

# Advocate Packet

EDC Lobby Day  
April 1-2, 2009

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## Getting Around on Capitol Hill

### Address for EDC Lobby Day Trainings

Basic Training, April 1, 4-6 PM

Message Training, April 2, 9-11 AM

St. Mark's Episcopal Church, 3<sup>rd</sup> and A Streets, SE  
Washington, DC 20003

EDC Lobby Day Training will take place in the same location as last year. Since traffic congestion may be heavy and there is no commercial parking garage in the area, please do not drive to the event. Arrive by foot, taxi, bus, or Metrorail subway. All buildings are wheelchair accessible.

### METRORAIL

Take a **BLUE** or **ORANGE** line train to the **Capitol South** Metro station (wmata.com). Go up the escalator and onto C St. and 1<sup>st</sup> Street. Then, keep heading in the same direction (north) on 1<sup>st</sup> Street, toward the Capitol. Part of 1<sup>st</sup> Street is closed to traffic, with the Cannon House Office Building on your left and the Library of Congress Madison Building on the right. At 1st Street and Independence Avenue, turn right (east) and walk two blocks to Independence Avenue SE and 3<sup>rd</sup> Street. Turn left (north) onto 3<sup>rd</sup> Street and St. Mark's Episcopal Church is at the end of the block. We are meeting in the Parish Hall.

### TAXI

If arriving by taxi, tell the driver that you are going to CAPITOL HILL, to St. Mark's Episcopal Church at 3<sup>rd</sup> and A Streets, Southeast behind the LIBRARY of CONGRESS. Make sure you say Southeast as that is very important.

## Schedule, April 1

- 3:30 Registration Desk Opens
- 4:00 Basic Training – Required for first-time advocates.
- 7:00 EDC Reception and Meet and Greet Social

## Schedule, April 2

- 8:30 Registration Desk Opens
- 9:00 Continental Breakfast & Message Training – Required for all.
- 11:30 EDC Lobby Day Team Appointments Begin\*
- 4:00 EDC Congressional Briefing\*\*

\* U.S. Capitol Complex, multiple locations

\*\*U.S. Capitol Complex, Rayburn House Office Building Room 2168

### LATE? EMERGENCY?

Call us by cell phone: Jeanine Cogan can be reached at 202-352-3208, and David Jaffe or Jeff Culang at 917-902-1319.

## Event Details



 Wednesday, April 1

### **Basic Training**

4-6 PM

St. Mark's Episcopal Church, Parish Hall  
3rd & A St SE, Washington DC 20003

Basic Training is required for all first-time advocates. You will learn what lobbying is, how to do it effectively, and the role of advocates in creating sound public policy. If you have participated in a previous EDC Lobby Day, this session is optional.

### **EDC Awards Reception and Meet and Greet Social (Additional Cost)**

7:00-9:00 PM

EDC Office/National Criminal Justice Association

720 7<sup>th</sup> Street, NW, Third Floor

Washington, DC 20001

Join us for an awards reception and meet and greet social featuring a casual buffet dinner. The reception takes place immediately after EDC Lobby Day Basic Training and is for registered attendees.

 **Thursday, April 2**



### **Message Training**

9-11:00 AM

St. Mark's Episcopal Church, Parish Hall  
3rd & A St SE, Washington DC 20003

Message Training is REQUIRED of everyone joining us for this EDC Lobby Day. You will review the talking points for the day and practice your messages with your EDC Lobby Day team members. A light breakfast is available at Message Training.

### **EDC Lobby Day**

11:30 AM - 3:30 PM

U.S. Capitol Complex

At the U.S. Capitol, you will work in teams meeting with elected officials and their staff. No one will lobby alone. Lobby teams will arrive for each appointment, deliver a packet of materials, and talk about how Congress can help.

To conclude the day, we will gather for a Congressional Briefing to discuss the FREED Act. Members of Congress and the media will also be invited to the briefing.



## Congressional Briefing

### The FREED ACT

A Federal Response to Eliminate Eating Disorders

4:00-5:00 p.m.

Rayburn House Office Building Room 2168

U.S. Capitol Complex



The EDC, in cooperation with Rep. Patrick Kennedy (D-RI), invites you to attend a Congressional Briefing, *The FREED ACT, a Federal Response to Eliminate Eating Disorders*. You will learn about a new comprehensive eating disorders bill to address research, treatment, and prevention services. Speakers include Jillian Croll, Ph.D., RD/LD, MPH, Ted Weltzin, M.D., Lisa Lilienfeld, Ph.D., and Johanna Kandel. This briefing is free and open to the public.



