

“Ten Percent is Unacceptable”

November 29th, 2012, Washington DC, US

Transcript of a Congressional Briefing on the High Mortality Rates for Eating Disorders and the Federal Response to Eliminate Eating Disorders (FREED) Act,

Sponsored by the Eating Disorders Coalition and F.E.A.S.T. (Families Empowered and Supporting Treatment of Eating Disorders), and Coordinated with the office of Senator Tom Harkin

SARA SINLGLETON

Legislative Assistant, Office of Senator Harkin, Iowa

Thank you and welcome. It is really exciting to see a full house with so many people here to learn about this important issue. As I hope you know, this is something that Senator Harkin had long been interested in and so I want to thank you all for coming to educate us about this important issue.

JEANINE COGAN (Video: 00:36)

Policy Director, Eating Disorders Coalition

Good morning everyone, I am Jeanine Cogan. I am the Policy Director of the Eating Disorders Coalition and I'll start our briefing today by thanking Senator Harkin for supporting this briefing. Actually, he's been a champion working with us to address eating disorders for years now. It started long before he introduced the FREED act – he's the lead of our signature bill. He helped us get some report language into the bill to address this very issue [mortality], actually, when we were trying to get the CDC to give us some good mortality data on the rates of eating disorders. So he has been a big champion and we're really grateful that we have him in our corner, so thank you so much to Senator Harkin.

Today we are addressing “Ten Percent is Unacceptable.” That [10%] really is the mortality rate associated with eating disorders. Eating disorders have the highest mortality rate of any psychiatric disability. When we think of someone having a mental illness, we tend to not think they are going to die from it. But with eating disorders, unfortunately, that is a reality that we are faced with. So, we are doing this briefing, the Eating Disorders Coalition in conjunction with F.E.A.S.T., and we are very grateful for that partnership.

I'm just going to list who our speakers are, and they are going to be in this order [as seated], and then they are each going to individually come up and so I won't reintroduce you. Thank you all so much for being here today and sharing your wisdom and experience with us.

Our first speaker is going to be Dr. Mark Chavez, from the National Institute of Mental Health, and the title of his talk is “What the research shows – mortality statistics for eating disorders.”

Next, we have Amy Snyder, who is a mother, and her talk is titled, “Who are we fighting for? People like my seven year old daughter.”

Next we have Julie O'Toole. She is the Director and Founder of the Kartini Clinic, and her talk is “Saving lives with early intervention, a pediatrician's perspective.”

Then, we have Joan and Justin Riederer, a mother and a brother, and the title of their talk is “Giving a voice to my family's years of support, hard work, and tragic loss of Erin.”

Then we have Laura Collins, who is the Executive Director, of F.E.A.S.T., and her talk is entitled, “The central role of families.”

And then I will come up at the end and wrap it up with how Congress can address this issue. So let's begin with our first speaker, Dr. Mark Chavez.



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*–Jeanine Cogan,
EDC*

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DR. MARK CHAVEZ, NIMH, (Video: 03:45)

“What the research shows – mortality statistics for eating disorders.”

So first, on behalf on the NIMH, I'm really happy to be able to participate in this meeting and I thank those groups who have invited me to do so. So, what I was specifically asked to do was to talk about data regarding mortality rates associated with eating disorders, and that is what I will do. And the data that I talk about, if anybody is interested in where any of these numbers came from, one of the things you can do is to send me an email. Just google “NIMH Mark Chavez” to get my contact information and I am more than happy to send you any of the references from any of this data, or any other questions you may have regarding these references.

OK. So before I talk more about the mortality rate, there is one point I would like to make before I give you those specific numbers, and I don't have a lot of time, so I'm not going to take a lot of time and I think probably I don't need tell this to all of you, and it is something that we think about back at NIMH... Let's put aside the mortality data just for one second, and if we do that, even independent of the mortality data, these eating disorders are incredibly serious and debilitating disorders and the psychological impact, the financial impact, the disability associated with this, not only how it effects the patients, but how this effects the families. I think these problems are immense, and I think the mortality data, one of the things that it does, is that it really brings home some of the severity, some of the seriousness... But, in and of itself, even independent of this data, these are very, very, very pernicious disorders, and for somebody not to be aware of that, or to trivialize that in any way, I think is ignorance.

OK. I think that one of the things that you [Jeanine] said, was that when we think about psychiatric disorders, we do not necessarily think about the mortality. A lot of what we have are suicides relating to not being able to cope; but, with eating disorders, there really is a very, very, high rate of both psychiatric and medical co-morbidities and I think that these are, a lot of the time, responsible for the mortality that we see associated with eating disorders. Some of the effects they have are on electrolytic balance, cardiovascular function, renal function, osteoporosis and bone growth, immunosuppression, effects on the immune system. And, there are high levels of depression and substance abuse, as well. These disorders, which are very deadly in and of themselves, when you combine them with some of the co-morbidities are very, very, serious, and very, very, dangerous disorders.

