

EDC Lobby Day
April 9-10, 2008

Advocate Packet

Advance Version

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Getting Around on Capitol Hill

Address for EDC Lobby Day Trainings

Basic Training, April 9, 3-5 p.m.

Message Training, April 10, 9-10:30 a.m.

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

EDC Lobby Day Training will take place in a new location. Traffic congestion will be especially heavy on EDC Lobby Day. There is no commercial parking garage in the area. Please do not drive. Arrive by walking, 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 1st St., then keep heading in the same direction (north) on 1st St., toward the Capitol. Part of 1st St. 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 St. and Independence Ave., turn right (east) and walk two blocks to Independence Ave. SE and 3rd St. Turn left (north) onto 3rd St. 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 3rd and A Streets, Southeast behind the LIBRARY of CONGRESS.

Schedule, April 9

- 2:30 Registration Desk Opens
- 3:00 Basic Training – Required for first-time advocates.
- 5:00 Meet and Greet Social
- 6:00 Reception for Miss America – Optional. Requires separate registration.*

Schedule, April 10

- 8:30 Registration Desk Opens
- 9:00 Continental Breakfast & Message Training – Required for all.
- 10:30 EDC Lobby Day Group Photo at Library of Congress
- 11:00 EDC Lobby Day Team Appointments Begin**
- 4:30 EDC Congressional Briefing***

* Credit Union House, 403 C Street NE, Washington DC 20002, www.cuhouse.com

** U.S. Capitol Complex, multiple locations

*** U.S. Capitol Complex, Rayburn House Office Building Room 2105

LATE? EMERGENCY?

Call us by cell phone: Marc Lerro 202-669-6086, Jeanine Cogan 202-352-3208

Event Details



 **Wednesday, April 9**

Basic Training

3-5 p.m.

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 about public policy, about how Congress makes laws, and you will review what Congress and the government has done - or not done - about eating disorders. If you have participated in a previous EDC Lobby Day, this session is optional.

Meet and Greet Social

5:00-5:45 p.m.

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

Join us for an informal "meet and greet" social featuring light snacks and other refreshments. The social takes place immediately after EDC Lobby Day Basic Training. Everyone registered for EDC Lobby Day is welcome.

Reception for Miss America Kirsten Haglund

featuring special guest Congressman Jim Ramstad

6:00-8:00 p.m.

Credit Union House
403 C Street NE
Washington DC 20002



The Eating Disorders Coalition proudly presents Miss America 2008 Kirsten Haglund! This special celebration will honor the new Miss America for selecting eating disorders awareness as her personal platform. The reception will include Hors d'oeuvres, wines, and other beverages in an elegant setting on Capitol Hill, the Credit Union House. Advance tickets are required for the Reception for Miss America Kirsten Haglund. The reception benefits the Eating Disorders Coalition, a non-profit organization working to advance the federal recognition of eating disorders as a public health priority. Business attire. Catering by [Cuisine Mondiale](#). Tickets: Adults \$50, Children \$20 Join us!



 **Thursday, April 10**



Message Training

9-10:30 a.m.

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 will practice your messages with your EDC Lobby Day team members. If you miss this brief session, you will not know your specific points nor your role in the team. A light breakfast will be served prior to Message Training.

EDC Lobby Day Group Photo

10:30 a.m. Steps of the Madison Building
Bring your cameras!



EDC Lobby Day

11:00 a.m. - 4:30 p.m.

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 end 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

4:30-5:30 p.m.

Rayburn House Office Building Room 2105

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 Margo Maine, Ph.D., FAED, Cynthia Bulik, Ph.D., FAED, Kathleen MacDonald, and Jeanine Cogan, Ph.D. This briefing is free and open to the public.



Treatment
Margo Maine,
PhD, FAED



Research
Cynthia Bulik,
PhD, FAED



Education & Prevention
Kathleen MacDonald



EDC Policy Director
Jeanine Cogan, PhD

Specific Requests for Elected Officials

U.S. House of Representatives

THE EDC REQUESTS:

1. **Co-sponsorship of The Federal Response to Eliminate Eating Disorders (the FREED Act).** We urge you to be an original cosponsor of this comprehensive eating disorders legislation to be introduced. The bill will offer federal action for the research, treatment, and prevention of eating disorders. Please contact Rachael Bornstein in Congressman Kennedy's office, 202-225-4911, to add your name as an original cosponsor.
2. **Passage of mental health parity this year!**
3. **Your presence in today's congressional briefing.** We will present details on The Federal Response to Eliminate Eating Disorders (the FREED Act), 4:30 in 2105 Rayburn.

