

Kathryn S and her granddaughter Kitty

- Kathryn took care of Kitty when she was born, for 5 weeks, as Kathryn was unknowingly coming down with "CFS" after a severe illness that lasted 4 months, and which she thought was over with. She believes she transmitted her reactivated Epstein Barr Virus and HHV6 to Kitty at that time.
 - Kathryn has been sick for 28 years and Kitty for 12.
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Tom

- Sick for 8 years
 - The Office of Women's Health is not for M.E.!
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Ren

- Ren is 24 years old and suffers from M.E. (Myalgic Encephalomyelitis) and helps to raise awareness by using social media; including a video blog documenting his life with M.E. and his mission to try and overcome it.
 - When he's able to perform, he's a talented singer-songwriter and enjoys composing his own musical material including lyrics and melodies. He expresses himself through music living with this horrendous disease.
 - He has severe food intolerances and malabsorption issues started at the same time as his battle with M.E.
 - Here's his fundraising page to help get treatment. <http://www.gofundme.com/boywhocanteat>
 - Patience | Ren Gill | M.E -song https://www.youtube.com/watch?v=284ugnS_ruQ
 - His FB Awareness page: <https://www.facebook.com/mevsmeblog>
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McKinna

- Photo is from 2011 at time of IVIG treatments.
 - She was 17 at the time of the picture.
 - She is 21 years old now.
 - Her mother is her caretaker.
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Crystal T.

- I've had ME/CFS & Fibro along with other pain problems since at least 2006 when diagnosed.
- I get through it by helping others, it makes me feel better.
- I have a pain advocacy page and a group for women with Fibro and CFS.

John H.

- I experienced an acute post viral onset in 1988.
- Since then it's been 27 years of watching too many people suffering terribly without a sincere honest commitment by the health department to adequately fund needed research.

Anna Mina

- I became ill with Severe Myalgic Encephalomyelitis in 1984.
- From that time on I could no longer work or participate in activities which I enjoyed prior to becoming 99% Housebound.

Tom C.

- ME/CFS (Myalgic Encephalomyelitis) sufferer since developing illness Jan 2014 while a sophomore at Stanford.
- Was a 4.0 computer science student with a dream research elective and summer job at Dropbox.
- Unable to do either due to ME/CFS which developed following a viral illness.
- Now bedridden 23/24 hours for 6 months, not even able to read messages on his phone.
- Likely to permanently be disabled unless research finds a cure.

Colleen S.

55 years of age and have been chronically ill for 25 years.

Originally diagnosed with Chronic Fatigue Immune Dysfunction Syndrome, I fit the expert's criteria for Myalgic Encephalomyelitis. This is a devastating illness which forever alters the lives of sufferers and their families. Every day since onset I have had a feeling akin to the flu, with pain throughout all the joints and muscles in my body, a dysfunctional immune system which leaves me vulnerable to viruses and bacterial infections and intolerant to a wide variety of foods leaving me with rashes and hives as well as thinning bones. Due to hypersensitivity to drugs, I am unable to take pain medications so acupuncture and a transcutaneous electrical nerve stimulation (TENS) unit are the only avenues I have to cope with relentless pain.

The hallmark symptom of this disease is activity of any kind (mental or physical) which exacerbates all symptoms. Because of this, I am unable to work and am mostly homebound. If I don't adhere to minimal activity, I risk becoming more severely debilitated and completely bedbound.

My story is typical of over a million sufferers in the U.S. Education about the horrific nature of this devastating illness and funding into biomedical research is desperately needed. Private biomedical research is showing promise and there are medications, which the FDA has resisted approving for use in this disease, which need to be studied to confirm effectiveness. As the founder of a local support group, I am confronted daily by people who are newly diagnosed and just beginning to realize their lives will never be the same. Suicide in this community is a serious problem.

Gabby Klein

My name is Gabby Klein and I suffer from Myalgic Encephalomyelitis.

Twelve years ago, at the age of 48 and at the height of my career as a manager in an insurance company, I fell violently ill with a stomach flu. Within six weeks I could no longer work and had to quit my job. I was bedridden with muscle pain, headaches and weakness.

I could no longer care for my children and home. I have remained disabled with this devastating neuro-immune disease for the past twelve years. I went from living a very productive active life, working and caring for others into a disabled person needing others to care for me.

There are currently no treatments for me and others with this disease. Very few doctors are educated and understand ME. The Department of Health and Human Services has not served ME patients well. The NIH has refused much needed funding for research in order to bring much needed relief for a million patients in the US alone.