At NIMH, when we talk about eating disorders, typically what the discussions revolve around are what is the research that we really need to see being done in order to give us a better understanding of the etiology? What is causing these things? What puts a person at higher risk? You know, understanding some of the pathophysiology, what connections are from the central nervous systems, as well as the endocrine systems that are really responsible, not only for the etiology, but also for the prevalence of these disorders.

There are some treatments for eating disorders. In some areas we have reasonably good treatments, in other areas I think they are very much lacking, and I think there is no question we would like to see an improvement in what we have. Not only an improvement in the treatments that we have, but we need to disseminate them and make sure that they are actually being implemented in the way that they are intended to be implemented. That is the only way they are really going to be effective. There are prevention programs that can be done and be established; prevention programs that will actually help, hopefully, to prevent a person from converting into a full blow eating disorder by catching it early.

These are some of the discussions we have at the NIMH and we look and see areas where we can improve, and there are a lot of areas where we really, really, do need the research. But, we never talk about “*Is this serious? Is this a boutique question? Is this a boutique problem? Is this really something that doesn't necessarily have to have the priority?*” We don't have these discussions because the data is all there to say “*absolutely,*” there is absolutely no question about that.



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*-Dr. Mark Chavez,
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I find it surprising, when I talk to a lot of the advocates, (again, I understand the disorders, and they also understand the disorders, and I think many in the room can appreciate this), that when you try and get a child treated, some of the..., some of the responses, and some of the treatments...(It is very good for people like me to come out here and actually do this) again, some of the ignorance (and based on some of the experiences that you have had), I find appalling, and very offensive. It is inexcusable.

So, what I am going to do is to talk about the mortality data associated with eating disorders. When we talk about mortality data, the way that this is generated is with standard mortality ratios, and so what you do is you take a very specific patient population, say anorexia nervosa, and you pick a time frame representing the data that is going to be analyzed, and what you do is take the patient population and then you also take the standard population that is going to be analyzed as a comparison. And that standard population gets matched on demographic variables, age, sex, those type, and they are put into the same time frame and we compare that ratio to each other: how many expected deaths would you see in a standard population to how many do you actually see in an eating disorder population.

That's how mortality is calculated from a medical perspective, and any time that number, that ratio, is greater than one, that means that in the study population, for example anorexia nervosa, there is excess death in the population relative to the general population. Again, keeping all the demographic variables and comparing with a population that has never had or currently does not have an eating disorder diagnosis, the mortality ratio for anorexia nervosa (and this is based on very good, very large populations from studies in Europe and in America - a very well done, very rigid study), the standard mortality ratio for anorexia nervosa is 5.7. **So, there is a 5.7 % greater chance of dying if you have, or have had, a diagnosis of anorexia nervosa relative to the general population. That is not a trivial number. The data for bulimia nervosa is 1.93, and the data for binge eating disorder is 1.52.** There are a lot of “eating disorder not otherwise specified” categories, but the data is not good for that. I am not comfortable talking about that because there are some numbers...that I think...and there are some problems that make it very hard for me to feel confident.

One thing I was happy to see is that these [campaign] buttons say “10%.” I didn't try to find numbers, I tried to find what I thought were the best studies and get from those the numbers. But these numbers, when you look at them, just these three categories; it really does equal about 10% (or 9.7 or 9.6) and that's actually very nice, to see that there is a clear correspondence between the two.

The last point that I wanted to make is that (*and when I saw these numbers for the first time, they shocked me*), looking again at the general population, but this time instead of looking at general mortality, we are going to look at suicide. So, with standard mortality and mortality due to suicide, we do the same thing. We take a study population with anorexia nervosa and a general population and match them up by age, sex, as close as possible. Again, you look at the ratio; and any time the number is greater than one, there is excess death due to suicide in that study population. So, the standard [suicide] mortality ratio for anorexia nervosa is 31. **So, your chance of dying from suicide, if you have been diagnosed with anorexia nervosa, currently have anorexia nervosa, or have had that diagnosis, is 31 times greater, relative to the general population. Again, that's... and they say these are not serious disorders? It really seems absurd.**

When you look at [suicide in] bulimia nervosa (and again I have data that I have confidence in talking about for bulimia nervosa - the other categories, I am not so sure), the ratio is 7.5. Again, these are very, very, high numbers. If you want any information on where these numbers come from, contact me, and I will send you those references.

OK, well, I think that is about all... Thank you very much for inviting me.

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AMY SNYDER, Mother, (Video: 12:11)

“Who are we fighting for? People like my seven year old daughter.”

So, I am here as the mother of a daughter who is seven years old; and, my 7 year old daughter, Olivia, has anorexia nervosa.

Olivia decided to eat healthy, and I didn't know. She didn't tell me about this, but I noticed that she was eating fewer sweets. And, in January, she had a birthday party and I noticed she just had one bite of her birthday cake. I didn't know that she was hungry, but that she was powerless to eat. We had no idea.

She did have some physical problems though, that I took her to the pediatrician for. She was itchy, and she was dizzy, and she had digestive problems - she had constipation. So, I took her to the pediatrician a few times for these issues, after January of this year. And, for itchiness, the doctor suggested Vaseline, and for constipation, she suggested a fiber supplement, and for dizziness, she suggested that my daughter not get up so fast. Needless to say, she didn't connect the dots.

