

Testimony

Laurel Bertrand

Dear CFSAC Advisory Committee,

Myalgic Encephalomyelitis (ME), often inappropriately referred to as chronic fatigue syndrome (CFS) in the U.S., is a serious and debilitating neuro-immune disease. While cases vary from mild to severe, studies have shown that many patients experience a level of disability equal to that of heart failure or late-stage AIDS.

It has been estimated that 25% of ME/CFS patients are fully disabled --often housebound or bedridden for years on end.

Yet, not many know the full spectrum of the illness because much of the suffering occurs behind closed doors. Patients are often too sick to tell their story. Some are living in darkness, some in silence and some in both. Some have not been able to leave their bed in years. Some struggle to eat, drink, speak and even breathe.

The following are just a few of those patients' stories.

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My name is Laurel. I was 24 years old when I came down with ME/CFS following an infection with mononucleosis. I was active, ambitious, successful and well-educated. I loved travel, adventure and spending time with friends and family.

I never expected, at the prime of my life, to spend over a decade bedridden --stricken with a horrible disease that has a trivial name and no effective treatments.

I am unable to stand, walk, speak above a whisper or fully bathe and care for myself. I have lost 15 years of my young adult life – 15 years which can never be retrieved.

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My fiancé, Jim, was a former athlete in high school and college who earned a PhD from Carnegie Mellon.

Jim fell suddenly ill at age 19 after developing mononucleosis. He's been sick for almost three decades - more than half his life.

His dreams and ambitions cut short, he's been housebound and unable to work for years. He requires a wheelchair because he can no longer walk. He longs for the day he can run again.

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Nina was struck down with ME/CFS at age 27 following a flu-like illness.

A young woman with many hopes and dreams, her life was suddenly turned upside down. She used to love to dance. Now she is unable to leave her bed and needs constant care.

At one point, Nina became so sick that she was struggling to eat, drink, talk and even breathe. She has been hospitalized several times. Her biggest wish is to be strong enough to sit in a wheelchair again, if only for a couple of minutes.

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Alexis -- an ambitious, successful and energetic young woman -- also fell suddenly ill in her late 20s. She has been sick and housebound for many years now. As a result, her hopes for her future have all been forced on hold.

Alexis recently suffered a severe setback, rendering her essentially deaf and blind due to the neurological problems imposed on her by severe ME/CFS. She must now live in darkness and silence 24 hours a day/7 days a week.

Her family currently communicates with her using Tactile Fingerspelling – a form of sign language for the deaf and blind. She cannot even tolerate the sound of whispers

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Ben was a healthy, active 18 year-old when he became suddenly ill following an infection with mononucleosis, which later led to a diagnosis of ME/CFS.

Now 23, Ben is essentially completely bedridden. On a good day, he can take a few steps with a cane. At 6'2 he weighs just 118 pounds. He needs others to wash his hair and cut his food.

Ben spends every day in bed as his friends and peers move on with their lives, doing and experiencing all the things he longs to do but no longer can.

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Marian was a former registered nurse (RN, MSN). She created a company called TrakMed, which provided trackside medical care for many auto racing teams. She partnered with General Motors Racing, providing innovative care for their drivers and teams.

Marian became suddenly ill in her 40s following a flu-like illness. She has been ill with ME/CFS for 10 years and is currently housebound and mostly bedridden. She often has trouble sitting up in bed, and she requires supplemental oxygen to breathe. Her sister, who also suffered from the illness, died of heart failure as a result of ME/CFS at age 49. Marian sometimes worries that she may meet the same fate.

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Emily became ill with ME/CFS when she was just 6 years old. She's now 30. She's been sick for 24 years --almost her entire life.

She writes: "I cannot be washed, cannot raise my head, cannot have company, cannot be lifted from bed, cannot look out of the window, cannot

be touched, cannot watch television or listen to music - the list is long. ME has made my body an agonising prison."

Emily's daily life involves medicine/fluid being pumped into her stomach through a tube, various injections, diaper changes, transient paralysis, and pain so severe she sometimes hallucinates.

"This wretched, ugly disease is made all the more so through the scandalous lack of research into its most severe form and the lack of necessary, appropriate support for those suffering from it. This is something that must change."

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Please listen carefully to the testimonies being presented today. Please see our faces, hear our stories and understand our desperate plight. Some of us are quite literally fighting for our lives.

In return, we are not asking for much. We are simply asking for the basics of what should be expected with any illness:

- a clear and accurate definition
- an appropriate name that doesn't belittle the disease
- adequate funding for serious biophysical research
- clinical trials of medications in search of treatments and a cure
- and increased awareness and education about the true nature of this horrible disease.

That's all. It's what is done for every other illness of equal severity. It's even what is done for illnesses of lesser severity. Why has it not been done for ME/CFS?

We've been waiting 30 years for the government to take action. We cannot wait any longer.

Thank you.

Sincerely,

Laurel Bertrand

Note: All patient stories are presented with permission.

My original testimony contained photographs (also used with permission) of each of the above-mentioned patients. However, I was told photographs would not be allowed as part of public record, and was asked to resubmit my testimony excluding the photographs. You can find my original testimony (with photos) at <http://www.dreamsatstake.com/2011/09/testimony-glimpse-into-severe-mecfs.html>

Due to my health, it took me over three months to complete this testimony.