U.S. Senate

THE EDC REQUESTS:

1. **A senate companion bill and original co-sponsors for The Federal Response to Eliminate Eating Disorders (the FREED Act).** Please contact EDC Policy Director Jeanine Cogan at 202-352-3208 or jcogan@eatingdisorderscoalition.org if you are interested in being the sponsor of this bill.
2. **Passage of mental health parity this year!**
3. **Your presence in today's congressional briefing.** We will present details on The Federal Response to Eliminate Eating Disorders (the FREED Act), 4:30 in 2105 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.

Talking Points

“For people with eating disorders, mental health parity is a matter of life or death.”

High prevalence rate. 9 million Americans suffer from eating disorders. Eating disorders cut across race, color, gender and socioeconomic categories. No one is immune. (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.)

On the rise and affecting children. The incidence of eating disorders appears to have doubled since the 1960s and is increasing in younger age groups, in children as young as seven. Eating disorders often begin in adolescence and are among the top four leading causes of burden of disease in terms of life lost through disability or death.

Impact on health. Eating disorders are commonly associated with substantial psychological problems, including depression, substance abuse, and suicide. They also can lead to major medical complications, including cardiac arrhythmia, cognitive impairment, osteoporosis, infertility, and death.

High death rate. Anorexia nervosa has the highest mortality rate of all mental disorders. One study reported an 11-fold increase in the risk of death for individuals with anorexia compared to those without anorexia.

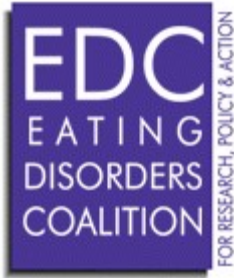
Treatment works. Research shows that eating disorders can be successfully overcome with early detection and adequate and appropriate treatment. Some treatments may be extensive and long-term. Yet less than half of people with eating disorders receive treatment.

Public support for parity. According to a nation wide poll commissioned by the National Eating Disorders Association, three out of four Americans believe eating disorders should be covered by insurance companies *just like any other illness*. A PARADE/ Research!America poll found that 65% of Americans “strongly agree” that mental-health services should be part of any basic health-care plan. (Intelligence Report®, The True Cost of Depression, by Lyric Wallwork Winik, October 1, 2006.)

Require health insurance companies to reimburse for eating disorder treatment. Insurance companies routinely limit the number of days they will reimburse for treatment of eating disorders, which force doctors to discharge patients with anorexia nervosa too early. Although patients with eating disorders typically require more than 6 weeks (42 days or more) of inpatient therapy for proper recovery, insurance companies typically offer an average of 10 –15 days a year. Early discharge is associated with relapse and death.

We urge Congress to pass mental health parity this year.

The Federal Response to Eliminate Eating Disorders



A comprehensive bill on eating disorders addressing research, treatment, education and prevention, being introduced by Congressman Patrick Kennedy (D-RI) and Congressman Mike Ferguson (R-NJ).

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

Research Initiatives

- **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.
- **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 nationwide.