On May 7th I was tucking my daughter into bed and she whispered to me, she whispered,

“Mommy, I have a problem.” And I said,
“Honey, what's your problem?” and she said,
“I'm hungry all the time, but I can't eat.”
“Why can't you eat?”
“Because I have a mean voice in my head that tells me not to eat,” and she said
“Because I'm afraid I'll get fat.”

So, I got her out of bed and I gave her a snack and I got her back into bed again. That night, I got on the internet and I began to do some research, and I was horrified to learn the reality of anorexia nervosa, the mortality rate. At the same time, I found some hope in a method called Family Based Treatment, also called Maudsley Method, that emphasizes that nutrition comes first - that we first have to raise the weight of the sufferer, and that would give us hope to get rid of this, this mean voice, and to help her recover psychologically.

I learned then that recovery was possible. I also learned that my daughter was really lucky, because I caught this early, and this meant she had the best prognosis. In most kids, anorexia isn't caught early and many children are ill for years. Why aren't they caught early? Well, just like with my daughter's doctor, pediatricians don't know how to connect the dots and figure out who has this illness.

So, a question to ask is *“How do we keep our children from dying of this disease?”* Well, we need pediatricians to be up to date and who don't take a wait and see approach. Parents need skills to feed their children. It is not easy to feed a person who has anorexia nervosa, because, essentially, the child is afraid to eat. They are afraid of food. But, there are skills that we can learn that make it possible to feed our children - to require eating.

We need insurance to cover evidence-based treatment, because insurance doesn't necessarily cover the things that you need.

To keep our children from dying, everyone needs to know not to wait; that kids do not choose to be ill with this disease; that the disease is not about the child trying to control their environment, or a child trying to control their family.

Anorexia nervosa is like Obsessive Compulsive Disorder in my daughter. My daughter has a mean voice in her head that tells her not to eat. She has had this mean voice (I've learned recently) as far back as preschool. She remembers mean voice telling her not to do, or to do certain things. But, mean voice wasn't always interested in what she ate – that came later.



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“I was tucking my daughter into bed and she whispered to me, she whispered, “Mommy, I have a problem.” And I said, “Honey, what's your problem?” and she said, “I'm hungry all the time, but I can't eat.”

*–Amy Snyder,
mother of a 7 year
old with anorexia
nervosa*

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Everyone needs to know about “Magic Plate,” which is a technique for re-feeding, and it worked well for my daughter.

To keep our children from dying, families need support – we have lost income, from taking time off of work. We went without income for three months this summer because we needed two parents to feed our daughter and, at the same time, take care of our son who has autism. We need insurance reimbursement for in-home caregivers, because people with anorexia may need supervision. My daughter will eat, if someone is watching. She came home from school one day with a full lunch box, and when she saw me pick up her lunch box, her eyes filled with tears and she said, “*I couldn’t eat, Mommy, ‘cause nobody was watching,*” because the person who was supposed to watch her at school wasn’t there that day.

I would love to see every medical practice have at least one physician on their staff that knows what they are doing, that is up to date, and can properly treat anorexia nervosa. It doesn’t have to be every single physician, but that everybody in the practice knows, “*OK, you need to see this person, instead of me, and they’ll get you squared away, and on your way to recovery.*”

So, how is my daughter doing today? Well, she is what’s called “weight restored.” Her weight is great, she’s got what she needs and more, and she’s growing taller – she wasn’t growing for a while. Her mean voice is weaker. With her weight being in an appropriate place, her compulsive exercise is way, way down and has even disappeared in the last week. This is common – compulsive exercise is common in starvation, but with the proper weight, it loosens its grip.

Olivia said to me, “*Mommy, now that I am eating, I can understand what I read.*” She’s like, “*Now that I’m eating, math is easier.*” She now says math is her favorite subject. Now that she is eating, she can have life.

So how do we keep our children from dying? Well, food is the medicine that fights anorexia nervosa. And if we all work together, we can prevent needless suffering and death. Thank you.

JULIE O’TOOLE, MD (Video: 18:40)

“Saving Lives with Early Intervention: a Pediatrician’s Perspective.”

My name is Julie O’Toole, and I am a pediatrician. I am the founder of Kartini Clinic which is a pediatric eating disorders clinic. We see children with all conditions of disordered eating in childhood. That means somewhere about 80% will have anorexia nervosa. Over the years we have seen greater than two thousand children. I am not a member of an academic institution..., or of the NIMH, nor of the NIH. I am a pediatrician slugging it out in the trenches, and I would like to talk to you about the prevention of unnecessary death in children and in young adults from eating disorders.

I’d also like to talk today about those children who don’t die, but whose lives and whose growth is stunted by chronic malnutrition and semi-starvation, and the effects of that on the brain. We should put it right out front, anorexia nervosa is a brain disorder, it is a chronic mental illness, it is highly heritable. Parents do not cause it (in fact, they could not cause it) and children do not choose to have it.

