The theme of our recent 2017 International Conference on Eating Disorders in Prague, *Diverse Perspectives, Shared Goals* was not only a fitting theme for the meeting - it’s a fitting theme for our organization as a whole. "Diverse perspectives" arise from the various professional backgrounds of our members, from their various roles (e.g. clinician, researcher, patient-carer, advocate, or activist), from the various stages of their careers, and from the wide range of geographic regions they come from. This variety is crucial to moving the AED forward as an organization and to advancing the broader field of eating disorders.

Acknowledging that "diverse perspectives" sometimes also lead to conflicting views, disagreement, and misunderstanding, we can be proud that our membership and our volunteers, as well as AED’s leadership and staff, pursue
“shared goals” with impressive energy and passion. They are all committed to achieving global access to knowledge, research, and best treatment practice for eating disorders - which is exactly the vision of the AED.

Before talking about the future and AED’s current strategic objectives, let me first come back to the 2017 ICED in Prague and thank all those who contributed to the huge success of this meeting. It was the third largest ICED ever held outside the U.S., with 855 attendees from 44 countries meeting in the heart of Europe, indicating that the AED has made remarkable progress in becoming a global organization. First and foremost, thanks go to conference Co-Chairs Unna Danner and Jennifer Wildes and the 2017 Scientific Conference Committee including Kelly Bhatnagar, Angela Celio Doyle, Ross Crosby, Leah Dean, Kelsie Forbush, Anthea Fursland, Anja Hilbert, Hana Papezova, Rachel Rogers, Kendrin Sonneville, and Annemarie van Elburg. Together with our Board members Jennifer Thomas (Director for Annual Meetings) and Ursula Bailer who chaired the Clinical Teaching Day/Research Training Day Committee, they created a truly outstanding program, so many thanks to all of them! I would also like to thank our presenters, experts, and mentors for sharing their research, clinical experiences, reflections, and visions with us in the numerous presentations, workshops, discussion panels, poster sessions, and other meetings. Feedback that we received during and after the conference indicates that the program and contributions were very well received by conference attendees, and I hope that those of you who were able to join us in Prague agree with this impression.

I would also like to thank our management team: our Executive Director Lisa Myers, our Deputy Executive Director Dawn Gannon, our Director of Meetings Margaret Jamborsky, and their colleagues at DMG. Their professionalism, hard work, and energy largely contributed to the success of this conference.

And finally, I also want to thank every one of you who attended the ICED. Many of you did so for the first time and I hope that everybody felt as welcome as I did many years ago at my first ICED and that many of you continue to stay involved with the AED long-term. We are already hard at work preparing the next ICED, which will be held in Chicago, IL, U.S. in April 2018. We hope to see many of you there!

I look forward to the upcoming months and to working with our amazing Board of Directors. We will miss Carolyn Becker and Donna Friedman, who rotated off the Board in Prague from their positions as Past President and Director for Patient-Carer Relations. I would like to offer my profound gratitude to both for their valuable contributions over the past years.

Also, I would like to thank Eva Trujillo, who transitioned to Past President, for her great leadership during her tenure as President. I was so fortunate to work closely with her and Carolyn over the past two years to ensure continuity in leadership. Kyle De Young now serves as President Elect. In Prague, we also welcomed two new Board members: Chevese Turner as Director for Patient-Carer Relations and Marisol Perez as Director for Communications.

I very much look forward to continuing working with the additional ongoing Board members: Bryn Austin (Secretary), Guido Frank (Treasurer), Jennifer Thomas (Director for Annual Meetings), Ursula Bailer (Director for Research-Practice Integration), Lauren Muhlheim (Director for Outreach), Jenny Lundgren (Director for Standards of Excellence), and Annemarie van Elburg (Director for Membership).

The Board of Directors heavily relies on and benefits from the AED’s many committee members and co-chairs that support our organization with passion and dedication on a voluntary basis. Their contributions enable the AED to move forward and their great work builds the basis for achieving our ambitious goals - so a huge “Thank You” to all our volunteers!

