NEDA Navigator program has been a special way I can give back. I find it to be one of the most inspiring, rewarding and esteem-able ways to help sufferers and their loved ones in their fight to overcome an eating disorder...a fight that can otherwise feel isolating and unbearable.

Having suffered an eating disorder from ages 11- 29, I understand the need to feel a part of something, to feel some form of self-esteem from the inside out. I never found that in the behaviors of the eating disorder. I tried, and I am sure that many of you reading this article tried also. The lies of an eating disorder are robust and painful. They tell all those who are suffering that IT (the eating disorder) is the solution to achieving their dreams, to gaining control, and to maintaining that sense of achievement that the sufferer has spent a lifetime searching for. The eating disorder is a liar. We who have overcome it know this now. We know that the way out is not through the acts of an eating disorder, but through the act of closing (and re-closing) the door on the eating disorder.

From my point of view of being a NEDA Navigator, I love that I get to be someone’s point of contact, someone who is searching for a solution for either themselves

or a loved one. I am a part of the solution, a part of change—I get to be the voice on the other end who says, “There is help, and you don’t have to go it alone.” As a Navigator, I help guide contacts to the support they need to finally quiet their, or a loved one’s, illness. I am not a therapist—that’s not my job. My role is to help connect people to the therapists. I get to be a helper, the kind I would have wanted years ago when I was screaming for help, but didn’t know how to get it. I get to help those people struggling to understand how to help their friend, sister, brother, daughter, lover. I get to be a person of hope...and sometimes, that’s all that people need, to give them the gentle nudge of encouragement to start recovery. Just by answering an email, or placing a pamphlet in a doctor’s office, I am allowing those who need it in my community know that they are not alone.

Today, I had one of the most rewarding experiences yet as a NEDA Navigator. I did my first outreach call to a local Planned Parenthood Clinic, where I spoke to the manager and asked her if I could provide the clinic with some NEDA pamphlets that would provide eating disorder awareness to the patients who sought it. She almost did a somersault. I kid you not! She shockingly told me that she had never been approached about it and that it was much needed in their clinic—to the point that she asked me to come speak with her staff to bring further awareness to them also. When I shared the statistic of eating disorders in adolescents they felt empowered to do something. They already do a superb job of bringing awareness of sexual issues to this age group, and now they plan to bring eating disorder

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Having suffered an eating disorder from ages 11- 29, I understand the need to feel a part of something, to feel some form of self-esteem from the inside out.

Why I Navigate *continued*

awareness to the next teen fair held in the fall.

Just like that, I made a difference. I left grinning from ear to ear, because I knew that the people who frequented their clinic from now on, who needed help with an eating disorder, would know that there was help. And help equals hope...for all of us.

Navigators are not treatment professionals. They are PFN members trained to provide informal compassionate support and help finding local treatment options, tools for identifying the best fit, educational materials, and to be a listening ear. All Navigators have had personal experience – either themselves or through supporting

a loved one – navigating the overwhelming emotions and complex systems involved in getting help. They are available to lend a hand to guide others toward treatment and recovery. If you could use the support of a Navigator, locate a volunteer in your area from the list provided at www.MyNEDA.org under NEDA Navigators in Programs & Events.



“ePATH” Research Study: An online tool for families

By Jocelyn Lebow, MS

It is not uncommon for the family of a teenager with an eating disorder to express the wish that they had “caught it sooner” and brought in their daughter or son “before things got really bad.” Once an eating disorder has taken hold, it quickly becomes increasingly difficult to treat. Research supports the fact that intervening earlier, before symptoms become intractable, generally leads to more positive outcomes. Further, the longer a teenager suffers from symptoms, the greater the impact is on other areas of their functioning, including social, cognitive and physical development. It is imperative then, that the search for effective eating disorder treatments also focuses on ways to intervene earlier, addressing the first signs of an eating disorder and preventing full-syndrome anorexia or bulimia from developing.