So, let’s talk about the effects of starvation on the brain for a second. It is true that most of our brain cells are formed before birth. However, the connections between the brain cells, which are what affects functioning, are being made throughout childhood and young adulthood. When you can’t focus and concentrate, you can’t learn; and anything that adversely affects learning, impoverishes and trims the connections between the cells in the brain.

The inability to focus and concentrate that you [Amy] mentioned, is almost universally reported by our patients and by our observant parents. It is a direct result of food restriction. And we are not just



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talking about the kind of learning that takes place in school. The limbic system, a central part of the brain known to be affected by anorexia nervosa, for example, controls emotions, attachment and memory - core features affecting what a child will be like as they grow up and, importantly, what happens to them later.

A child's frontal lobes are the last to become connected. Major functions of the frontal lobes are judgment, insight, and impulse control – behavioral attributes whose under-development can lead directly to the depression, despair and eventual suicide, reported in half of the ten percent who go on to die of their illness. Happiness, hopefulness and resiliency are necessary human traits in the quest to prevent a young person from becoming overwhelmed by despair. And I think those of you who have ever seen anorexia nervosa, as only one eating disorder, like bulimia nervosa,...understand the depths of shame, despondency and despair that these illness cause.

In the past, pediatricians have assumed that only starvation during infancy profoundly affects the brain. However, more recent work on famine really shows that malnutrition throughout childhood can affect brain development. Some of the studies have even challenged the notion that the effect of starvation on the brain is entirely reversible. The specter of irreversible damage to the brain of a child is one of the reasons, one of the serious reasons, why we have got to get serious about treatment and prevention of anorexia nervosa, which brings me to my second point, loosely called “Prevention,” but actually called “Secondary Prevention.”

We don't know what actually causes eating disorders. The biology of these brain disorders is very poorly elucidated. Whenever that is the case, primary prevention is not possible. For example, we couldn't prevent tuberculosis until we understood that it was an infectious disease. We are literally at that stage in understanding the biology of eating disorders. This leaves us with what is called secondary prevention, otherwise known as early recognition and intervention. That's what we're here to talk about.

It is clear from our clinical experience and that of other eating disorder physicians who see children, that even children as young as six years of age can develop eating disorders and begin to starve; typically, slowly at first, with simple food refusals, and more intensely later, with weight loss. When a child this young, somewhere between the ages of six and twelve, has their brain growth stunted along with their physical growth, and this goes unrecognized, we may never be able to completely restore them to health. So, weight loss is a critical clinical sign and symptom that goes under-recognized by pediatricians across this country, and indeed, across the world. Educating pediatricians, nurse practitioners and family doctors to recognize the symptoms of early onset eating disorders, and to take them seriously, is critical to secondary prevention. Educating the general public to the newer scientific findings: that these illnesses are life-threatening brain disorders, and are not caused by parents, or by misguided ideals of thinness portrayed in the media (seductive though that concept may be), is going to be essential to moving forward in secondary prevention. Once the genetics and neurochemistry is better defined, and we understand the mechanics of how this can happen to the brain of a child, we can talk about primary prevention—but not until then. Until then, we need to focus like a laser on early recognition to prevent disability and death. And to this end, teach parents, as the best observers of their own children, and utilize parents as a kind of “early warning system” for pediatricians. Teaching pediatricians not to brush off the concerns of parents is going to be critical. It sounds simple, but it needs a concerted educational effort. In this quest, we ask your help.



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JOAN RIEDERER, Mother (Video: 26:00)

“Giving a Voice to my Family’s Years of Support, Hard Work, and Tragic Loss of Erin”

Good morning and thank you for the opportunity to be a part of this congressional briefing.

My name is Joan Riederer, and I am from Elm Grove Wisconsin, and I am a mother of a young adult woman who was diagnosed with anorexia nervosa at age 11. Sadly, our daughter Erin, lost her life to anorexia in June of 2010, after seventeen years of battling this malignant disease.

From the very beginning our family realized that there was no straight course to recovery. This disease required involvement of the entire family, and it was up to us to find caregivers knowledgeable in eating disorders. Thus began my involvement with the National Eating Disorder Association. Each year I would attend the conference, searching for information, talking with those I was told were the best in the field, afraid that I would miss a presentation that held the clue to our daughter’s recovery. I gradually became more involved as a member of NEDA committees, joined the Eating Disorder Coalition, participated in Lobby Days, and became a Charter member of the Eating Disorder Dream Bill of 2007. Shortly thereafter I joined the Academy of Eating Disorders and was appointed to the international committee of the World Wide Charter for Action on Eating Disorders. In 2007, I was one of the first parents that was invited to speak to the AED membership. On that day I implored the field to address the death issue for anorexia and eating disorders. It is now five years later, our daughter is now a statistic, and we are no closer to finding the key to the treatment of eating disorders. How many generations of families will lose their loved ones to this awful illness?

The years passed quickly. Before we knew it Erin reached the chronological age of adulthood. This is when the nightmares truly begin for the parent of an anorexic child. The most important element of their recovery, their family, is the enemy. Legally, parents are not allowed information regarding their loved one. Anorexia loves this as the very nature of the disease is to protect the anorexic self. Our daughter exercised her legal rights to maintain her eating disorder. There was no legal assistance or support to help us as a family.