Speaking of goals, I would like to highlight some of the AED’s current strategic objectives and initiatives. All of them are multi-year projects and part of our long-term strategic plan. Some of the things we want to focus on in 2017-2018 are:

1. **Continue to increase AED’s reach and visibility around the globe.** The AED currently has more than 1,500 members from over 50 countries which is truly impressive - but still not enough! We continue to work toward increasing our membership from all over the world and plan to particularly target countries and regions where there is an absence of professional networks. We also hope to engage many of the over 300 new members who joined the AED in 2017 with our organization for the long term. If you are new to the AED, hello, and welcome! Please let us know how you would like to get involved.
2. Further enhance access to knowledge and training, especially in underserved regions. We plan to make content from future ICEDs available electronically after each meeting so that professionals who are unable to attend the conference may still benefit from the program. In addition, we will further enhance electronic resources that we offer professionals via the website and continue to expand our social media activities. The webinar schedule for the next couple of months looks exciting and I would like to invite you to join one or more of these outstanding remote educational opportunities. If you miss a webinar “live,” as a member, you can go back and “listen and learn” at your convenience by tapping into one of the webinar recordings online. We are working on securing CE and CEU credit for your participation in the U.S. and Europe initially, and elsewhere as appropriate.

We are aware that in order to disseminate resources to underserved regions we need to reduce the language barrier. We created an AED Translation Board comprised of members who volunteered to translate AED materials into their languages to help us plan and implement a multi-lingual dissemination of the best and most current research and practice. You will already find online our important Medical Care Standards Guide, version three, in eight languages, with more in the works. The AED Nine Truths About Eating Disorders has been translated into more than 40 languages - including most recently, Sign Language, and a translation of webinars is currently in preparation.

We are also excited about launching AED’s Emissary Program which will disseminate evidence-based knowledge and training to parts of the world where there are currently no eating disorder experts, to provide training to colleagues on evidence-based care to patients.

3. Further enhance networking. We will continue to develop strategic alliances within and outside the eating disorders field. We are confident that we will see a growing number of Partner and Affiliate Organizations and more Patient-Carer groups (“Friends of AED”) connect with the AED in the coming year. Also, we are excited that at an inaugural meeting in Prague there was broad consensus among members from European countries to initiate an EU Chapter within the AED that will be officially established within the next few months, joining the already active Hispanic Latino Chapter and Nordic Chapter.

We will also enhance networking on the advocacy level in order to gain timely information about active advocacy efforts within the global eating disorder community. Learning about efforts from around the globe, offering support to groups or organizations world-wide, and helping to disseminate their initiatives and achievements will increase global visibility for eating disorder-related advocacy. A survey will go out shortly to assess the needs and priorities of AED members from outside the U.S. to better tailor our support to the challenges they face in their countries.

I look forward to working toward these goals together with the Board, volunteers, and staff over the next year. I am sure that our work will benefit from our diverse perspectives while we are working towards the ultimate shared goal of alleviating the burden that eating disorders put on those affected and on their loved ones! Or, to reiterate the AED vision, we will work together to ensure global access to knowledge, research, and best treatment practice for eating disorders around the world.

Message from the Editor

Welcome to your latest edition of the AED Forum! If you missed ICED 2017, this issue will get you up-to-date on the AED’s members, committees, and partner organizations post-ICED happenings. We also welcome our new President, Steffi Bauer, and her first article in the Forum as president, in which she highlights some of her strategic plans for her tenure as president. The Patient-Carer committee discusses what they consider the “PCC’s most significant project,” the World Eating Disorder Healthcare Rights - a document written in order to promote excellence in care for patient-carer-professional partnerships, and the Research-Practice Integration committee discusses their annual Global Think Tank held at ICED. Finally, newly appointed Forum Book Reviewer, Camden
Jessica Baker, writes a review of Stand Tall Little Girl.

I would like to thank all of the individuals who submitted articles for this issue of the Forum. I also would like to extend a thank you to Anna Ciao, who is the incoming AED Forum Editor and served as Associate Editor for this edition.

I encourage interested readers to submit articles, letters, and announcements for the next issue of the Forum. Please submit your contributions and suggestions to Jessica Baker at Forum@aedweb.org. The deadline for submissions to the next issue of the Forum is November 1, 2017.