Drs. Angela Celio Doyle, Daniel Le Grange and Jocelyn Lebow, MS at The University of Chicago Eating and Weight Disorders Program are currently developing an adapted version of Le Grange’s Family Based Treatment (FBT) that could be used

as this sort of early intervention. Specifically, the group is testing the feasibility of a new program, “Empowering Parents and Adolescents Towards Health” (or “ePATH”), for participants showing the first signs of early bulimia nervosa. ePATH is an 8-week guided self help program, designed to help parents implement the empirically-supported principles of FBT. To increase cost effectiveness and accessibility, the 8-week program is offered entirely online. It is important to note that the program is not intended to replace face-to-face therapy, but rather, help parents intervene before early symptoms worsen. The program offers educational materials, interactive activities and weekly monitoring aids tailored for parents, affected teenagers and siblings. The password-protected program also includes a moderated discussion board for all participants to interact with other families going through similar experiences.

Currently, the research team is looking for parents and adolescents ages 12-17, with early signs of an eating disorder. Eligible families will receive three assessments for eating

disorders and other psychological disorders, as well as 8 months access to all program materials and discussion board.

Interested in participating in the University of Chicago study, or in learning more about the ePATH program for families of teens with early signs of an eating disorder? Visit the website at: www.ephathprogram.org

For more information or contact Jocelyn Lebow at: ephathprogram@gmail.com.

*Dr. Angela Celio Doyle was a 2007-2008 NEDA Young Investigators Grant recipient for this study.



Young Leaders in the Fight Against Eating Disorders

By Melissa Ostering, NEDA Junior Board

About five years ago the CEO of the National Eating Disorders Association (NEDA), Lynn Grefe, had an intriguing idea to develop a young generation of philanthropists, leaders, advocates, and policy makers within the field of eating disorders. This group would serve within the NEDA framework as the NEDA Junior Board. Lynn had a couple of talented people in mind to spearhead the effort. By 2007 Lynn approached the inaugural members, launching the NEDA Junior Board in 2008.

The mission of the NEDA Junior Board supports NEDA's mission – supporting individuals and families affected by eating disorders to serve as a catalyst for prevention, cures, and access to quality care – through programs, special projects, and events. Specifically, the NEDA Junior Board decided to focus on building awareness at college campuses and schools during National Eating Disorder Awareness Week. This group started small with only three members. Presently, the Junior Board has expanded to nine members across the US, all bringing special expertise, talent, and passion in the fight against eating disorders.

With continuous growth since 2008, the NEDA Junior Board has expanded its events and special

projects, reaching thousands of young people across the country. For NEDAwareness Week 2011, members actively participated in panels, legislative advocacy, NEDA walks, and the launching of a national college survey to create a database of eating disorder resources on college campuses. The preliminary results from this survey were proudly referenced in a Newsweek article titled, "Eating Disorders on Campus Get Scrutinized," with further results to be disclosed this fall.. Recent Junior Board events include: A 2011 speaker panel in New York City, which was composed of friends, family members, and those in recovery from eating disorders to provide insight, tips, and hope in the Road to Recovery; an Orlando NEDA Walk held in partnership with the Eating Disorder Network of Central Florida, which raised over \$16,000; and a Wine Tasting Fundraiser – a huge success with over \$20,000 raised to support NEDA programs!

Looking forward in 2011, the NEDA Junior Board is excited to announce a Teen Summit being held in conjunction with the Annual NEDA Conference in Los Angeles, CA on October 15th. The NEDA Teen Summit is titled "Making *Real* the New *Ideal*: Body image, self-esteem, and media." It will be a half-day of



Junior Board members at the 2011 New York Benefit Dinner

events and leadership training for teens, composed of a panel session and workshops exploring self-esteem, peer pressures, mass media, body image, role models, and more. Input from teen participants will be used to help shape directions for NEDA teen programming impacting their peers across the country! Registration is only \$10 and currently open to teens 13 to 17 at www.myneda.org. Additionally, NEDA will launch its new interactive teen website, Proud2Bme.

In the future, the NEDA Junior Board is excited to develop more programs and events that will positively make an impact across the nation. If you are interested in volunteering at Junior Board events and learning more about what we do, email us at development@myneda.org.

The Beginning of H.I.P.S.: Teen leaders for activism and education

By Bonnie Deal and Rebecca Kaiserman, Founders of H.I.P.S.

"The mind is a terrible thing to waste. The waist is a terrible thing to mind."