Despite continued treatment at numerous treatment facilities across the country, Erin’s illness would not abate. We found it necessary to obtain legal guardianship of Erin, eventually having guardianship in two states - another legal and financial nightmare. The laws regarding legal guardianship vary from state to state. Many patients are treated out of state, requiring coordination of these guardianships. On one occasion, Erin was admitted into treatment as our own state guardianship was expiring. Within days this psychiatric hospital enacted a Chapter 51, State Guardianship of our daughter. Erin was admitted to a hospital for medical stabilization and frantically phoned us to tell us she was being transferred to a hospital with a general psych unit, having no eating disorder expertise. I arrived at the hospital to advocate that Erin be sent to a specialized eating disorder facility. I was told I would be arrested if I obstructed this decision made by the state. After a six week stay at this facility she was discharged at an unacceptably low weight, and no follow up care. In my opinion, a State Guardianship is a death sentence. Another mother from our state described how her daughter was transported to a state run facility in handcuffs, with prisoners. Also, we learned that many major hospitals will not admit eating disorder patients with guardianships, without the patient’s written consent. Is this not the reason a parent would obtain?... This is true folks – major institutions! In addition, now these young women are labeled as treatment resistant and chronic.

The financial toll on our family also needs mention. Early on in our daughter’s treatment we found it necessary to challenge our insurance company after they denied residential treatment. It was necessary to remortgage our house as waiting to start treatment was not an option. After a very lengthy battle we were successful in obtaining full coverage. Unfortunately, all the insurance in the world did not make a difference in the outcome for our daughter.

Erin’s treatment history was lengthy: admission to inpatient or residential treatment for months, with weight gain, discharge, and relapse again. Along the way in our daughter’s treatment there were

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*–Joan Riederer,
Mother of Erin*

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numerous setbacks in her care. Well-meaning caregivers, who unfortunately were not educated in the medical care of malnutrition and re-feeding, were not uncommon. An emergency room physician continued to administer IV fluids while not monitoring Erin’s albumin blood levels, resulting in severe pitting edema in both legs. She required hospitalization for six weeks to resolve this problem during which she had a heart related incident. Luckily Erin survived this. These events could have been avoided with proper care. In the final month of her life, improper follow up care resulted in her ultimate demise. A primary care physician failed to order stat lab tests combined with a hospital that had no policy for returning lab results in a timely manner. Our daughter died alone in her apartment at age 28.

Over the many years of searching for quality treatment, and reading every piece of research we could find, we have learned that without an extensive increase in research dollars, there will be no cure for this disease. Without increased dollars for education of caregivers, we will continue to have eating disorder patients fall through the cracks resulting in an ever increasing death rate. It is our opinion that an increased response by our federal government is necessary to enforce regulation of Article Four of the United States Constitution. Article Four is the “whole faith and credit clause.” This article states that the “*Full Faith and Credit shall be given in each State to the public Acts, Records, and judicial Proceedings of every other State.*” This would allow families to act as guardians of their loved ones and access immediate care regardless of the location of treatment providers.

Ten percent is not acceptable. Thank you.

JUSTIN RIEDERER, Brother of Erin (Video: 34:25)

Hello. My name is Justin Riederer and I am the little brother of Erin. I am currently a senior at the University of Wisconsin, Madison. I am studying neurobiology and after I graduate, in May, I plan to attend medical school.

My sister was always in the business of making those she loved happy. For me this part of her personality was summed up as me and my parents traveled to Colorado to clean out her apartment after her passing in June of 2010. There, in her closet, I found an already wrapped present with a card on top that read “Thanks for coming to visit me, little brother.” I was supposed to visit my sister in Colorado, just weeks before her passing. Unfortunately, she had to cancel because she was too ill.

Growing up as the younger brother of Erin, I saw my sister so thin it was a miracle she could stand. I saw her in too many hospital beds to count. I saw her with feeding tubes in her stomach as we opened presents around the Christmas tree. I saw her in tears so many times – more times than I wish to remember - from this eating disorder that was destroying her life. Through much of this I felt like a helpless observer, my big sister’s life being shattered in front of my eyes, and me having no control over what will happen next. Even before her passing, in 2010, anorexia nervosa took my sister away from me. As I got older, seeing her more than once a year was rare. She was always in treatment and I couldn’t just visit her whenever I wanted to. While in high school, the longest I got to see her was a few month stretch while she was treated in a local hospital. My only chances to see my sister were when treatment brought her close.

I also saw anorexia nervosa strain the relationships between everyone in our family - countless arguments between my parents and sister about the most minute, smallest amounts of food; arguments between my parents about how to pay for the treatment my sister needed. Growing up, dinner table conversations, like “*Is insurance going to cover her treatment?*,” the legality of my parent’s guardianship, and “*Have you eaten today?*” were the norm. I felt like I was always caught in the crossfire, not wanting to say anything that would upset my parents, or my sister.

Of course, my memories of Erin are not all bad. I can always picture the photograph that hangs in the kitchen cupboard in our house in Wisconsin. There she is hanging upside-down on a pair of monkey bars. It sums up everything that my sister could have been had she not been defeated by



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this disease. It captures her intelligence, her goofy sense of humor, and how much she could love life.