*Education and Prevention*  
Jillian Croll,  
PhD, RD/LD, MPH



*Treatment*  
Ted Weltzin,  
MD



*Research*  
Lisa Lilienfeld,  
PhD



*Personal Story*  
Johanna Kandel

## Specific Requests for Elected Officials

### U.S. House of Representatives

#### THE EDC REQUESTS that you:

1. **Cosponsor the Federal Response to Eliminate Eating Disorders (the FREED Act).** We urge you to cosponsor of H.R. 1193, which is a comprehensive eating disorders bill. H.R. 1193 provides action for research, treatment, education and prevention of eating disorders. Please contact Laurel Havas in Congressman Kennedy's office, 202-225-4911, to add your name as a cosponsor.
2. **Cosponsor the Eating Disorders Awareness, Prevention, and Education Act of 2009.** We urge you to cosponsor H.R. 26, which will raise awareness of eating disorders and create educational programs in the schools. Please contact Jackie Abba in Congresswoman Judy Biggert's office, 202-225-3515.
3. **Attend today's congressional briefing.** We will present details on The Federal Response to Eliminate Eating Disorders (the FREED Act), 4:00 in 2168 Rayburn.

### U.S. Senate

#### THE EDC REQUESTS that you:

1. **Cosponsor the Federal Response to Eliminate Eating Disorders (the FREED Act).** We urge you to cosponsor the FREED act, which is a comprehensive eating disorders bill. This bill provides federal action for research, treatment, education and prevention of eating disorders.
2. **Your presence in today's congressional briefing.** We will present details on The Federal Response to Eliminate Eating Disorders (the FREED Act), 4:00 in 2168 Rayburn.

Jeanine Cogan, Ph.D., Policy Director  
jcogan@eatingdisorderscoalition.org  
202-352-3208

# Eating Disorder Statistics

## *9 Million Americans Hundreds Dying Each Year*

Millions of Americans suffer from eating disorders, known as anorexia nervosa, bulimia nervosa, binge eating disorder, and eating disorders not otherwise specified (EDNOS). Eating disorders have serious mental and physical health consequences including death. In fact anorexia has the highest mortality rate of any mental illness.

### **9 Million Americans...**

The first nationally representative study of eating disorders in the United States appeared in the February 2007 edition of Biological Psychiatry. The National Comorbidity Survey Replication (NCS-R) is a nationally representative survey of the U.S. population that was administered face-to-face to a sample of 9,282 English-speaking adults ages 18 and older between February 2001 and December 2003. Among the results:

- Eating disorders frequently impair the sufferer's home, work, personal, and social life.
- Researchers found a surprisingly high rate of anorexia and bulimia among men, representing approximately one fourth of the cases of each disorder
- Binge eating is more common than anorexia or bulimia and is commonly associated with severe obesity.
- Eating disorders display substantial comorbidity with other mental health disorders.
- While eating disorders often coexist with other mental health disorders, **eating disorders often go undiagnosed and untreated. A low number of sufferers obtain treatment for their eating disorder.**

Assuming a population of 300,000,000 Americans...  
1.3 million women with Anorexia Nervosa  
450,000 men with Anorexia Nervosa  
2,250,000 women with Bulimia Nervosa  
750,000 men with Bulimia Nervosa  
5,250,000 women w/ Binge Eating Disorder  
3,000,000 men w/ Binge Eating Disorder

Scientifically speaking...  
Lifetime prevalence of individual eating disorders is 0.6-4.5%.  
Lifetime prevalence of anorexia nervosa is .9% in women, .3% in men.  
Lifetime prevalence of bulimia nervosa is 1.5% in women, .5% in men.  
Lifetime prevalence of binge eating disorder is 3.5% in women, 2.0% in men.

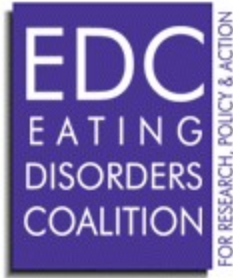
**Approximately 9,000,000 Americans with an Eating Disorder** (some people experience more than one eating disorder at a time)

Source: James I. Hudson, Eva Hiripi, Jr., Harrison G. Pope, and Ronald C. Kessler (2007). Biological Psychiatry, "The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication," pp. 348-358.

### **Hundreds Dying Each Year...**

We estimate that hundreds of Americans die each year of eating disorders as the cause of death, yet there is no federal entity documenting and reporting the mortality of eating disorders. The EDC urges the Centers for Disease Control and Prevention to begin regular reporting on eating disorders listed as either the primary or contributing cause of death.

