Missing since childhood:
Sarah | Germany

"My name is Sarah. I am 42 years old live in southern Germany. I have been suffering with ME since I was a small child.

During the last 10 years my ME has been getting worse and I have deteriorated further.

I'm forced to rest in bed for 23 hours each day. I see my son only a few minutes a day."

Missing since 1987:
Karen C. | Sacramento

"My career was just getting started -- I'd been offered my first political appointment -- and had to turn it down because of my health. February 1987…

I've already been sick more than half my life.
In a few months it'll be 30 years.

**And still no treatment, no cure,
because of politics."**

#MillionsMissing

Missing since 2015:

Lizzie | Chicago

"I am Lizzie. I love all kinds of sports. I played basketball, softball and soccer. I really love the Bears. I was the fastest girl in my 4th grade class for the mile run. I am a really good student. These are all things still part of me. But now I have ME and I can't do anything I once did.

I can't go to school for more than an hour, my head explodes with pain. I hurt <u>allll</u> the time. I miss seeing my friends but I get too tired – I would rather not see them.

Now, I spend a lot of time doing crafts and in my bed.

I did this cardboard boat race with my sister a few weeks ago. After we finished the race (we didn't sink!), I was in bed for 4 days exhausted and with a huge headache and stinging ears. But it was fun and worth the effort to recover."

Missing since 2000:

Lori B.

"This WAS me, a successful executive, training for a marathon, and with a very active social life. I was ALWAYS on the go and worked many long hours to get ahead in my career… and I loved it.

One morning I woke up, went to get up, and couldn't stand up. That was the start of an ongoing 16-year battle with CFS/ME. A brick wall stopped me from running and exercising.

I was finally diagnosed in 2004 after being told my symptoms were all in my head, and that I just needed antidepressant medicine.

My neurological symptoms worsened noticeably in 2008, and by 2010, I had to give up my life as I once knew it.

I have lost my career, social life and friends. I spend most of my waking hours resting or laying down. I have had many of the neurological components of the disease (including POTS and seizures) and have not found a neurologist who believes in ME.

People will say to me, 'well you look fine', which drives me further into seclusion...."

Missing since 2013:
Jamie D. | California

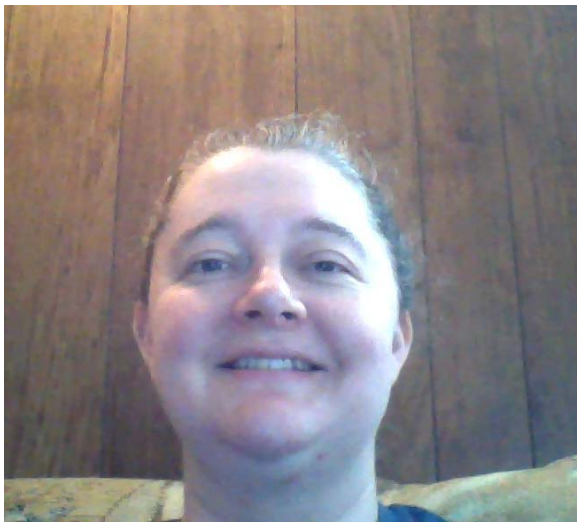
"I am 26 and have been sick for two-and-a-half years too long. I was graduating from college, working full-time, when I started to lose weight, get profoundly fatigued and cognitively impaired after mold exposure and two back-to-back viruses. I was a surfer with a knack for psychology, concerts, dancing, and so much more. I always loved science and healthcare.

Since my diagnosis, I have lost friends, family, jobs, school, and dreams.

The unknowingness is the worst. Having ME means never knowing how I will feel minute to minute, whether I will be left bedridden again, and if so, for how long this time? How much money I will spend on treatment… will I be left homeless and unable to take care of myself again? Will there ever be a cure?

I fight tooth and nail every day to hold onto hope that I will one day live the life I deserve to – along with the millions of other people who have ME."

Missing since 1992:
Heather E.



