

NEDA's 1st Annual Congressional District Advocacy Day Message Training

Katrina Velasquez, Esq., MA
NEDA's Washington, DC Representative

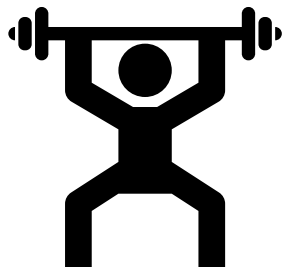


Objectives for this Training

- Truth about Advocacy
- NEDA's Policy Focuses
 - Eating Disorders Prevention in Schools Act
 - NIH Research Funding
- The “Pitch”
- Meeting Structure
- Personal Story(ies)

The Truth About Advocacy





You have the power!

**As a “constituent”, you are the
Member of Congress’ “Boss”**

Sharing your personal stories can change hearts, federal stigma, and policy

www.nationaleatingdisorders.org



**54% OF CONGRESSIONAL STAFF AGREE
THAT AN IN-PERSON VISIT FROM A
“CONSTITUENT” HAS THE MOST
INFLUENCE COMPARED TO OTHER
FORMS OF ADVOCACY**

- Congressional Management Foundation, 2015 Perceptions of Citizen Advocacy

Congressional Staff Rank Effectiveness



**Most Positive
Influence is In-Person
Visits**

1. In-person Constituent Visit- 54%
2. Personalized Emails- 30%
3. Letter to the Editor Referencing Member- 22%
4. Comments During Telephone Town Hall- 18%
5. Form Email Message- 3%

Preventing Eating Disorders at the School Level

Eating Disorders Prevention
in Schools Act



Eating Disorders Start Young, but Federal Law Only Focuses on Obesity

- Studies show large numbers of students meet criteria for high eating disorder risk or warrant clinical referral:
 - 58% of students living in high weight bodies
 - 34% of normal weight students
 - 25% of underweight students
- **1M adolescents every month** resort to weight-control behaviors; and **2/3rds of children living in high weight bodies** are at-risk of developing an eating disorder or engaging in unhealthy weight control practices
- Many federal policies require school programs for nutrition education and obesity prevention, **but do not include** the other side of the coin- **eating disorders prevention**

If passed, Local School Wellness Policies (LSWPs) would...

1. Require “eating disorders prevention” inclusion
2. Encourage screening for eating disorders
3. Include mental health experts within the development of LSWPs and Training & Technical Assistance provided to schools (through SAMHSA)

Eating Disorders Prevention in Schools Act Leads

Congresswoman Alma Adams
(D-NC-12)

Republican TBD



www.nationaleatingdisorders.org



Original Co-Sponsor the Eating Disorders Prevention in Schools Act

First Request of your Member of Congress

www.nationaleatingdisorders.org

Increasing Eating Disorders Research Funding

FY 2021 NEDA National Institutes of
Health (NIH) Spending Bill Request



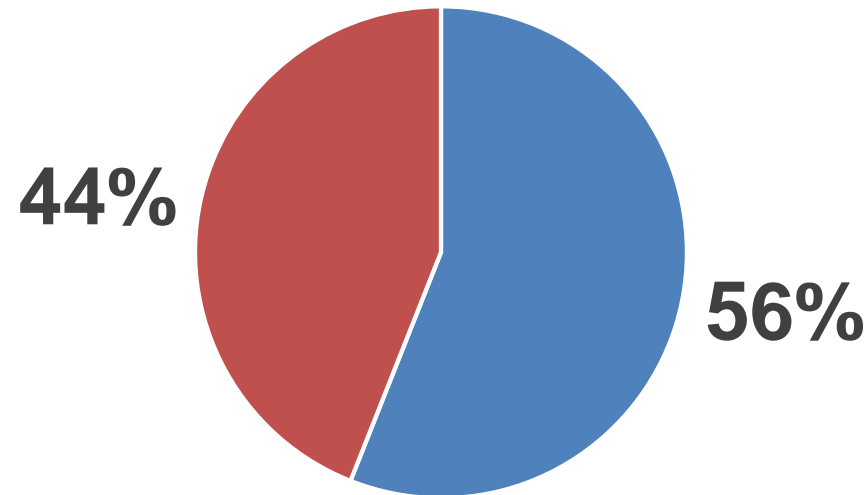


THE AVERAGE AMOUNT OF RESEARCH DOLLARS SPENT PER AFFECTED PERSON WAS JUST \$0.93 FOR EATING DISORDERS, COMPARED TO \$81 FOR SCHIZOPHRENIA AND \$44 FOR AUTISM