I've now come to the point where I can remember my sister and think of all those qualities that made Erin my big sister. These are the things I want to remember, not my dad stopping me in the den of our home and telling me that my sister had passed away from this illness.

LAURA COLLINS, Executive Director of F.E.A.S.T., (Video; 37:30) **“The Central Role of Families”**

My name is Laura Collins, and I am the Executive Director of F.E.A.S.T., and we are an International organization of parents and caregivers. It is a tremendous honor, to have this opportunity, to have you hear from these families, and to hear how very dangerous, and grueling this illness is, and how it effects families. We are really, very honored to be here with the Eating Disorders Coalition, because I believe that the only way we are going to make progress with this disorder is for all of us to stand together; for families to stand up as we have never done. We have been ashamed, and we have stood back and we have been embarrassed, and at times felt guilty unnecessarily. And so, being able to have this opportunity to do this with all of you, feels to me like we are entering another era where we are all together and we have made some progress. Because ten percent, this number, is something that we keep talking about as if there is no way to change it – and I don't believe it. Let me tell you about it.

Eating disorders are not just about eating, and that's often what we keep saying “it's about eating;” but, it's a mental illness, it is a brain disorder, it is incredibly serious. There is nothing about it that has to do with vanity, or bad parenting; and we need to stand together with the science on this and understand – it's not just about eating.

As we've established, eating disorders kill people. They also destroy lives and destroy families. We know that patients do not choose to become ill, and I think the analogy to OCD is far more accurate to the science.

Families do not cause eating disorders and I'm sorry that I even have to say that, because it should be assumed now, as it is with other mental disorders. We need to just stop saying it, and very soon, I hope to stop having to repeat it as a denial, because we won't just start with that assumption any more.

We also need to know that treatment works. I think there is a defeatism out there that makes people think, “Well, this a horrible illness, how awful, people are dying.” But, we're not talking about the fact that good treatment does work, and families who stick with it, and stick with their loved one through thick and thin, can be successful. Not always; but, this 10% statistic is something we've gotten stuck in and we need to stop accepting it.

Eating disorders can be successfully treated, families can be involved; but, we are not doing it. The science is not making it out to the people, although I appreciate that for researchers, it's just a given. And, that for certain pediatricians, that they're on board, and a lot of us families are on board. But, the fact is that getting adequate treatment that brings you through from diagnosis, to intervention, to remission, and keeps going to prevent relapse, is not happening because of real things that we can change. And that's one of the reasons we are going to be talking about the FREED act.

So, my organization of over 2000 families around the world, and clinicians, want to make this the day that we stop saying that 10% is the mortality rate for eating disorders. It is only that rate because we have allowed it to be. And we are going to change, and we are going to stand together, and we are going to do it.

The Board of Directors of my organization, our Advisory Panel, and our members are calling for us to make a worldwide declaration that we find the 10% statistic unacceptable from this day forward. We

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*–Laura Collins,
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F.E.A.S.T.*

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have to make recovery the rule, and the loss of life as a rare and tragic exception. This has to be the last generation, and I really believe we can do this, where a family goes on the internet or goes to a doctor's office, and hears that their precious child has a one in ten chance of dying. We don't have to do that.

So, now I would like to hear about the FREED act, which is something we all can do about it.

JEANINE COGAN, (Video: 42:10)

Policy Director of the Eating Disorders Coalition

“How Congress Can Address the High Death Rate of Eating Disorder”

I want to offer another story as context, as then tie in the FREED Act. I want to continue a theme that has come up through a number of people's talks, and that is, what happens with the stigma and misunderstanding that we are currently up against with eating disorders.

So, let's imagine a 19 year old girl comes to an emergency room, breathless, in excruciating pain, clutching the side of her stomach. She is pale and weak and doubled over in discomfort. The doctor on duty does a cursory exam, asks the patient a few questions, while checking her vital signs, and determines, *“You are having an appendicitis attack.”* The doctor immediately schedules surgery, the infected appendix is removed, and the patient recovers and heals, and returns to her college classes and resumes her daily life.

But what if the doctor decided not to treat this patient? Can you imagine that? A person with a ruptured appendix, who is doubled over in agonizing pain, not being treated and she dies. Not because the doctor misdiagnosed her - she dies because the doctor refused treatment.

That is exactly what happened to Leslie George - Leslie, a 19 year old student at James Madison University, right around the corner, just a few hours away here in Virginia. She was in unbearable stomach pain after a severe eating binge. She said she felt like her stomach would burst. At the emergency room, while on the exam table, Leslie told the doctor, *“I'm bulimic,”* and that she had eaten a huge amount of food. The doctor stopped. He refused to pump her stomach once he learned the reason for her pain. The doctor walked away from his patient. Because Leslie George couldn't slay the dragon of bulimia alone, she sought help, and she was refused. Although she remained in the hospital, the next morning, Leslie died. She died of septic shock. Her organs shut down. Medical staff tried to intervene to save her, but it was too late.

