

# **Join Us In The Fight Against Eating Disorders!**



## **Federal Lobby Day**

Washington, DC

# Welcome to Federal Lobby Day!

We're so glad that you've joined us on this important day!

This is our chance to educate our representatives about eating disorders and the need for legislative action.  
Enclosed please find:

1. The team assignments and schedule for today's appointments (To Be Supplied on 10/10)
2. Legislator information - know your audience! (To Be Supplied on 10/10)
3. Leave-behind packets for legislative offices (To Be Supplied on 10/10)
4. Background information: Why are we here?
5. Tips for meeting with legislators
6. Talking points for meetings
7. Answers to possible questions from legislators
8. Notes from meetings

## NEDA thanks our Federal Lobby Day 2013 Partners:

### Co-Sponsors:

- Academy for Eating Disorders (AED)
- International Academy of Eating Disorders Professionals Foundation (iaedp)

### Community Partners:

- The Anxiety and Depression Association of America
- Eating Disorder Foundation, Colorado
- Eating Disorder Hope
- Eating Disorder Network of Maryland (EDN-Maryland)
- The Elisa Project
- Fairwinds Treatment Center
- Girl Zone
- Helping Other People Eat (HOPE)
- Maudsley Parents
- National Association of School Psychologists
- Newton-Wellesley Eating Disorders
- Project HEAL
- Residential Eating Disorders Consortium (REDC)
- Rhode Island Eating Disorder Association
- Rock Recovery
- Shoreline Center for Eating Disorder Treatment
- Someday Melissa
- T.H.E. Center for Disordered Eating
- Tri-State Eating Disorder Resource Team

## **BACKGROUND: Why are we here?**

The prevalence of eating disorders is high. In the United States, 20 million women and 10 million men will suffer from a clinically significant eating disorder at some time in their life. The rate of development of new cases of eating disorders has been increasing since 1950.

Eating disorders can have a devastating impact on health, causing severe, chronic illness and even death. Eating disorders impact every organ system in the body, including cognition. They can result in such medical conditions as retarded growth, osteoporosis, kidney problems, ulcers and heart failure. Anorexia has the highest premature fatality rate of any mental illness.

## **What are we asking for?**

**Today, we are asking the following:**

If they are a member of the House, invite him/her to:

- Join the National Eating Disorders Awareness Caucus, whose current initiative is to request a research study from the GAO (Government Accountability Office). The request has been written and approved by Rep. Ellmers and Rep. Lowey, the co-Chairs of the Caucus, and it spells out the questions pulled from the FREED Act, as pertains to research.
- Sponsor/co-sponsor the Mental Health Improvement Act of 2013 House version (updates to come)
- Co-sponsor and vote yes on the Federal Response to Eliminate Eating Disorders (FREED) Act of 2013.

If they are a member of the Senate, invite him/her to:

- Send a letter requesting a research study from the Government Accountability Office (GAO) (there is no formal Caucus in the Senate)
- Co-sponsor S.562, the Mental Health Access Improvement Act of 2013 Senate version

## **Why are these initiatives necessary?**

**Lack of adequate treatment negatively impacts recovery.** Only 1 in 10 men and women with eating disorders receive treatment. Only 35% of people who receive treatment for eating disorders get treatment at a specialized facility for eating disorders, this is despite the fact that with appropriate treatment the mortality rate decreases from 20% to only 2-3%. In a recent poll, individuals and families affected by eating disorders **reported that cost of care and insurance coverage were the top factors impeding successful recovery.** Early detection and treatment provide the best outcomes for those suffering with an eating disorder.

**Despite the prevalence of eating disorders, they continue to receive inadequate research funding.** Research dollars spent on Alzheimer's Disease averaged \$88 per affected individual in 2011. For Schizophrenia the amount was \$81. For Autism it was \$44. For eating disorders the average amount of research dollars per affected individual was just \$0.93.

## Tips For Meeting With Legislators

The following points will help you to most effectively lobby while in your meetings today. This is your chance to ask your government to support something that is important to you and vital to others around the country. Follow these steps and you are sure to make a lasting impression!

1) Determine your goal.

What do you want from your legislator(s)? Go in with your clear, one sentence message in mind.

2) Do your homework – be informed about the lawmakers you are visiting.

Refer to the legislator information page in this packet. Before each meeting, read up on the lawmakers you are meeting with. Find out what committees they are on, what party they belong to, what their areas of interest are and areas of influence. Have they been involved in health, mental health or eating disorder issues in the past? These are very important things to know, so that you can take the legislators' knowledge base and stance into account when you address them.