The inspiration to begin this club, H.I.P.S. (Health, Image, Power and Success) came from seeing girls just 9 years old already beginning to hate their bodies. It came from the diet industry growing into a phenomenon that consumes women's lives. It came from seeing an unnaturally thin 14 year old girl having trouble finishing dessert because she did

not want to get made fun of at school for being "fat." But it mostly came from the want – the need – to change all this; to empower girls, boys, teenagers, men and women to believe in themselves, rather than looking to our society's mirror for approval. In no way does this club promote throwing healthy diets to the wind, but rather it promotes

being conscious of healthy behaviors and choices while accepting that no one can ever be perfect.

H.I.P.S., created by Bonnie Deal and Rebecca Kaiserman, was recently approved by the administration of Trumbull High School (April 2010). Although the club is fairly new, the need for information on these topics

(continues on next page)

Speaking Out: A tool in my recovery | By Gillian Calig

I remember sitting in an eating disorders clinic listening to Aimee Liu give a lecture about her first book, *Gaining*, when I was first introduced to the idea of speaking out, quite loudly, about my eating disorder. Here was a woman, who considered herself recovered, who was using her experience to influence my recovery. That was when I first decided I would use my voice to do the same.

For that reason, after speaking with the *NY Times* and publishing some of my poetry, when I was approached by Aimee Liu to write a piece for her next book, *Restoring Our Bodies, Reclaiming Our Lives*, it was an honor and opportunity that I could not pass up. Since my first encounter with Aimee, I had decided that I would not let my experiences, good or bad, go to waste. For me as a recovering anorexic, I felt that if I could use my trials and battles to support just one suffering person, or to go as far as to inform the entire world about the dangers and truth of the disorder, then my own struggles would not have been in vain. Everyone's recovery is different, and not everyone will feel compelled to write and speak

about their struggle, but for me it was an important component of my recovery process.

It is incredibly empowering to decide that my experience with this vicious disorder can be turned into something positive. To go through every meal suffering is an arduous task, and each meal seems to come faster than the last. However, the thought in the back of my mind, that my firsthand experiences with anorexia may support somebody else, or that perhaps the knowledge I have to share could save somebody from going down the same path I have, forces me to keep going. It gives my daily – or “meal-ly” – battle a purpose.

By writing a piece for Aimee's new book, I felt I would be a part of something meaningful. I would be a part of a book that may help a struggling individual find solace, or a book that could inform medical practitioners about the depths of eating disorders. I have learned through personal experience that not only does having an eating disorder isolate a person from almost everyone around him or

her, but when one goes to medical professionals who are supposed to be adept at treating these disorders, a person can often feel even more isolated if that medical professional has not been given the proper training. Now, I in no way am saying that it is the fault of the medical professionals, however the fact that eating disorders are a very secretive disorder makes it critical that there are people willing to speak out. There is no way that anyone with an eating disorder can expect to receive the proper care if nobody is willing to discuss what really goes on within these disorders. By writing for Aimee Liu's book, I hoped that I would be able to enlighten health care professionals. I hoped that this book would make a difference for many people struggling to survive and struggling to learn, and that I could say that I was a part of it. For that reason, being a part of Aimee's new book presented multiple opportunities all in one.



The Beginning of H.I.P.S. *continued*

is certainly not. The club plans to develop and grow based on the needs and suggestions of its members. We recognize that eating disorders affect both men and women, and do not discriminate by race, size, family background or socioeconomic status. We draw attention to the fact that eating disorders are often, but not always, accompanied by anxiety disorders, depression and/or body image disorders, can be potentially fatal and should be treated with professional care.

So what does H.I.P.S. do? The mission of H.I.P.S. is to raise awareness of the growing epidemic of eating

disorders, give teenagers the opportunity to voice their concerns about society's impact on young girls' body image and brainstorm ways to help prevent these illnesses for future generations. H.I.P.S. plans to organize and hold fundraising events for organizations such as NEDA — part of the club is about raising money for the cause and bringing attention to such organizations. H.I.P.S. will also promote events such as NEDA awareness Week, Fat Talk Free Week, and To Write Love On Her Arms Day (in order to bring awareness to teen depression, as well). We'll also hold informational seminars for teens about society's impact on body image

and how to protect themselves from becoming influenced by unrealistic images provided by the media. The club also plans to hold educational seminars for parents and teachers on how to prevent and identify eating disorders and other mental illnesses.