Anorexia or appendicitis, bulimia or bronchitis, binge eating or broken bones - it is unbelievable that one illness would be given preferential treatment over another, but, it happens.

So, one solution to this high death rate, that everyone on the panel has addressed, is the Federal Response to Eliminate Eating Disorders Act, the [FREED Act](#), which Senator Harkin and Senator Klobuchar, and Senator Franken have introduced. This is the first, only eating disorders bill, comprehensive eating disorders bill in the history of Congress, so that's more than 200 years.

By focusing on research, education, prevention, and treatment, the FREED act ends up being a beacon of hope that people will no longer be misunderstood and mistreated due to such ignorance. The FREED act has a section in it that basically will make sure that doctors and nurses do not need to live with the kind of memory that Leslie's emergency room doctor is now living. What a tragic mistake, and what a devastating loss for Leslie's parents. And it is unnecessary.

The FREED act will give our medical professionals better training, and tools for treating people with eating disorders, just like they treat patients with leukemia or lupus. We need more research dollars in order to uncover the best treatment approaches to treating eating disorders. We need better access to care, so those who are suffering from eating disorders have a chance, and a fair opportunity to recover.

And I just love the vision that Laura just outlined for us - that we will be able to really talk about



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recovery as the norm. People can and do recover, and it is unnecessary that people are dying. And so the FREED act has different pieces in the bill that will, in fact, be part of the solution here.

So, we urge members of congress – you are part of the solution. You can save lives and 10% is unacceptable, so we urge you to review the bill and add your name, to sign on to the FREED act today. Don't wait, we've run out of time.

In the Senate it is S-481 and we have a whole section on research. The research is basically, that section is designed in such a way, that we have more research dollars, we bring in more experts into the field, so they can have training. There is some training money in there to bring more scientists into the pipeline, so that we can have a better understanding of the death rates, so we can understand the etiology, and of course, most importantly, good science based treatment, treatment that works.

In the prevention section, we have grant programs that train health professionals - that's what I was alluding to earlier - so the doctors and nurses and pediatricians, etc., all have some training in terms of what are the signs and symptoms and how do I appropriately address this with wisdom.

We also have a section in here where people, educators in the school system will be able to identify when someone might be suffering from an eating disorder, and how to effectively respond to that, who to refer them to, what are the appropriate resources there. There are also public service announcements. There is a section talking about how anti-obesity initiatives really need to have a whole understanding of eating disorders in their efforts, so we don't create more problems as we try to address that issue.

And then, in the treatment section, we have... Basically, it's all about how to have more access to care, so that people who are seeking treatment, aren't refused simply because they don't have money or resources to pay. So, we look forward to seeing more Senators sign on to this bill after coming to this briefing today.

I would like to open the floor; we have ten minutes, so, I would like to open the floor...go ahead Laura.

Laura Collins: (Video: 49:40) Actually, there is something that I asked all of the parents... We asked all the parents coming to bring pictures of their families. So I'd like to ask all the parents to stand up, and show us who is affected by this illness. [parents hold up their family photos]

Jeanine Cogan: If you would like to just look around the room, you can see all the pictures that parents are holding up.

Laura Collins: And along with these are grandparents, and aunts, and uncles, and brothers, and sisters. And all of these families represent just one small sliver of those affected.

Sara Singleton: Hi I'm Sara Singleton with Senator Harkin's office, and I really have more of a comment than a question. I want to thank Jeanine so much for putting this together today, and F.E.A.S.T. and the Eating Disorders Coalition, you all have done a great job of bringing awareness to this issue. And Jeanine, thank you so much for your discussion about the FREED Act. Senator Harkin, as you mentioned, is the chief sponsor of this legislation and if anyone has any questions, or wants to co-sponsor or get any additional information, feel free to get in touch with me, Sara Singleton, because we would love to have more support for the legislation. And for all the families that are here, you are the most powerful advocates we can have in trying to bring attention to this issues, so thank you for attending today, and thank you for your work this afternoon, going around and trying to raise awareness of this legislation.

Jeanine Cogan: Let's give Sara and Senator Harkin's office a huge round of applause. We're going to pass this bill! How about questions or comments?



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Question: (Video 51:40) Can you explain where the bill is? I know it's been on the table a number of times, but where are we as far as the bill?

Jeanine Cogan: Sure. The bill has been referred to the committees of jurisdiction, so in the Senate, that's the HELP Committee, and in the House, that's the Energy and Commerce Committee. And we currently have 27 co-sponsors in the House and 9 co-sponsors in the Senate. So, next year, session starts over (for all you in the audience who know this, forgive me, but we start a whole new session, so we will re-introduce the bill then, or a version of the bill. We will be re-introducing everything then, and then you kind of have to start all over.

Question: So the bill wasn't brought on to the Senate for a vote?

Jeanine Cogan: No. This is a pretty young bill. It takes a while typically to pass bills. I think the second parity act took twelve years to pass. We just introduced it for the first time in 2009 in the House and 2010 in the Senate. So this is only the second time that it has been introduced, this particular session. So the way this works is that you have to introduce the bill and then you have to do a lot of things like this [briefing], a lot of legwork and constituents calling and calling and meeting with their members to help them see how important and useful, this particular legislation is. So that's where we're at, and doing, in some ways, a really good job. And we'll get this passed eventually.