3) Be informed about the issue.

Be sure to read the fact sheet and talking points in this packet. Be able to talk about how the legislators' constituents will benefit from the action you want taken.

4) Be courteous with the legislative staff.

It's the right thing to do. They should want to be helpful to serve constituents, but, also, please know that they can often be helpful and influential to your cause! In some cases, you may be meeting with staff rather than the actual legislator. This is OK. Staff can be very influential.

5) Be concise and to the point.

Be brief and focused. This is not an opportunity to lay out a laundry list of problems or to be long-winded. Go in with a clear agenda that is specific. Only 3 things need to be covered:

- 1) Who you are and why you are there;
- 2) What you want from the legislator (what bills you would like him/her to support); and
- 3) Why the legislator should care.

6) Use personal stories.

Personal stories capture attention. Most legislators went into office because they genuinely want to help people; let them know how they can help.

7) Educate the legislator in a polite, non- combative manner.

You probably know more about eating disorders than the legislators. It is our job to educate them so that they can be our voice for change. Provide the legislators you visit with fact sheets.

8) Don't forget to thank them! Please send a letter or making a phone call in the days following.

9) It is always best to leave before they ask you to leave ☺.

## TALKING POINTS

### Message:

House members: "Please join the National Eating Disorders Awareness Caucus in order to request a study from the Government Accountability Office."

Senate members: "Please send a letter requesting a study from the GAO" (there is no official Senate Caucus)

- *The House Caucus is co-chaired by Congresswoman Nita Lowey (D-NY) and Congresswoman Renee Ellmers (R-NC):*

Current members: Nita Lowey (D-NY), Renee Ellmers (R-NC), Alcee Hastings (D-FL), Ted Deutch (D-FL), Carolyn McCarthy (D-NY), Richard Hanna (R-NY), Gerry Connolly (D-VA), Lynn Jenkins (R-KS), Henry Waxman (D-CA), Charles Rangel (D-NY), and Ed Whitfield (R-KY).

- *Eating disorders are real, complex, and devastating conditions that can have serious consequences for health, productivity, and relationships.*

In the United States, 20 million women and 10 million men suffer from a clinically significant eating disorder at some time in their life, including anorexia nervosa, bulimia nervosa, binge eating disorder, or an eating disorder not otherwise specified (EDNOS) (Wade, Keski-Rahkonen, & Hudson, 2011).

A review of nearly fifty years of research confirms that anorexia nervosa has the highest mortality rate of any psychiatric disorder (Arcelus, Mitchell, Wales, & Nielsen, 2011).

- *Americans recognize that eating disorders are serious illnesses, and want their representatives to encourage awareness.*

According to a national survey conducted in 2010, 82% percent of respondents believe that eating disorders are a physical or mental illness and should be treated as such, while 80% believe conducting more research on the causes and most effective treatments would reduce or prevent eating disorders

The National Eating Disorders Awareness Caucus's mission is to increase national awareness about eating disorders and support those who suffer by seeking to enhance prevention, facilitate therapeutic advances and improve access to treatment.

- *Despite the prevalence of eating disorders, they continue to receive inadequate research funding.*

Research dollars spent on Alzheimer's Disease averaged \$88 per affected individual in 2011. For Schizophrenia the amount was \$81. For Autism \$44. For eating disorders the average amount of research dollars per affected individual was just \$0.93 (National Institutes of Health, 2011).

The current initiative being pursued by the Caucus is to ask the Government Accountability Office to conduct research on eating disorders. This request is set to be submitted in the following days, and the results of the study will be crucial in helping to advance our field on all levels.

In the Senate, a similar letter will be sent to the GAO requesting this study. Please show your support by sending a letter.

**Message:**

House members: “Please sponsor/co-sponsor and vote yes on The Mental Health Access Improvement Act of 2013”

More information to follow but we have a tentative sponsor, will know more soon.

Senate members: “Please co-sponsor and vote yes on S562, The Mental Health Access Improvement Act of 2013.”

**What it does:** This legislation, sponsored by Senators Ron Wyden (D-OR) and John Barrasso (R-WY), amends title XVIII of the Social Security Act (Medicare) to provide for coverage of marriage and family therapist services and mental health counselor services under Medicare part B. NEDA is working diligently on a companion bill in the House, and we are very close to securing a sponsor.