Access to Adequate and Appropriate Treatment

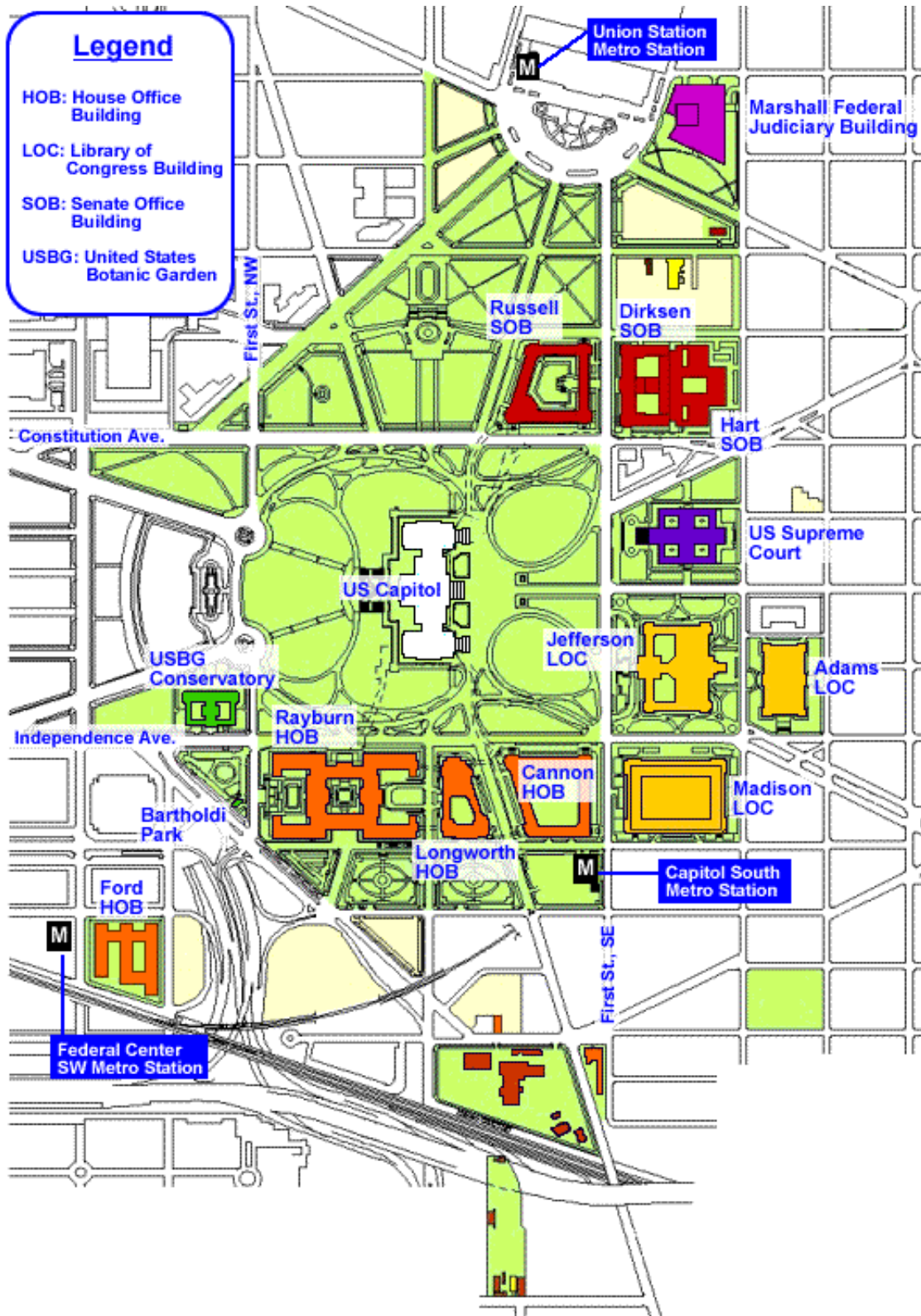
- **All Americans with eating disorders deserve access to care.** Any insurer that provides health coverage for physical illness must provide coverage for eating disorders.
- **Care according to universally accepted criteria.** Insurers are to follow standards of care as written in the Practice Guidelines 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
jcogan@eatingdisorderscoalition.org
202-352-3208

Map of Capitol Complex Buildings



EDC Board of Directors

Officers

President 2007-2008: Kitty Westin, Anna Westin Foundation

Vice President 2007-2008: Cynthia Bulik, Ph.D., Academy for Eating Disorders

Treasurer 2007-2008, Gail R. Schoenbach, Gail R. Schoenbach/F.R.E.E.D. Foundation

Directors

Katherine Brown, Ed.D.

Mary Gee, Family and Friends Action Council (FAC)

Gail Kennedy (January 1, 2008-December 31, 2010)

Margo Maine, Ph.D., National Eating Disorders Association

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

EDC Staff

Marc Lerro, Executive Director (2002-2008)

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

EDC Member Organizations 2008

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

Davis Y. Ja and Associates

Eating Disorders Association
of New Jersey

Eating Disorder Center of Denver

Eating Disorder Hope

Eating Disorders Information Network

The Elisa Project

Family and Friends Action Council

Gürze Books

International Association of Eating

Disorders Professionals Foundation

Kristen Watt Foundation

Laureate Psychiatric Clinic & Hospital

Maudsley Parents

Monte Nido Treatment Center

Multi-service Eating

Disorders Association

Pennsylvania Educational

Network for Eating Disorders

Puente De Vida

Rader Programs

Rogers Memorial Hospital

Rosewood Center for Eating Disorders