Please help us lead a normal, pain-free life and urge NIH to spend the much needed money in biomedical research for ME.

Sally Burch

Age 52

My illness probably started in 2011 with a series of severe viral infections, but a lady's operation in March 2012 tipped the balance and I have been unable to work since that day.

Previously I was a Biology lecturer in Further Education, and I led an active and busy life, including:

- riding horses with my daughters
- training my dogs for agility competitions
- keeping a smallholding with my husband where we raised livestock and organic produce for our own consumption
- and regularly hosting foreign visitors on a Help Exchange programme

In those days I could tackle any physical challenge to which I set my mind.

Becoming ill with ME was an immense shock to my world.

I have now learned how to limit my physical activities to prevent further decline, but this has now left me unable to walk beyond the house, and in need of powered wheels to get out. I can socialize for only very short periods, and need an incredible amount of horizontal rest time daily. I feel as though my active life has been stolen from me.

Research funding is urgently needed!

Vanessa Yeuk Lin Li

Vanessa came down with ME (Myalgic Encephalomyelitis) when she was 19 years old and during the last fifteen years of her life she suffered from severe symptoms of ME, which could leave her completely debilitated and bedbound for months at a time. She suffered from severe pain from crushing migraines and tortuous muscle cramps in her limbs, as well as many other symptoms that when flaring would make living in her own body unbearable.

Notwithstanding the toll living this illness took from Vanessa, she was a kind and beautiful young woman, a talented artist with a quick and insightful mind and a wonderful sense of humor. She was well known in the ME patient community, with many friends and admirers. She was a committed patient advocate using what little bits of energy that she had to try to bring awareness and funding to this illness. She was also a beloved daughter to her mother and father and loving sister to her two brothers.

To her family and friends her death was a gut wrenching tragedy that left a swath of heartbreak across the globe.

Vanessa's death resounded among the patient and medical communities, a gauntlet thrown down to challenge the world to see the truth that ME is really, a terrible and frightening disease that steals the heart and soul of a patient's body and leaves them without hope for the future.

It is for patients like Vanessa that we are out on the Mall marching today!

We want the government to help us fight for patients living with this illness. We don't want one more young person to have their hopes and dreams cut short and find themselves living in purgatory.

We bring Vanessa's memory with us today to keep her memory alive and to honor her wish that her death have meaning beyond the suffering she endured.

TRACEY SMITH

Diagnosis:

- Myalgic Encephalomyelitis [ME, severely moderate patient per ICC]
- Chronic Fatigue Immune Deficiency Syndrome [CFIDS 1989, aka CFS]
- Fibromyalgia [2003]
- Follicular Non-Hodgkins B Cell Lymphoma [F-NHL 2011, in remission]

History: 26 Years battling Myalgic Encephalomyelitis [ME] (misnamed CFIDS/CFS) . Disabled; Home-bound; 90% in bed; difficulty w/ self-care. Suddenly became sick at age of 15 with Stomach/Respiratory Virus; Bacterial Pneumonia; Severe Case of EBV (aka mono). Though pneumonia cleared up, remained severely ill and homebound.

Was then diagnosed with CFIDS. Took 5 years to gradually go into remission (never fully regained my health but functional enough to work). Flares would still happen; longer to recover from infections than the average person. Then relapses started happening after clusters of viral infections/adverse vaccine reaction. Drastic lifestyle changes were made in order to allow time to rest. This stopped the decline. Remission would be achieved each time. This repeated until 10 years ago when a progressive decline began and I could no longer work.

About 6 years ago, the rate of decline increased. I was unable to pace as needed because I could not afford hired help to take care for myself/household. Nor did doctors order the needed bedrest or home care. My parents moved nearby, and my mother semi-retired to care for me and my family because I could no longer care for my children or myself.

At the age of 37, I discovered my cancer; one that is normally found in those over 60. Many ME researchers/clinicians recognize there is an increased risk of Non-Hodgkins Lymphoma in severe/moderate ME patients, but oncologists and general doctors are not taught this by the government. Prior to finding the tumor in my cheek and enlarged lymph nodes, I learned of the risk through a history book of ME/CFS, Osler's Web by Hillary Johnson. Because of that book, I understood what my symptoms meant, and insisted on a scan. The cancer was diagnosed and treated before it could reach my brain.

