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**Testimony Before the U.S. Congress Field Hearing on Parity for Mental and Addictive Disorders
March 16, 2007**

My name is Deirdre Drohan Forbes. I am an addict. My father was an addict. My husband is an addict. My daughter is an addict. Fortunately we're all in recovery. This coming May, I will celebrate 20 years clean and sober. I happen to have a co-occurring disorder, Major Depressive Disorder. My grandmother my mother struggled with it as well. I wish I had an exact date I could point to when my depression went into remission, as I can with my alcohol addiction, but that kind of information is not readily definable.

My daughter was genetically loaded for facing the same issues from day one. My husband's family genogram is much the same as mine.

Other risk factors were also at play. In first grade this bright articulate girl was diagnosed with a learning disability. No matter how we tried to keep this label positive —focusing on Goldman's identification of multiple intelligences — she quickly became convinced she was different, dumb and doomed to failure.

She made friends easily but always chose the highest achievers in her class — not nerds but quirky types. When one of these "best friends" became anorexic, she joined in the starvation. That was about the only thing we ever caught in time. A nutritionist — not covered by insurance — helped pull her from that deep hole. Later came diagnoses of ADHD, ODD, depression and substance abuse.

Our daughter was 5 when she saw her first psychotherapist. Our insurance partially paid for her treatment. We had to stop, however, when we were forced to change insurance companies and could not afford the co-pays. Our school district then became our mental health care provider.

There she saw a psychologist once a week, as well as a learning specialist. But she grew worse. The district placed her in an "emotional support program" in another school district. We again found an outside therapist and psychiatrist partially paid for by insurance. She was prescribed antidepressant medication.

At this time my husband was freelancing and we had to buy our own insurance. Year after year, our premiums increased. We struggled to pay them in order to continue coverage—mental health coverage in particular. The monthly fees became larger than our mortgage, and this didn't include the out-of-pocket payments not covered in mental health and substance abuse care.

The first time we our daughter entered a rehab for substance abuse treatment, we were told to take her home after four days. My husband spoke with a supervisor at the insurance company, who told us our daughter needed a "less restrictive" program. My husband replied that she had been attending a "less restrictive" program and they had determined she needed to go to a "more restrictive" environment. Then the supervisor said that the reason our daughter had to leave rehab was that she was not using drugs. Incredulous, my husband replied, "the only reason she's not using drugs is because she's in rehab!!!" Our daughter got two more days. We wonder how different things might have been if her treatment on that first admission, at age 15, had been based on medical need rather than financial expediency.

As it turned out, our daughter was in more than a dozen re-habs, wilderness programs or de-toxes before she recovered from her illness. After dropping out of high school and running away from home, she lived on the streets of New York and Philadelphia, getting deeply involved in drugs and addicted to heroin. It should be pointed out that she was introduced to IV drug use not on the lower east side of NY, where she wandered for some time, but in our own upscale suburban village by a neighbor.

On the occasions we could reconnect with her, we knew the only true treatment that would help her had to be long term.

But our insurance wouldn't pay for it, we couldn't afford it, and she probably wouldn't go if we could afford it. In desperation we prayed she'd get arrested and be either sentenced to rehab or jail — the last hope for affordable mental health and substance abuse coverage.

At one point by searching the internet, we found a long-term rehab for women run under the auspices of the Catholic Church. It accepted payment on a sliding scale we could afford. She lasted there three months and was then back out on the street and homeless until she met up with an older man with whom she squatted in numerous basements on the lower east side. Months would go by when we wouldn't hear from her. We didn't know if she was dead or alive.

Finally, she wound up in Coney Island Hospital where it was suggested she go to a methadone treatment program. We didn't find out about this until months later, when we tentatively allowed her back into our lives. She spent over two years at the clinic. For 18 months she detoxed from methadone, wanting to be free of the drug and the clinic with its rules and often time punitive regulations that kept her from progressing in her recovery. But we are forever grateful for methadone and Medicaid, which gave her back an opportunity for life. Today she's attending community college and just yesterday we learned that she has been accepted into a professional writing program in a small college in New England with a partial scholarship. With help, recovery works.

Because of our experience we became active advocates for the passage of Timothy's Law. We didn't want to see other parents suffer as we did, and other children go untreated and die due to lack of insurance coverage. While we're happy New York has a new law, it will only cover a fraction of those who need help. And it would not have helped our daughter in any significant way.

Last week, to my utter amazement I learned passage of Timothy's law would not benefit my family at all! Unbeknownst to me, and I'm sure to many thousands along with me, those who work for institutions, corporations and businesses which "self-insure" are not subject to state mandates under federal Erisa statutes. I've been told that in the past this was instituted to simplify insurance coverage for businesses operating in more than one state with differing mandates. I've been told many of those businesses abided by the mandates anyway. I work for a large medical institution in New York. One would think if any business would abide by Timothy's Law they would. But our health care system does not seem to deal in logic. For the thousands perhaps millions like me the only way we will ever have the full parity we deserve is with passage of federal legislation such as you propose.