# The Federal Response to Eliminate Eating Disorders



A comprehensive bill on eating disorders addressing research, treatment, education and prevention, introduced by Congressman Patrick Kennedy with bipartisan support.

*We urge you to be an original co-sponsor of the FREED Act.*

## Research Initiatives

- **Establish Centers of Excellence.** Develop an integrated system of Centers of Excellence for eating disorders, which will provide training opportunities for research, fund research programs, and coordinate the development of a research infrastructure.
- **Know the numbers through a national data base and other initiatives.** Determine the prevalence, incidence, and correlates of all eating disorders (anorexia nervosa, bulimia nervosa, binge eating disorder and eating disorder not otherwise specified).
- **Know the death rates.** Determine the morbidity and mortality rates associated with all eating disorders and provide a public report of this data annually.
- **Know the costs or “economic burden” of eating disorders.** Undertake the necessary investigations to conduct an economic analysis of the costs of eating disorders in the United States, including years of productive life lost, missed days of work, reduced work productivity, costs of medical/psychiatric treatment, prescriptions medications, hospitalizations, costs of medical and psychiatric comorbidities, (cost to family, cost to society) etc.

## Access to Adequate and Appropriate Treatment

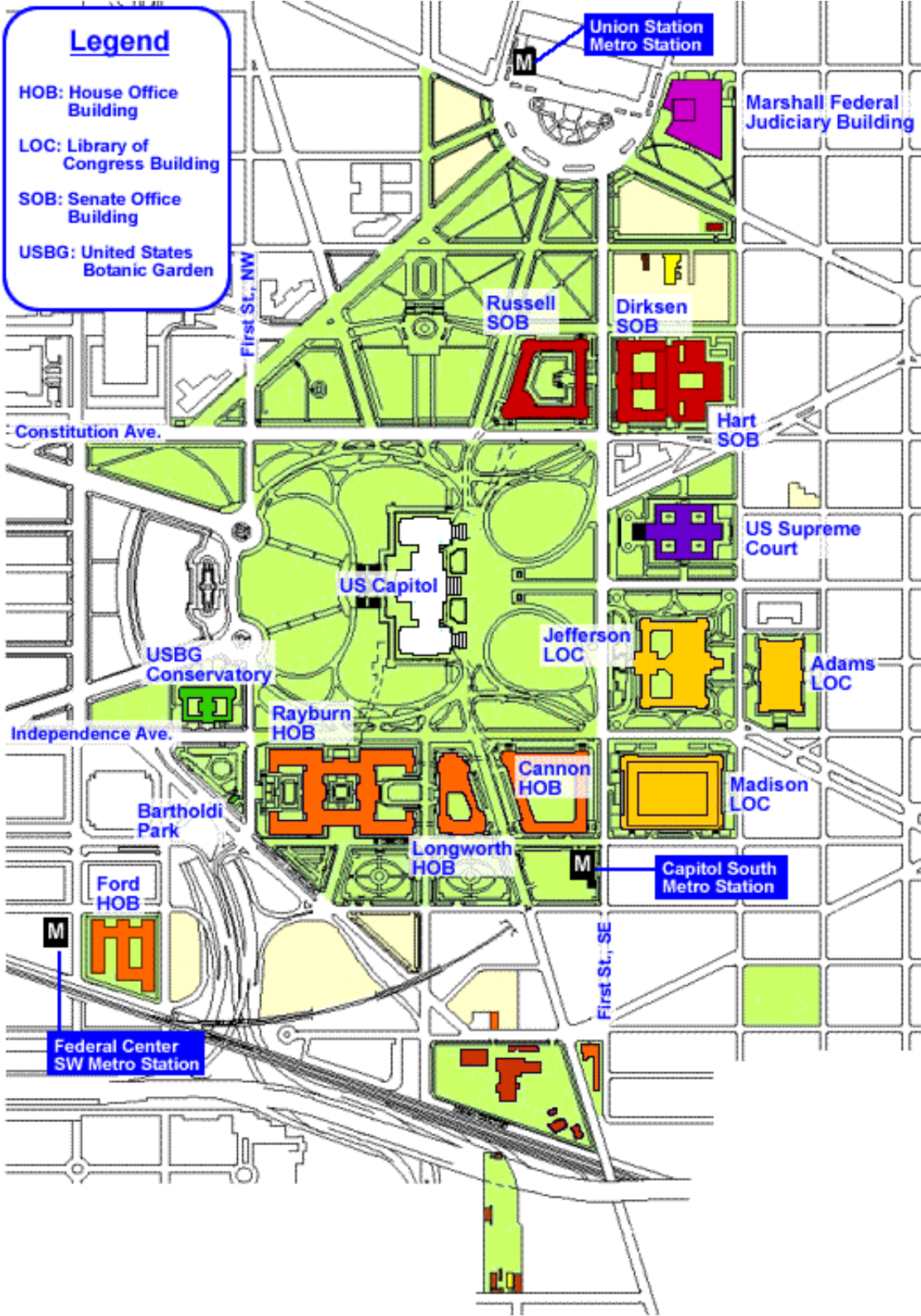
- **All Americans with eating disorders deserve access to care.** Any insurer that provides health coverage for physical illness must provide coverage for eating disorders.
- **Care according to universally accepted criteria.** Insurers are to follow standards of care as written in the Practice Guidelines for the Treatment of Patients with Eating Disorders by the American Psychiatric Association.
  - ✓ **The treatment setting must be appropriate to the patient’s needs and clinical presentation.** Decisions regarding the treatment setting must include individual variables such as age, sex, ability to manage severity or co-morbidity, family involvement, and staff expertise and training.
  - ✓ **Eating Disorders are complex conditions and require comprehensive treatment approaches.** All treatment modalities should be covered, including but not limited to family, individual and group therapies, nutrition counseling, psychopharmacology, body Image therapy, and medical treatment.