Greetings from The Executive Director

Two things happened today that made me clench my teeth in frustration. The first was an email we received from a member of the AED seeking advice on a referral for a patient suffering from anorexia nervosa who had reached a very low weight and was refusing treatment. It brought to the front of my mind patient A.G., a 29-year-old woman with a longstanding diagnosis of anorexia nervosa who sued successfully in the New Jersey Supreme Court for the right to choose palliative care as opposed to force-feeding through a nasogastric tube in conjunction with an experimental program of Ketamine as recommended by the Department of Human Services in New Jersey. She died shortly thereafter.

The second teeth clencher occurred at a meeting at the FDA where almost 80 U.S. Food and Drug Administration professionals heard brilliant presentations from Chevese Turner of BEDA, Claire Mysko of NEDA, and Cynthia Bulik of the University of North Carolina on the importance of considering the impact on patients with eating disorders when reviewing and approving drugs and medical devices to treat obesity. An FDA staffer - a scientist - stood and related his personal frustration as a care-giver for a family member with an eating disorder, who was unable to obtain insurance coverage for treatment and was staggering under the burden of the personal out-of-pocket costs of accessing care.

This was a senior FDA staffer; credentialed, successful, and wired to the medical community. Can you imagine how difficult obtaining coverage for appropriate early intervention and treatment is for the average person? Because you are a part of the AED, if you are in the U.S., you don't have to imagine. You must see this disparity every day.

Those of us in the U.S. were joyfully gratified by the inclusion of eating disorders specifically in the 21st Century Cures Act and the Joint Commission Eating Disorders Care Standards enacted this past year. Morgan Shields, a former STRIPED trainee and now a doctoral student in health care policy at Brandeis University, recently wrote a blog for the online journal Health Affairs about what the 21st Century Cures Act and Joint Commission Eating Disorders Care Standards may or may not be able to do for eating disorders care access and quality of care: How could the 21st Century-Cures Act and the Joint Commission improve eating disorder care. It's a great victory, but there is still so much to be done. As Morgan points out, the “access” is still ambiguous as insurance companies and individual states have wide latitude to interpret the Act. And while the Joint Commission, the primary U.S. body responsible for certifying the competence of institutions providing care, took a huge step last year in implementing a set of 11 new standards for both outpatient and residential eating disorder care, the quality and consistency of that care remains, at best, uneven.

The first step in creating policy change is to get our facts straight. The arguments for better funding for research, and access to evidence based care, are compelling - and they are life and death issues. As a
small community of professional care givers, your resources are already taxed. But your participation in
the public policy arena around access and quality of care is critical to our success as a community.

In the months ahead, the AED will be developing and providing more information and training on advocacy
and on the ways that you can make an impact in your community - and we will be calling on you to
provide insight into developments and relevant issues - whether your community is in Texas, New York,
Argentina, Italy, Japan, Moscow, or somewhere else. We will be issuing some specific requests for help in
assessing and tracking public policy around the world, and we are counting on you to step up to find a
little time to fight these important battles.

E pluribus unum - Together we are something!

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AED Committee Updates

Advocacy and Communications Committee

Emily Pisetsky

The Advocacy and Communications Committee (ACC) of the AED is pleased to inform the membership of our
activities over the past few months.

The ACC wants to thank everyone who participated in the second
World Eating Disorders Action Day (WeDoAct), which took place on
June 2, 2017. We want to particularly thank our outgoing ACC
Co-Chair Kristine Vazzano, who served on the WeDoAct Steering
Committee, for her leadership and organization. Several other
AED members, including Past President Eva Trujillo, also served
on the Steering Committee. The theme of the 2017 World Eating
Disorders Action Day, #WeDoActTogether, focused on partnerships
that move us forward as affected people, carers, clinicians, and
researchers. The goal was to recognize and drive the meaningful
relationships and connections that are vital to recovery from
eating disorders.

Please visit http://www.worldeatingdisordersday.org/ for more
information.

The ACC would also like to welcome our newest members to the committee: Hallie Espel, Rachel Millner, Renee
Rienecke, and Courtney Simpson. We look forward to their involvement in the ACC and to an exciting year
ahead!