H.I.P.S. hopes other teens will do the same in their school and is extremely grateful for any support and interest in forming additional branches. Join us...we can make a difference! Just find us on Facebook by searching H.I.P.S., or follow us on Twitter: www.twitter.com/H_I_P_S



Book Review – Restoring Our Bodies, Reclaiming Our Lives

Review submitted by Lauren Calig

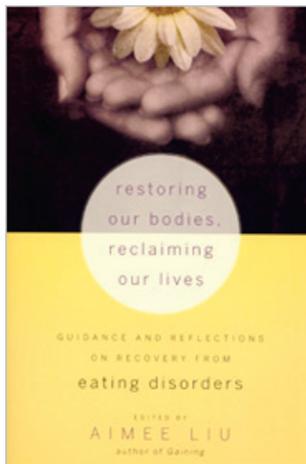
Author: Aimee Liu
(Trumpeter Books, 2011)

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 review author. NEDA does not endorse any specific books or authors.

I received an email from Aimee Liu, the author of *Gaining*, a little over a year ago, with an exciting opportunity to share my family's story in a book about recovery. We had met when she came to speak at an eating disorders treatment center. We had kept in touch, as I too am working on a book and asked her for advice and feedback. In her email, she explained the premise of her book and asked if I would like to contribute a piece; in addition to this, she asked if my daughter, Gillian, would also submit a piece of writing and some poetry. Both Gillian and I were honored to be asked and never hesitated for a moment.

Aimee's book and journey were familiar to me. My daughter, Gillian, had been struggling with an eating disorder (ED) for a number of years. From the beginning, I was very vocal and honest about her ED; I never once hid her pain, our pain or our journey from family, teachers or friends. As a result, six years later, Gillian and I have spoken to countless people about eating disorders, our journey, the insurance system, different types of treatment and medication.

Restoring Our Bodies, Reclaiming Our Lives includes such a diverse group of people who have contributed their stories about their ED, their turning points, their recovery, their treatments, and their current lives. It is an



honest and often painful account of how ED can rob you of yourself, with a central focus on the realistic and complex process of recovery. The book maps out EDs in a unique, engaging way. The reader is able to intimately delve into the mind of a person with an eating disorder and examine his/her feelings at each point of the recovery process. Liu gives the reader the gift of feeling the feelings, sharing the thoughts and being aware that recovery looks different for every single person. As a parent, this is invaluable. It allows us to know that our child's recovery journey may look very different from those described in the book, and this is okay. This does not mean that our child is on the wrong path; it means that he/she is on their own path.

Liu has written a book that can be easily read by individuals in recovery, their parents, family members and friends. Liu has opened the window and invited us into the minds and struggles of those with EDs by allowing them to tell their stories in a way that is insightful and responsible. Experts in the field provide critical information on many topics such as treatment modalities, medications, finding the right therapist, supporting recovery, and more.

The take-aways from this book were many and will be different for each person that reads Liu's book. As a parent, the book gives me cautious, realistic hope for my daughter. One contributor's words resonated with me long after I read the book, and I trust these words will stay with me forever:

"I'm proud to say that after years of battling ED, I am fully recovered. To me, being recovered means looking in the mirror and seeing someone with a few more pounds to lose, regardless of how much I weigh. It means having self-doubt and minor insecurity arising every now and again. It means having a special and complicated relationship with food, probably forever. But more than this, it means loving and accepting myself with all of that. It means knowing, deep inside, that no matter how hard it gets and how tempting it may be to go back to old behaviors, I will never give in to them again. I will always remain in some form of struggle with my disorder, but I will triumph, always..."

Maya's words gave me the comfort to know that although my daughter may struggle and life will get messy, her ED does not need to be her way of coping.



Join Us in Thanking Yoplait

In June, we emailed you about how we contacted Yoplait (General Mills) about their cheesecake yogurt advertisement that many NEDA supporters told us they found very troublesome. After meeting with General Mills leadership, they listened carefully and agreed to discontinue the ad. They explained it may take several weeks to dismantle the campaign, but agreed to do so. Tom Forsythe, vice president of corporate communications for General Mills said “Any correlation was certainly unintentional. But if even a few people could take from the ad that mis-impression, then the right thing to do was to pull the ad—and we have.” This shows a great level of responsibility and sensitivity to health, obesity, and mental health of Americans. They deserve to be applauded.