## Education & Prevention Initiatives

- **Study mandatory BMI reporting in school.** Determine the outcome of measuring BMI in schools and reporting the results to parents (including measuring eating disorders symptoms, and incidence of teasing or bullying based on body size).
- **Grant Program of the Education and Training for all Health Professionals.** Train health professionals, to identify, prevent, appropriately treat and address the complications of eating disorders (using a team approach).
- **Grant Program for the Education and Training for School/Higher Education Professionals.** Train education professionals in evidence-based education programs about eating disorders, education professionals include teachers, professors, school nurses, school aides, community liaisons, cooks, dieticians, social workers, counselors, coaches, athletic departments, and other.
- **Educating the public through Public Service Announcements (PSAs).** Use PSAs to educate the public on types and the seriousness of (prevalence, comorbidities, health consequences –both physical and mental) eating disorders, how to obtain help, discrimination and bullying based on mental illness, body size, and the effects of media on self esteem and body image.
- **Bring eating disorders into already existing obesity initiatives.** Federally funded campaigns to fight obesity should also address eating disorders. Federal studies should include eating disorder related questions.

Jeanine Cogan, Ph.D., Policy Director  
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# Map of Capitol Complex Buildings



## **EDC Board of Directors**

### Officers

President 2007-2009: Kitty Westin, The Emily Program

Vice Chair 2009: Margo Maine, Ph.D., National Eating Disorders Association

Treasurer 2007-2009, Gail R. Schoenbach, Gail R. Schoenbach/F.R.E.E.D. Foundation

### Directors

Gail Kennedy, Family and Friends Action Council (FAC)

Lisa Lilienfeld, Ph.D., Academy for Eating Disorders

Sam Menaged, J.D., Renfrew Center Foundation, President 2005-2006

Ted Weltzin, Rogers Memorial Hospital

## **EDC Staff**

David Jaffe, Executive Director

Jeanine Cogan, Ph.D., Policy Director, Co-founder (2000)

## **EDC Member Organizations**

Academy for Eating Disorders

Anna Westin Foundation

CRC Health Group Inc.

Eating Disorders Institute/

Park Nicollet Health Services

The Emily Program

Gail R Schoenbach /

F.R.E.E.D. Foundation

National Eating

Disorders Association

Renfrew Center Foundation

Remuda Ranch

A Chance to Heal

AABA of Philadelphia

Alliance for Eating Disorder Awareness

Avalon Hills Residential

Treatment Center

Center for Change

CEDAR Associates

Eating Disorders Association

of New Jersey

Eating Disorder Center of Denver

Eating Disorder Hope

Eating Disorders Information Network

EDReferral.com

The Elisa Project

Family and Friends Action Council

FEAST

Gürze Books

International Association of Eating

Disorders Professionals Foundation

Kristen Watt Foundation

Laureate Psychiatric Hospital

Maudsley Parents

Monte Nido Treatment Center

Multi-service Eating

Disorders Association

Ophelia's Place

Pennsylvania Educational

Network for Eating Disorders

Puente De Vida

Rader Programs

Rogers Memorial Hospital

Rosewood Center for Eating Disorders

Shepard Pratt

Timberline Knolls