National Institutes of Health, 2011

NIH Eating Disorders Research Averages \$32M between 2015-2018

NIH Eating Disorders Funding Breakout



- National Institute of Mental Health (NIMH)
- Other 16 NIH Institutes Studying Eating Disorders like NIDDK

www.nationaleatingdisorders.org

Requesting More Research Funding Within FY21 “Spending Bill”

1. Highlights the severity of eating disorders and that multiple institutes study eating disorders
2. Emphasizes existing gaps in research
3. Strongly urges NIH to increase ED research funding across multiple institutes/centers including NIMH
4. Directs NIH to provide a report of what they do for FY 2021

Congressional Leaders of NIH Research Funding Request

House of Representatives:

- Rep. Kendra Horn (D-OK)
- Rep. Brian Fitzpatrick (R-PA)



Rep. Horn



Rep. Fitzpatrick

Senate:

- Sen. Tammy Baldwin (D-WI)-
Committee
- Sen. Amy Klobuchar (D-MN)



Sen. Baldwin



Sen. Klobuchar

“The Pitch” for Congressional District Advocacy Day



What to Expect

- Meetings will be 30 minutes or less, be on time
- Congressional staff may be young and have a limited attention span
- Conference rooms may not be fancy
- For Friday meetings, the Member of Congress may swing by
- Congressional staffers may not hold the exact political beliefs as the Member of Congress

Step-by-Step Meeting ~30 Minutes to Pitch~



- Introductions
- Eating Disorders 101
- Personal Stories
- Policy Pitches
 - Issue; Solution; Request
- Questions

Step 1: Introductions

1. Introduce yourself as NEDA Advocates-
 1. “We are advocates with the *National Eating Disorders Association. NEDA is the leading non-profit organization in the U.S. supporting individuals and families affected by eating disorders*”
2. Everyone in attendance introduces themselves:
 1. Full Name
 2. Where you Live (City within the Congressional District)
 3. Your profession (i.e. student, mom by day/superhero by night, researcher, etc.)

Step 2: Eating Disorders 101

- Remember: You likely know more about eating disorders than your Member of Congress' Congressional “staffer”
- Keep it Basic and Explain Eating Disorders...
 - Are a **serious mental illness** that affect **30 million Americans** during their lifetime
 - Have the **second highest high mortality rate out of any psychiatric illness**, with one person losing their lives every 62 minutes as a result of an eating disorder
 - **Don't discriminate**, and affect all genders, ages, races, ethnicities, socioeconomic classes, and sexual orientations
 - Are **bio-psycho-social** illnesses, making them very complex to treat, and have co-occurring medical and mental conditions such as diabetes, PCOS, substance use, PTSD, amongst a list of others

Step 3(a): Eating Disorders Prevention in Schools Act Policy

Issue

- **Hand the Infographic to the Staffer**
- Eating Disorders and disordered eating habits begin young
- 1M adolescents/month partake in weight-control behaviors
- High numbers of students are at high-risk of/warrant clinical referral for ED- 58% HWB, 34% normal weight, 25% underweight
- However, our School Wellness Policies only require nutrition education and obesity prevention

Solution

- Including eating disorders prevention within school wellness policies will help to prevent eating disorders early
- Bipartisan ED Prevention in Schools Act led by Rep. Adams (D-NC)/Rep. TBD (R-) will:
 - Require ED prevention within school wellness policies
 - Encourage screening for EDs
 - Ensure mental health experts are included in the development of and training/technical assistance for LSWPs