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**Testimony Before the U.S. Congress Field Hearing on Parity for Mental and Addictive Disorders
March 16, 2007**

Good morning and thank you for the opportunity to testify. My name is Thom Forbes. This January, I had prostate surgery at Memorial Sloan Kettering Cancer Center. Sloan Kettering is not in our insurer's regular network of hospitals, but there is a special cancer resource provision under our plan that allowed me access to several world-renowned institutions and doctors.

The bill for my 24-hour hospital stay and surgery was \$17,616.66. My out-of-pocket charge was \$300; insurance paid the rest.

I could be cured. Or I could have a relapse, requiring radiation. Chemotherapy could extend my life for many years after that. If our coverage remains the same, my expense will be minimal.

I am very grateful for the care I received, and for how little it cost me. But I am perplexed about why the standards have not been the same for my daughter and wife when they battled diseases that came much closer to taking their lives than cancer did mine.

I recently came across a journal that my wife, Deirdre, began writing in the spring of 1997. It had been ten years since she had last had a drink or recreational drugs, but she was in treatment for depression. The journal began:

"My brain is filled with noise. Mostly disturbing noise — no happy sounds, sounds of chaos, sounds of failure. I don't like this. I don't like this therapy stuff..."

"I don't think these drugs are working. I'm in the basement again. I want to crawl into a deep dark space ..."

"I'm being sorely tempted to drink and drug. I don't know where this person came from but I wish she'd go away before I lose sense altogether of that other one — the one who loves her husband, son and daughter."

Six weeks later she wrote:

"Knocking at the gates. Anyone take me in? This is not living. Bother too many people. Just made two people cry with pronouncement of suicide. Don't want that — keep mouth shut from now on. Pipes, hoses, tailgates — maybe I don't need a garage..."

Then, in the midst of more madness like this, Deirdre suddenly wrote:

"Don't quit five minutes before the miracle happens."

Just ten days later — after she'd been prescribed yet another new combination of antidepressants — that flicker of hope seemed to manifest itself. She wrote:

Over lunch with Nancy, I said, “If I still feel this way next Monday at my next doctor’s appointment, I’m going to walk in, shake his hand and say, “Dr. Sacks, let me introduce myself; we haven’t met before but I’m Deirdre Forbes.”

But that was not the happy ending it appeared to be. Again the following winter, I’d find her huddled in the back of our closet — mute, dark-eyed and disheveled. Once I had to call the police because a friend alerted me that she had driven off from a support group meeting talking about ending it all.

Nine years ago tomorrow, Deirdre was admitted to New York Hospital in White Plains. She had deteriorated to the point that doctors advised that she undergo electroconvulsive therapy. It thankfully brought her back from the abyss. After her ECT treatments, she continued talk therapy as her psychiatrist searched to find the right mix of medications to stabilize her depression and psychosis.

I’ve been very fortunate. Deirdre is not only beside me testifying today, but she has helped countless other people as an advocate, as an active member of the recovery community, and as an addictions professional. I’m lucky because my daughter is in recovery and attending college thanks to a methadone program and, more recently, suboxone. I’m lucky because, despite the vagaries of our income, we’ve managed to scrape together what is surely well over six figures to pay for treatments — at times by breaking into IRAs, going heavy into credit card debt, or by taking out a second mortgage.

Deirdre’s talk therapy alone this year will cost \$9,600. We will be responsible for \$6,600 of this. Why is the formula different for her life-saving treatment than it is for any other medical condition?

Through our testimony here today, Deirdre, Carrick and I wish to leave you with these five points:

1. The diseases of mental illness and addiction are often intertwined.
2. There are many paths to recovery, but recovery does happen, and those who recover can make a great impact on the lives of others.
3. Recovery is not always a straight line. As tempted as she was, Deirdre never drank again — but her mental illness took several years to stabilize. She thankfully did not quit five minutes before her “miracle” happened — a miracle that was clearly the result of treatment.
4. Deirdre’s and Carrick’s diseases were more life threatening than mine, yet mine is almost fully covered at one of the best institutions in the world and we are forced to pay most of the cost for theirs.
5. These diseases are based in biology and genetics. We’ll leave it to the experts to make the scientific case, but I can testify that I am an alcoholic, my father and his four brothers were alcoholics, their father was an alcoholic, and my great grandfather was an alcoholic. As you’ve heard, Deirdre carries a similar pedigree.

There is no logical reason why these diseases should not be treated the same way as any other. Lack of treatment is killing people we love; people who *can* recover and make a difference in our world, just as my loved ones have and will continue to. Thank you, again.

Submissions:

DVD of “Saving Carrick,” a Dateline NBC documentary originally broadcast on July 29, 2005. For further information and the back story, see *The Elephant on Main Street: An Interactive Memoir of Addictions and Recoveries*, www.elephantonmain.com.

“Silent Treatment: Addiction in America,” a national, multimedia public education initiative produced by Public Access Journalism LLC, supported by the Robert Wood Johnson Foundation and distributed by McClatchy-Tribune Information Services, August 2006. For more information, see www.silenttreatment.info.