The ACC provides regular Forum updates concerning initiatives related to public awareness and advocacy. For
more information about the ACC, please email Alli Spotts-De Lazzer (alli@therapyhelps.us) or Christine Peat
(christine_peat@med.unc.edu), ACC Co-Chairs.

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Patient-Carer Committee
Judy Krasna

It was great seeing so many of you at ICED 2017! The Patient-Carer Committee (PCC) had strong representation at the conference, and we were thrilled to be able to network and promote our committee's activities.

The PCC’s most significant project this year was the World Eating Disorder Healthcare Rights. This document was written as a global blueprint for promoting excellence in care for patient-carer-professional partnerships.

To promote World Eating Disorder Healthcare Rights, I did an AED Twitter Chat with former Social Media Committee Co-Chair Ashley Solomon on the topic of how patients, carers, and providers can collaborate in eating disorder care, which can be viewed here.

I was also given the chance to speak briefly about World Eating Disorder Healthcare Rights at the Partner Chapter and Affiliate Committee (PCAC) event at the ICED, which was very meaningful for me since I live in Israel, which is part of the PCAC. I expressed my personal motivation for developing World Eating Disorder Healthcare Rights, which stems from receiving compromised care for my daughter’s eating disorder due to limited patient and caregiver rights. As a result, not only did my daughter’s care suffer, but our family suffered as well.

It is the hope of the PCC that you will all help us disseminate World Eating Disorder Healthcare Rights so that it becomes widely accepted in practice, because every patient and their family deserves to be treated with respect, and to be included in treatment to the fullest possible degree.

Research Practice Committee

Karen Jennings & Caitlin Martin-Wagar

The Research-Practice Integration Committee would like to thank all who attended our 2017 ICED events in Prague: our workshop on June 9 (Shifting Away from DSM Diagnostic Labels and Towards Dimensional Phenotypes: Will This Make Research More Clinically Useful or Widen the Research-Practice Gap? Let’s Talk About It), and the annual Global Think Tank on June 10. Both sets of panelists facilitated intriguing dialogues about translating research into clinical practice. The diversity of speakers and audience engagement allowed for thought-provoking discussions during and after the sessions.

During the workshop, panelists and audience members discussed new research trends studying brain systems and behavioral phenotypes, and how such research may eventually translate into clinical practice. Further discussion centered on encouraging participants to seek out funding opportunities to continue treatment-oriented research to complement more biologically-focused research.

After describing “evidence-based practice,” the Think Tank focused on experiences of evidence-based practice (or lack thereof) of the panel members and attendees. The panel included a former patient (Jenni Schaefer), a parent/carer (Lisa LaBorde), a clinician (Suzanne Dooley-Hash), and a clinician-investigator (Heather Thompson-Brenner). A lively discussion about barriers to overcoming the research-practice gap helped increase understanding of what members of the AED community feel they need to better integrate research and practice. Access to quality, evidence-based eating disorder treatment was highlighted as a priority by panelists and many attendees. Overwhelmingly, researchers, clinicians, and patients/family members alike were enthusiastic about further integrating research and practice.

We hope that these discussions help foster practice-research collaborations and promote the transfer of knowledge among all stakeholders of eating disorders treatment.
We are still coming down from the excitement ICED 2017 held in the beautiful city of Prague. It's safe to say the Social Media Committee (SMC) had a noticeable presence at the conference. The conference hashtag #ICED2017 was even trending on Twitter! We sent hundreds of diverse tweets, allowing people following the hashtag to experience many aspects of the conference. Hopefully, this instilled curiosity in some who will consider joining our next conference.

On the first official day of the conference, the SMC held our annual Tweet Up - Tweet Out, attracting over a dozen participants. This was an opportunity for people to network and share how they use social media professionally.

This year was the first that the SMC featured broadcasts via Facebook Live from specific events. These videos received hundreds of views and offered snapshots of the conference for attendees and those unable to attend.

Additionally, two members of the SMC were among four presenters at a workshop about creating dialogues in the eating disorders field through social media engagement. This workshop provided an excellent opportunity to learn more about social media platforms and interactions from presenters and audience discussion.