Original Co-Sponsor of the Eating Disorders Prevention in Schools Act

First Request of your Member of Congress

www.nationaleatingdisorders.org

Step 3(b): Increase NIH Research Funding Policy

Issue

- **Hand the Infographic to the Staffer**
- Eating Disorders research has historically been **underfunded** despite the **high prevalence rate, high mortality rate, and highest treatment cost compared to other psychiatric illnesses**
 - NIH spends 0.11% and NIMH 1.27% on eating disorders research
- However, NIH has recognized the complex need for eating disorders research, with 44% of funding coming from NIH institutes outside of NIMH

Solution

- Congressional pressure to increase eating disorders research funding in multiple Institutes
- Bipartisan effort in the House of Representatives from Rep. Horn (D-OK)/Fitzpatrick (R-PA) to:
 - Strongly urge NIH to increase eating disorders research funding through **Committee Report Language** within the FY 2021 Spending Bill, and
 - Direct NIH to provide a follow-up report on their actions to increase funding



**Sign-on to the FY21
Appropriations Letter to Increase
Eating Disorders Research
Funding by March 6th**

Second Request of your Member of Congress

www.nationaleatingdisorders.org



**STEP 4: TELL YOUR
PERSONAL STORIES**

Telling Your Personal Story: Dos and Don'ts

- **Limit story to 2-3 minutes, Practice Makes Perfect**
- **Include details about how it affected your life**
 - I.e. missed work, poor grades, distant from family, had to quit hobby
- **Loop in details about your Congressional District**
 - i.e. Bob's Middle School tested our BMI during gym class, and that's when I started dieting
- **Connect your story to the “policy asks”- prevention in schools or more research**
- **Keep the #s at home; telling story responsibly**
 - Instead of: “I purged X times a week”
 - Try: My ED behaviors were so out of control that I didn't have time for anything else (social life, family, friends, work, school, hobbies, etc.)

Step 5: Final Ask & Questions

- “As you’ve heard from these personal stories, it is so important that we work to prevent eating disorders in schools and fund more research.
- We ask that our Representative:
 - Co-sponsor the Eating Disorders Prevention in Schools Act
 - And**
 - Sign-on to the FY21 Appropriations letter to increase eating disorders research funding
- NEDA will be following-up with all materials

www.nationaleatingdisorders.org

Final Tips

- Be nice and build a relationship with the staffer
- Be on time, and call if you will be late
- Stay bipartisan, not all staff share the same political beliefs as their boss
- Pause between each section
- Take their “cues”
- If more than one person attending, take notes
- Send short “thank you” email after the meeting

Next Steps



Next Steps from NEDA:

- ✓ Send Advocacy Day Materials to Advocates by Feb. 20th:
 - ✓ Infographic for Eating Disorders Prevention in Schools Act
 - ✓ Infographic for Increasing NIH Eating Disorders Research Funding
 - ✓ Congressional Sign-on Letter for Increasing NIH Eating Disorders Research Funding
 - ✓ **Internal for you: Cheat Sheet**
- ✓ Send Advocates Survey follow-up survey by Feb. 28th
- ✓ Help advocates with any questions
- ✓ Follow up with all Congressional offices after meetings