Since then, NEDA has received many congratulations and thank you’s, as well as some critical messages from the public, from people who clearly did not understand our problem



was not with the product, but the misguided ad. It also reminds us how so many Americans normalize the dangerous inner dialogue and thought process characteristic of those suffering from an eating disorder – belaboring ways to negotiate calories, categorizing foods into “good” vs “bad” and contemplating extreme compensatory behaviors. Clearly there is still much work to be done as we advocate for healthy relationships to food and one’s body.

We encourage you to write Yoplait/General Mills directly to express your gratitude. Yoplait has demonstrated that it is a responsible corporation concerned with our society’s mental and physical health, and we applaud them for making their consumers’ health a top priority. [Click here](#) to send a letter now.

Are you a member of the Media Watchdogs? Join today!

The Media Watchdog program advocates for healthy media messages regarding body size and shape, weight and beauty. The program brings together students, educators, health professionals, parents, individuals affected by eating disorders, and concerned consumers to encourage advertisers and entertainment media to be accountable for the impacts of their messaging on consumers.

Join the new and improved Media Watchdogs [Facebook Group](#). The new group format allows members to connect with each other and coordinate efforts via chats and document sharing, and get new Watchdog updates/alerts from NEDA.



Meet NEDA – Andrew Beyer, Database Manager

Andrew Beyer serves as Database Manager at NEDA, after joining in 2009 as a Development Assistant. He is responsible for NEDA’s database and many other technology related projects. Andrew has a BS in Computer Science from Rensselaer Polytechnic Institute, and came to NEDA after previously working in software development. He is happy to be able to apply his skills in an environment where they have a real benefit to people.

Andrew has lived in Seattle for 11 years, and enjoys the Pacific Northwest outdoors, but is also excited to be moving back to the east coast when NEDA relocates it’s headquarters to New York.



NEDA Network Spotlight – Andrea’s Voice Foundation



Andrea’s Voice Foundation came into being following our 19-year-old daughter Andrea’s death after one year of bulimic behaviors. Although a tragic loss for our family, the lessons we’ve learned in the 12 years since her death have helped others with their healing journeys. Our non-profit’s efforts in support, resources, and education have become Andrea’s legacy. She lives on through our work and our book, *Andrea’s Voice, Silenced by Bulimia*.

As a NEDA Network Member, we just hosted our first NEDA Walk in downtown Napa, California on June 11. It was a great success. Our newest Board Member, Paraag Marathe, the Chief Operating Officer of the 49ers football team shared the compelling story of his

sister’s struggle with anorexia. She, too, sadly died from the illness but the core of his message was one of hope. Through Paraag’s honest vulnerability, he gave others permission to recognize and to feel all their emotions. It appeared to be as cathartic an experience for the listeners as it was for Paraag.

Jenni Schaefer told her story of triumph and survival so that attendees could hear our ultimate message that healing is absolutely possible. There were numerous “head-counts” of the day. By official registrations we were to have 186 people with us, but there were many who came and did not register bringing that number to well over 200. Some “counters” said we surpassed 300!

In the coming year, we hope to finally offer the first DVDs from our Family & Friends Support Group Curriculum, and continue our collaborations with the local hospital and school district in offering body image classes to students K-12. Our national talks at conferences, universities, and organizations will continue as well so that we can meet our goal of “transforming perspectives, one person at a time.” For more information on Andrea’s Voice, please visit us at <http://andreasvoice.org/> or contact me via email at doris@andreasvoice.org.



Share your Thoughts

If you have an idea for an article, a question you’d like us to research or would simply like to share your story, we’d love to have you participate in our newsletter! Email us at pffnetwork@myneda.org. Be sure to include your full name, email address and daytime phone number so we can contact you. The PFN Newsletter is by parents, family, and friends for parents, family and friends!

Need support in the process of seeking treatment and caring for a loved one struggling with an eating disorder? The NEDA Navigators are here for you! [Click here](#) to locate a NEDA Navigator in your area.

**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.*



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