As with most events, not all of the SMC's grandiose ideas about projects during the conference materialized. However, the projects that did were a great success, which was rewarding to experience, and they provided new insights and opportunities to improve for future conferences.

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**Association Updates and Other News**

**Book Review Corner**

*Camden Matherne, AED Book Reviewer*

*Stand Tall Little Girl* written by Hope Virgo (Trigger Press, 2017, 145 pages).

Patients of mine often struggle with expectations for recovery - I often hear comments like, "How do I recover? I feel like I need a roadmap. Shouldn't I feel better?" At times, patients even express frustration at the positive accounts of recovery they read or hear about, as the road to recovery is often bumpy and winding, and the day-to-day walk is hard. In *Stand Tall Little Girl*, Hope Virgo provides an honest look into the development of her eating disorder (anorexia nervosa) and her battle through recovery, including her experience in inpatient care, adjustment to life outside of the hospital, and continued recovery following a relapse. Hope's narrative is complemented by excerpts from her journal detailing her daily mindset and commentary from her mom, which juxtaposes Hope's experience with that of her family.

Hope begins her story by providing background detail into her intrinsic nature and formative years. She self-describes as "rebellious," but notes dispositional anxiety and an innate tendency to help and please others. Hope discusses an early sense of body image dissatisfaction that even baffles her - she finds it hard to understand how her schoolmates feel comfortable at a swimming party, while she wants to hide in a t-shirt and shorts. She also paints a vivid picture of her experience of familial distress - complete with frequent marital conflict, concern for her siblings, and a sense of inadequacy and helplessness in bettering her world for herself and those she loves. This sets the stage for the arrival of Hope's eating disorder, which is kicked off by weight loss during a period of sickness after
Hope's description of treatment gives the reader an in-depth view into her mindset as she begins in outpatient treatment and progresses to an inpatient setting. She describes her eating disorder's rebellion to the pressures of treatment and increased parental supervision, and describes in detail the many "tricks" she uses to maintain her eating disorder during this process, including initiation of purging behavior. Hope's descriptions are at times difficult to read - her pain is raw, and you see her eating disorder quickly spiraling out of control. Hope's experience is complimented by that of her mom, who describes the difficulty of watching Hope deteriorate, and arriving to the point of realizing that inpatient care is needed. While Hope spends a year in the hospital, her mother struggles to manage the other children at home and her volunteer responsibilities, all while regularly travelling an hour to and from the hospital to visit Hope. Hope's mom's narrative served as a good reminder of how incredibly destructive eating disorders are to family life.

The turning point in the book comes during Hope's inpatient admission, when, with the help of hospital staff and her individual therapist, she begins to view her eating disorder in a different light - "I was beginning to learn that my Anorexia hadn't really been my friend... she had destroyed me. She had had made me think she was helping me, but she wasn't." From this point forward, Hope engages in battle. Her diary entries detail that battle, including slips, ambivalence for change, and eventual re-commitment to recovery. What I loved most about Hope's progress in recovery is how she gradually learns to let others back in - both emotionally and logistically - to support her in recovery. This transition is most evident following Hope's relapse that is triggered by her grandmother's death several years after Hope is into her recovery. We see how easily Hope's eating disorder re-enters her life to help her manage the pain of her grandmother's death, and it even takes Hope to a place of contemplating suicide. Ultimately, Hope reaches out to a friend, then more friends, family, professionals, and eventually co-workers, to help keep her accountable in her recovery.