M.B. Krohel: People have to understand that this is not anorexia “nervosa,” this is anorexia “fatalis” and the idea that this is some nervous condition that we are going to get rid of easily is just ridiculous. When you see your child just spiral down,.. they're not there...it's not really well understood in our culture, people just have no clue...this idea of choice, the idea of just eating a cheeseburger that one pediatrician told me “Just give her piece of jewelry and she'll eat a cheeseburger.” A clinician actually said that to me! People need to know – this is a fatal disease – and we need to do a whole lot more. There is a lot of disordered eating in our country, but there's not as much eating disorders and they're really, really not the same thing.

Dr. Chavez: (Video: 54:45) It is very important that we don't mix this up with a lot of things that do not have the same clinical significance. And I think for exactly some of the reasons you are talking about, like the stigma associated and sometimes just the ignorance associated with eating disorders and I think that's why some of that does actually get trivialized...Again I don't think... I absolutely agree with the point that you're making. This is something where one of the things I want to make sure is *not* in the initiative, the initiative asking for specific types of research, is disordered eating, because that thing is defined in twenty different ways, it is clearly opportunistic, and half the time doesn't even get to the crux of what the real problem actually is. And also talking about obesity as an eating disorder, from a psychiatric point of view, it absolutely isn't and the DSM 5 committee, the committee that is now making changes to the diagnostic category of eating disorders, there is a clear consensus that they will absolutely not allow that to happen. It is not that obesity is not a public health problem, it absolutely is, but these are very, very, different and interfusing the two scientifically makes no sense.

Jeanine Cogan: What I'd like to do, I want to make sure as we have a couple of minutes, is there anybody from congressional offices that had a question or comment? No? OK, then we have time for one more.

Question: I have a question for Dr. Chavez. It is clear from what you are saying that there is a good understanding of the lethal aspects of eating disorders and the seriousness of the problems, but when you look at the website, in terms of research, there is not that much being done and I'm wondering if people like you talk to the people who decide where the research dollars are going or what the priorities are within the NIMH. If you could just comment on that...

Dr. Chavez: A very good question. And I've seen the numbers, we actually have the numbers and when we look at the amount of research funding that goes into these specific disorders, there is no question that for the eating disorders, there really is less research money than for schizophrenia or depression. A couple of things through that a person has to understand to put this in a certain context, and I don't think anybody at the NIMH is pleased with this – I don't think this where we think the state of the



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science needs to be, this is absolutely a priority for the Institute, and I can honestly say this and it is very personal for congressman Harkin. Every time we have applications coming in, he always wants to find the eating disorders applications to see what's going on with this and which ones we can fund, so there is no question that this is a priority, but you have to remember at NIMH, we can't fund applications that we don't receive and the extramural research community is a very small community, relative to the number of investigators who study schizophrenia or who study depression, it's a very very small extramural research community.

And so when you look at the difference between depression and eating disorders and the amount of NIMH funding that goes into it, it really does reflect the number of applications that we receive. And also, one of the things we can't do, is we can't fund bad science. Just because someone submits an application it goes through a peer review process. People like me don't make a decision about whether it is funded or not. It depends on the scientific expertise of their peers who give it a certain priority score about the scientific merit of that application. If it is viewed as being meritorious, that something important will come out of it, then that application would be funded. But if it's not good science and they don't think it is good science, then it gets a very bad score. The last thing we want to do is to be putting money into people asking questions that aren't good questions that aren't going to be moving the field forward. First of all, because it just puts out there more bad information and more noise. The second thing is that those people could be doing some very important research. If they get finding for doing bad research, then they spend four or five years doing bad research. We need them to be doing the good research.

Again, it is a very small community. There are some very, very, good investigators as I'm sure you know...like Cindy Bulik and Walter Kaye, but we do need more of them. And one of the jobs I have at NIMH is to look at young investigators, people in medical school, people who are hoping to go into research ...people in graduate schools, people earning post-docs, and assistant professors. And again it is very frustrating because we don't see that many of the junior people coming up. Now we're getting ready to fund a grant from Columbia, focusing specifically on eating disorders and that's – I'm very pleased with that, but we need more young investigators...I'm with you, I'm very frustrated, but I don't know what more I can say.

Jeanine Cogan: Thank you very much. There is actually a part in the FREED act that would provide funding for new investigators, so that's a positive component of it. Thank you everyone. That is the end of our time. I want to thank the speakers again for their participation.

RESOURCES:

F.E.A.S.T. (Families Empowered an Supporting Treatment of Eating Disorders)
www.feast-ed.org

Eating Disorders Coalition
<http://www.eatingdisorderscoalition.org>

The Federal Response to Eliminate Eating Disorders (FREED) Act
<http://www.eatingdisorderscoalition.org/documents/freedActhouseandsenate.pdf>



Video of: US Congressional Briefing: Ten Percent is Unacceptable
<http://www.youtube.com/watch?v=Uokh0bHZS-E>
or use QR Code



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