**NEDA has made a commitment to the American Mental Health Counselors Association should this legislation pass, to help provide support and trainings through our field of experts in the area of eating disorders.**

**Why to support it:**

- *This bill expands access to care for millions of Americans with mental illnesses:*

Millions of people with mental illness rely on Medicare as a health and economic lifeline. About 26% of all Medicare beneficiaries (more than 13 million Americans) experience some mental disorder every year.

Mental illness is especially prevalent among beneficiaries who are under 65 and eligible for Medicare based on their disability. Six out of 10 Medicare recipients under age 65 were diagnosed with a mental disorder.

- *As the Medicare population is growing rapidly, we need good cost-effective measures to keep spending low:*

The more access to mental health services that Medicare subscribers have available, the less likely they are to put off seeking treatment until they require expensive hospitalization or long-term care.

Private sector health plans have covered licensed professional counselors for many years, because they recognize that counselors are cost-effective providers of mental health services.

- *MHCs and MFTs fill a large gap in access to mental health care:*

About 50% of rural counties have no practicing psychiatrists or psychologists. MHCs and MFTs are often the only mental health providers in many communities, yet they are not recognized as covered providers within the Medicare program.

MHCs and MFTs represent over 40% of today’s licensed mental health practitioners.

- *Training for Mental Health Counselors and MFTs is comparable to LCSWs, but Medicare does not cover them:*

	<b>Licensed Mental Health Counselor</b>	<b>Licensed Clinical Social Worker</b>	<b>Licensed Marriage and Family Therapist</b>
<b>Education</b>	Possesses a master’s or doctoral degree in mental health counseling or a related field	Possesses a master’s or doctoral degree in social work	Possesses a master’s or doctoral degree which qualifies for licensure as a marriage and family therapist pursuant to State law
<b>Experience</b>	Two years of post-graduate supervised mental health counselor practice	Two years of post-graduate supervised clinical social work experience	Two years of post-graduate clinical supervised experience in marriage and family therapy
<b>Licensure Requirement</b>	Licensed or certified as a mental health counselor within the State of practice	Licensed or certified to practice as a clinical social worker by the State in which the services are performed	Licensed or certified as a marriage and family therapist within the State of practice
<b># of State-licensed providers</b>	~120,000	~200,000	~55,000
<b>Covered by Medicare?</b>	No	Yes	No

Message:

House members: “Please co-sponsor and vote yes on the FREED Act, H.R. 2101”

**What it does:** This legislation, introduced by the Eating Disorders Coalition and sponsored by Representative Ted Deutch (D-FL), would greatly improve the lives of those with eating disorders in America through various initiatives:

Research:

1. Know the prevalence of eating disorders through a national data base and other initiatives.
2. Know the death rates associated with these illnesses
3. Know the costs or “economic burden” of eating disorders on the country
4. Establish Centers of Excellence

Access to care:

1. All insurers who provide health coverage for physical illness must provide coverage for EDs
1. Requires insurers to follow standards of care mapped out by the American Psychiatric Association
2. Allows for the coverage of comprehensive treatment approaches in settings appropriate to the patient’s needs

Education:

1. Study mandatory BMI reporting in school
2. Grant program for the training and education of health and school/higher education professionals
3. Educate the public through Public Service Announcements
4. Bring eating disorders into already existing obesity initiatives

**Why to support it:**

- *Limited access to quality care can be extremely harmful for those with an eating disorder:*

About 80% of the girls/women who have accessed care for their eating disorders do not get the intensity of treatment they need to stay in recovery – they are often sent home weeks earlier than the recommended stay.

Delayed, inadequate, and truncated care has contributed to rates of relapse that range from 25-50%. Without treatment, up to twenty percent (20%) of people with serious eating disorders die.

- *The cost of care and burden on individuals and families is enormous:*

The treatment of an eating disorder in the US ranges from \$500-\$2000 per day.

The average cost for a month of inpatient treatment is \$30,000. It is estimated that individuals with eating disorders need anywhere from 3-6 months of inpatient care.

Families are all too often forced to choose between bankruptcy and their loved one’s life.



- *Training for both school and medical professionals could improve early detection and intervention of eating disorders:*

Due to lack of understanding, medical professionals are often not equipped to recognize or intervene as appropriate, and this oversight can lead to severe, chronic, even deadly, conditions.

Studies have demonstrated a link between early intervention and treatment outcome.

Physicians are beginning to understand the need for training to treat patients in the community. In February 2012, the American Medical Association's (AMA) released its latest online course, Screening and Managing Eating Disorders in Primary Practice in an attempt to train more medical professionals on eating disorders. The course – the first of its kind - provides a basic diagnostic overview of the range of eating disorders and briefly describes the role of the primary care physician in treating patients with eating disorders. However, more needs to be done to promote this type of training. The FREED Act will fund grants to train these professionals on eating disorders.