Hope's progress in recovery is not perfect - as I often tell my patients, there is no perfect recovery. Hope describes her many slips and use of ineffective coping along the way - running excessively to manage anxiety and using alcohol to make up for caloric deficit, among others. And, there are times when I didn't agree with Hope - for example, when she asserts her belief that mental illness is not biological. Overall, however, I really enjoyed reading Hope's story - it is real, it is raw, and ultimately it is successful. It provides a realistic account of one person's experience in illness and recovery. Hope wraps up her story by noting the ways she wants to continue in her recovery - she is introspective about her progress, she describes the coping skills that keep her on track, and she states her desire to continue challenging herself to be more flexible. A word of caution - Hope describes her pre-recovery behaviors in vivid detail. This book is written for individuals who are stable enough in their recovery that exposure to these descriptions would be motivational in nature, rather than triggering of new eating disorder behaviors. Hope's story is also a good reminder for providers and parents alike that recovery from an eating disorder is an uphill battle that requires persistence and support. Of note, Stand Tall Little Girl is part of the Pulling the Trigger book enterprise that aims to increase discussion about mental illness and support recovery efforts. The series includes a number of support and recovery books founded in a cognitive-behavioral and compassion-based approach as well as inspirational books for individuals trying to recover from mental illness.
An Evening Unmasking Eating Disorders, featured special guests Trojan Bellisario, Janet Mock, Iskra Lawrence, Jaimie Alexander, Jasmine Poulton, and many more. NEDA was also honored to recognize Hillary Clinton with the Lifetime Achievement Award.

In partnership with Facebook, NEDA continues to grow their Crisis Support Over Messenger feature. Users can chat live with a trained Helpline volunteer directly through Facebook Messenger. Since launching this new channel, NEDA has seen a 30% increase in contacts to the Helpline.

Visit Facebook.com/NationalEatingDisordersAssociation to learn more and connect with a volunteer.

NEDA is also busy preparing for their 2017 Fall walks season. NEDA Walks raise awareness and funds for the fight against eating disorders and build local communities of support and recovery. Walks will be held in cities across the country including Denver, CO (9/24), New York, NY (10/1), Portland, OR (10/7), Central NJ (10/14), Charleston, SC (10/14), Milwaukee, WI (10/14), Chicago, IL (10/15), Houston, TX (11/4), San Francisco, CA (11/4), and Sacramento, CA (11/18). Find the full schedule of NEDA Walks at NEDAWalks.org. We hope to see you at a walk in your community!

Upcoming Conferences, Meetings, and Seminars

The Australia & New Zealand Academy for Eating Disorders invites you to attend its 15th annual conference, being held on the iconic Sydney Harbour on September 1-2, 2017, with the theme Creating Connections, Harbouring Knowledge.

Keynote speakers are Dr. Josie Geller, University of British Columbia, and Kate Carnell AO, leading Australian business administrator. There will be two conference plenaries: Harbouring Knowledge from Beyond the Field of Eating Disorders, with expert speakers from the body dysmorphic disorder, gender dysphoria, and complex trauma fields, and Eating Disorders and Obesity - Connections and Controversies. In addition, there will be 16 introductory and specialist professional workshops covering prevention, early intervention, group work, family work, neuroscience of eating disorders, dietetics, treating adolescents, severe and enduring conditions, body dysmorphia, and more. Plus, there will be one carer and clinician workshop by Dr. Geller! The conference will also include over 100 short oral presentations and posters and special interest meetings. The social event highlight will be a cruise on Sydney Harbour.

Please see the conference website for details or email conference@anzaed.org.au.

XXIIIrd Annual Meeting of the Eating Disorders Research Society
University of Leipzig - Campus Augustusplatz
Leipzig, Germany
September 14-16, 2017

Jubilaumskongress Essstörungen 2017
Eating Disorders Alpbach 2017
Anorexia & Bulimia Nervosa, Binge Eating Disorder, Adipositas / Obesity
The Jubilee 25th International Conference
19-21 Oktober 2017
Alpbach, Tyrol, Österreich / Austria
Open to sufferers, carers, and professionals
info@netzwerk-essstoenungen.at
www.netzwerk-essstoenungen.at
Join us in the "Big Apple" for a very special program focused on collaboration in the interest of the greater good. The aim of BEDA and NEDA's partnership is to bring together the voices of the many groups and individuals who are collectively a part of the eating disorders community. We believe that together we will take larger steps and make more progress in fighting these serious illnesses than when we stand apart.

Questions? Call 855.855.2332, ext 3.

Join AED in Chicago to celebrate our Silver Anniversary and ICED 2018, April 19-21.
You can make your hotel reservations and submit an abstract for consideration for presentation before September 2nd via this link.