Reason for Advocacy: I saw an urgent need to share the political and scientific history of ME. Most doctors are not educated on this disease, and are not aware of the knowledge that has been gained by the disease expert researchers/clinicians who defined the disease in the 2011 International Consensus Criteria for ME. I am fighting for proper definition, treatments, and research because not only has the disease threatened my life but also my family members. There is a risk my husband and children can become ill, and the risk increases for children once they reach adolescents. Early diagnosis and treatments can save them from becoming disabled. The United States HHS/NIH/CDC government entities have mishandled this disease for 30 decades and continue to go against the advice of the disease experts. Through social media, I have met so many other individuals and families struggling to survive; I want to help lessen the suffering. Too many have died, too many have suffered.

Experience: B.S. in Microbiology/minor in Chemistry; Medical Diagnostics Product Specialist/ Quality Assurance (7 years); ME survivor for 26 years, cancer survivor for 4 years.

Joni

Diagnosis: Myalgic Encephalomyelitis (M.E.) Chronic Lyme Disease

History: Hi my name is Joni, from central Iowa. Another person is stepping in for me, to be my voice and a presence because I am physically unable. Thank you for listening to me and my advocate.

I could be your sister, friend, cousin, daughter, mother or neighbor. This disease can affect anyone from adolescents to adults; male and female; all races; and worldwide. An estimated 1 Million in the U.S. alone have this; most misdiagnosed or undiagnosed, 14 Million worldwide. I have survived 18 years of my life with this chronic illness and it is progressively getting worse.

The harsh and debilitating symptoms that I experience involve: the heart, central and autonomic nervous systems, neurological and immunosuppression, viral, fungal, and bacterial infections. These are keeping me mostly bedbound/ housebound.

Reason for Advocacy: Sadly, many of us are misdiagnosed or untreated; mistreated by medical establishment; isolated; and often times, the disease is misunderstood by doctors, nurses, family, and friends. Suicide rates are high due to lack of effective treatment, support, and care.

Our plight is a quiet one. Our loss of income, loss of strength and abilities; prevents many of us and those who are healthy from stepping forward and advocating for us. They are too busy being our caregivers or stepping in to care for our families and struggling with the loss of funds. Those that do advocate for other patients, do so sacrificing precious energy and funds.

ME's symptom severity runs like a rollercoaster subjected to highs and lows caused by attacks to the immune and metabolic (energy producing) systems. This very nature is common with many invisible, chronic illnesses at various stages. So those that do not suffer with a chronic illness easily miscomprehend the totality of the disease. When we are at our best, we are amongst others; not hidden in a darkened bedroom, unseen, and unheard. Those that are mildly affected are struggling to not lose their jobs, drag themselves through basic household duties before collapsing. This most often keeps them from advocacy. We ask for your help.

Help us DEMAND: Funding, Biomedical Research, Effective Treatments, & Medication

The international ME experts created International Consensus Criteria/ Canadian Consensus Criteria guidelines for doctors to learn, diagnose, and provide some symptom relief. This criteria aligns with the World Health Organization's ME diagnostic neurology code since 1969! Although ME is a debilitating disease that affects millions, the U.S. government has maintained a flat line of just \$5 Million/ year, less than hay fever or male pattern baldness. We deserve a decent quality of life. Your help is appreciated!

For more information see: MEadvocacy.org

Please help us by learning more about the disease at MEadvocacy.org and push for more bio-medical funding to get the answers we desperately need.

Thomas Hennessy, Jr.

Thomas Hennessy, Jr., an M.E. patient and advocate, was the creator of the annual International Awareness Day, which is held during the week of May 12th in recognition of all who suffer from Complex Immunological and Neurological Diseases (CIND).

He was the Founder of RESCIND INC., which stands for (Repeal Existing Stereotypes about Chronic Immunological and Neurological Diseases) he gave a quarter of a century of his life for this important cause. He lost his battle with this serious and debilitating disease on Sept. 9, 2013.

He was a severely affected patient who suffered from extreme pain. The U.S. medical system let him down with their lack of support and treatment. He was a beloved champion and an outspoken advocate determined to make a difference in the lives of those who suffer the most. He is missed by many.

A quote from Mr. Hennessy:

“If a cause and cure are to be found for ME, FM, MCS, GWI, "Chronic Lyme Disease" and other related C.I.N.D. illnesses in the near future, government and medicine must be made fully aware of their scope and impact.

Despite the efforts of a number of dedicated groups and individuals, there are still vast pockets of ignorance and misunderstanding. To this day, many patients run directly into a medical establishment that, in general, knows very little about these serious threats to human health.

It is therefore crucial that all those affected by the illnesses make their voices heard, especially on May 12th of each year.”

– Mr. Thomas M. Hennessy Jr.