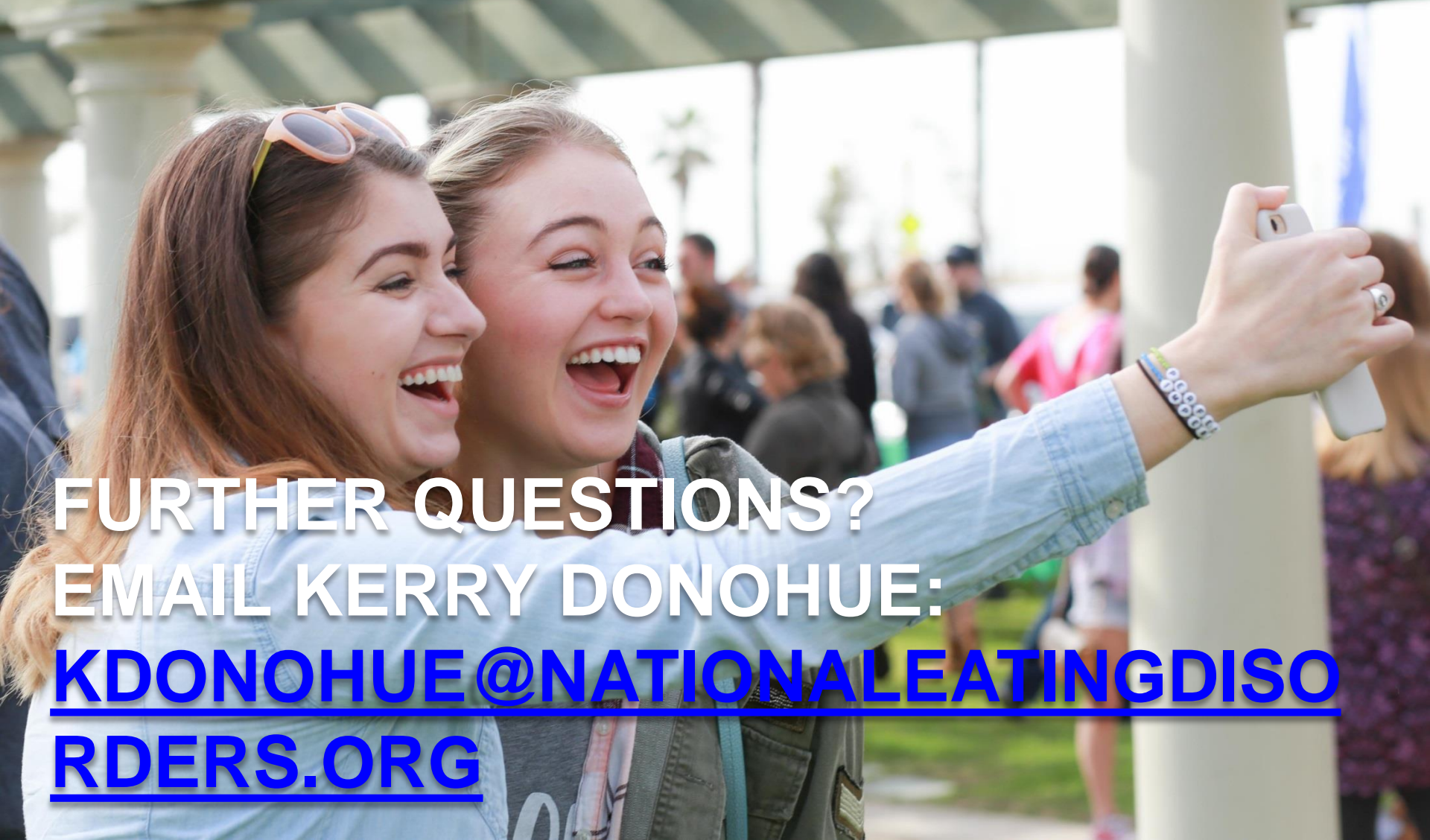
www.nationaleatingdisorders.org

Next Steps for Advocates:

- ✓ **If you scheduled the meeting:**
 - ✓ Send an email confirmation to the staffer
 - ✓ If you have other advocates joining your team, ensure they know where and when to meet
 - ✓ *Recommend meeting 30 minutes prior to get to know one another*
- ✓ Print 2 copies of the 2 Infographics and Appropriations Letter
- ✓ Practice the Policy Pitch
- ✓ Practice your Personal Story
- ✓ Send a short “thank you” email after the meeting
- ✓ Complete the NEDA survey following the meeting
- ✓ **Day of: Take Pictures and use #NEDAwareness**

Questions?





**FURTHER QUESTIONS?
EMAIL KERRY DONOHUE:
KDONOHUE@NATIONALEATINGDISORDERS.ORG**

www.nationaleatingdisorders.org