The majority (73 to 88%) of adolescents with ED reported some contact with service providers, such as mental health specialty care, school services, or general medical services.



## **Possible questions from legislators**

### What will the Mental Health Access Improvement bill cost?

There are no appropriations that come along with this bill, so there are no direct costs should it be signed into law. We do not have an exact estimate with regard to Medicare payouts, but we do know that this bill is cost-effective. Giving individuals access to mental health care will help to prevent their illnesses from becoming entrenched, which may require extensive and expensive hospitalization down the road.

### What Does the Mental Health Access Improvement bill have to do with eating disorders?

A number of people with eating disorders are on Medicare, and in some rural regions of this country, mental health counselors are the only mental health resources available. We need to ensure they are included in the Medicare coverage. In addition, we are committed to work with the American Mental Health Counselors Association to provide support, information and trainings to their members for the area of eating disorders.

### What will the FREED Act cost?

This bill, if passed, will be cost-effective in that medical professionals will be better able to identify and treat eating disorders, which will help to prevent the illnesses from progressing. It will also expand access to care so that more preventative measures will be covered, before more expensive medical attention is required. The FREED Act does have a large dollar amount for appropriations, but it is an all-encompassing bill that will help to make eating disorders a thing of the past.

### Aren't eating disorders a choice? Why don't people with eating disorders just eat?

Eating disorders are complex, serious illnesses. Up to 83% of them have been found to be biologically based, that means there is a genetic component that makes someone vulnerable to an eating disorder. We believe that genetics load the gun and culture pulls the trigger, meaning our culture makes it very difficult to resist this genetic predisposition. Considering the havoc that eating disorders wreck on people's lives, there is no way someone would choose an eating disorder.

### Who gets an eating disorder? Doesn't it affect only young women?

Research shows that all ages, races, genders are affected. It skews 90% female and 10% male, but the incidence in males is growing.

### I don't see a need.

There are 10 million men and 20 million women who suffer from an eating disorder in America.

### Don't Insurance Companies cover eating disorders already?

Insurance company coverage for an eating disorder depends upon each person's mental health policy. Typically mental health conditions are authorized for 5 – 10 days of treatment which is insufficient for eating disorders.

The American Psychiatric Association (APA) has developed treatment guidelines based on research, best practice and expert opinion. According to these guidelines use of the full spectrum of integrated care including inpatient, residential, partial hospitalization, intensive outpatient and outpatient services is necessary for many individuals to obtain full recovery. Insurance companies do not fully comply with these guidelines and often follow their own criteria to certify

insurance coverage. This means the insurance company determines medical necessity against the advice of eating disorders treatment teams.

While it is typical to receive some insurance coverage for an eating disorder, rarely do those suffering get enough coverage for sufficient treatment to get well. Denial of treatment while a patient is partially through their treatment is extremely difficult for patients and families. Relapse is common when treatment is stopped early.

What type of research will the GAO be doing if requested by the members of Congress?

Letter to be submitted:

Gene L. Dodaro  
Comptroller General of the United States  
U.S. Government Accountability Office  
441 G Street, NW, - Room 7100  
Washington, DC 20548

Eating disorders - such as anorexia, bulimia, and binge eating disorder - include extreme emotions, attitudes, and behaviors surrounding weight and food issues. They are serious emotional, mental, and physical problems that can have serious health and even life-threatening consequences for people regardless of gender, age, race, etc. Eating disorders directly or indirectly impact each and every one of us.

We, the undersigned members of the National Eating Disorders Awareness Caucus, are writing to request that the Government Accountability Office (GAO) undertake a review of the prevalence, mortality rate, and economic impact of eating disorders in the United States.

Specifically, we request that GAO's examination look into three areas:

- Who and how many people suffer from eating disorders?
- What is the mortality rate resulting from eating disorders?
- What is the economic impact of eating disorders in the United States?

Attached we have included a list of specific questions we would like answered so that we as a caucus, as well as a nation, have a better understanding of how individuals as well as our economy, are affected by eating disorders. The greater understanding that comes with the results of this study will assist in our nation's ability to prevent, detect, and treat eating disorders throughout the United States.

Sincerely,

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Hon Renee Ellmers  
Co-chair  
National Eating Disorders Caucus

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Hon Nita Lowey  
Co-chair  
National Eating Disorders Caucus

## Notes from Meetings

### Team #:

1)

Legislative Office:

Met with:

In favor or Opposed?

Comments:

2)

Legislative Office:

Met with:

In favor or Opposed?

Comments:

3)

Legislative Office:

Met with:

In favor or Opposed?

Comments:

4)

Legislative Office:

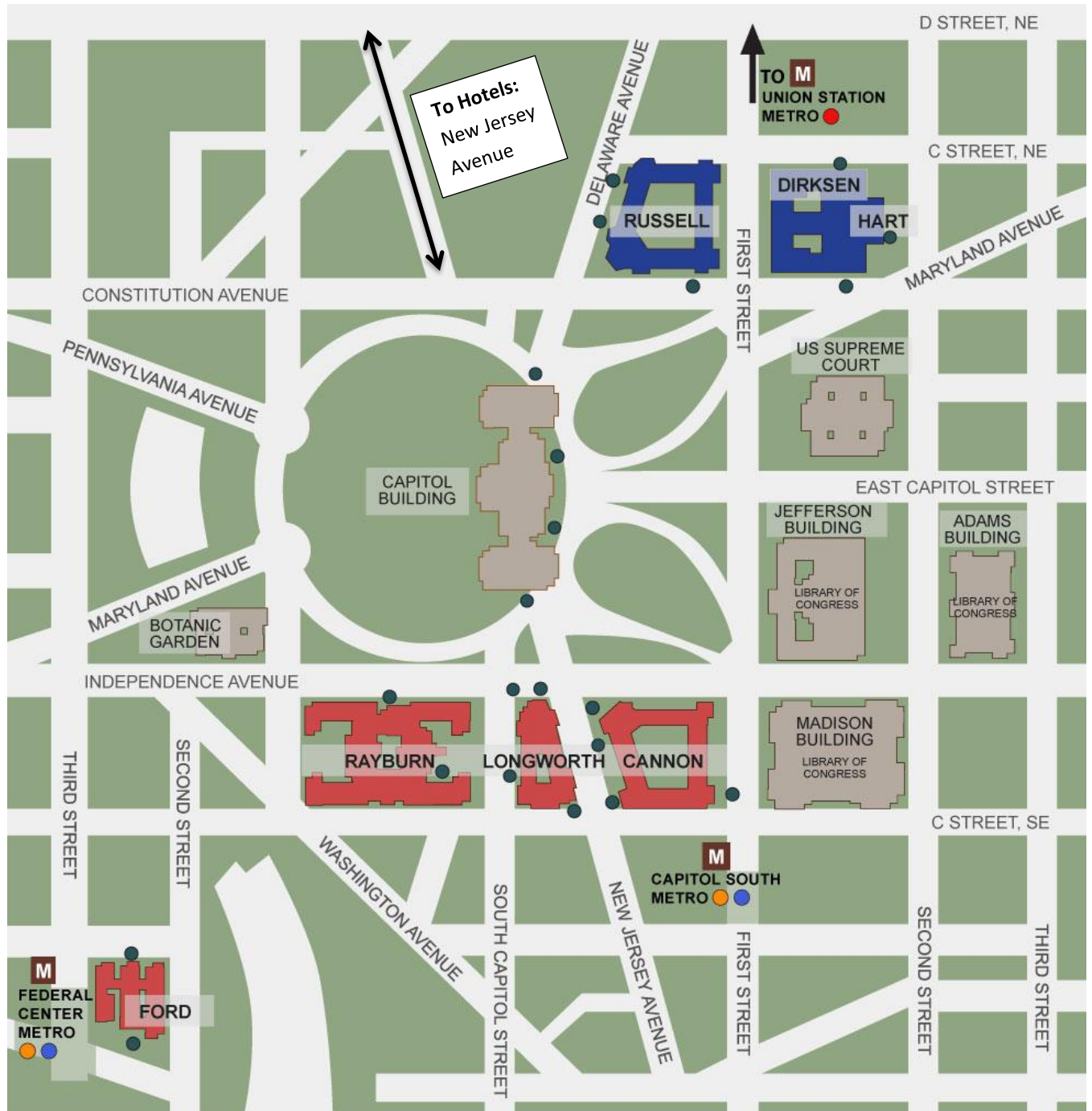
Met with:

In favor or Opposed?

Comments:

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■ **House office building** (Rayburn, Longworth, Cannon, Ford)

■ **Senate office building** (Russell, Dirksen, Hart)

● **Building entrances**

■ **M Metro station**

● Red line   ● Blue line   ● Orange line