"I am a Spanish translator, substitute teacher, and Christian counselor. I have had ME/CFS for 24 years.

Before I got terribly sick, I did a lot of traveling.

I currently am almost entirely homebound. I can only translate online. I am not able to take on many counseling clients due to my symptoms.

Here are pictures from before and after I got sick.

Please continue to research this illness as many of us are suffering horribly."

Missing since 2014:

Shar | Washington

"I am bedridden in a dark room as heat, light and sound trigger my symptoms: I try to sleep during the day and do anything I absolutely must at night.

The black DNR bracelet (in photo) is on my arm at all times now as energy levels have been steadily declining each year.

In 2016 I am taking high dose, long term antivirals to fight against high level Epstein Barr Virus as well as other tablets for pain, brain fog, insomnia, and debilitating fatigue.

My home has become my hospital. ME/CFS can and does spread (via saliva), but there is no one diagnosis, treatment or cure or even name which is what 4 million patients in America are trying to change - mostly from their beds.

Missing since 2003:
Amy E. | California

"This might not look like a photo of a sick person. But the healthy me would be upright, smiling with friends around, without dark glasses and able to look into someone's eyes.

Jan. 13, 2003, a severe travel-related infection triggered sudden-onset ME. Previously very energetic and healthy, I can no longer work and support myself, enjoy time with family and friends, or contribute to the community. I don't even move or breathe normally.

Almost 14 years ago I had biked every day, studied yoga, hiked, climbed and camped. I am now 80% housebound and cannot leave the house unattended more than 2 hours every 10 days."

Missing since 2011:
David B. | California

"In September 2011, I lost my life as I knew it to ME. This happened before I could fulfill my dream of graduating from college and pursuing a doctorate in Physical Therapy. I went from an extremely active and fully functional college student to being mostly bed- and house-bound, lying in a dark room each day for most of the last five years.

At my worst, I was unable to speak or make facial expressions, and could have been classified as legally blind. With a severely weakened immune system, my four failed attempts to return to school led to serious lung infections. I am still fighting them today.

Whenever I began to experience improvement, I followed exercise therapies recommended by the US Centers for Disease Control (CDC) that caused massive relapses. I learned too late the CDC's recommendations are based on a flawed medical study and that exercise can be dangerous for M.E. patients. I've sought a cure from more than 15 doctors in a variety of specialties, but have been met with mostly ignorance about this "Invisible Illness."

Fortunately, I have recently been blessed with several months of improvement. I am using the energy I have to try to help the 2.5 million Americans who are suffering with ME finally get increased federal research funding."

Missing since 1999:

Alana G. | Virginia

"In 2001 I was the architect of a $100 million airport renovation and expansion.

That was my last project before I was forced to admit that I had to go on disability. I had been on top of the world, where my dreams had led me – and I had pushed to be able to be - since I was 14 years old.

In my life I have always been go, go, go and pushing myself to the point where I couldn't possibly push any further, an over-achiever for sure.

Later on, society is responsible for pushing and not being supportive when we needed to be allowed to properly care for our health, most often begging for our very lives and being flat out ignored."

Missing since 2013:
Oihan U. | Spain

"I am the webmaster of the largest web-fishing lures in Spain. I traveled many places in the world to fish. Now I cannot fish and I had to quit my job.

I did not recover from a bad flu in April 2013.

95% of the time I'm home; if I go out I pay the price."

Missing since 2008:
Lucy M. | Wiltshire, UK

"Today I am sicker than ever and am currently casting about for viable medical help.

Two things keep me going: stubborn determination that there is a path to recovery and savouring small gifts of compassion.

We may be unable to affect the outcome of a hellish circumstance, but the way it is experienced can always be altered and improved."

Missing since 2014:
Henderson F. | São Paulo

"Here I send a picture of a great day,
with adventure,
joy, outside activity,
and that is what
I miss the most.

I am missing adventure –
I miss so much skydiving."
= (

#MillionsMissing

Missing since 2014:
Sigrid V. | Norway

"I had one year left of a physio course in England. I'm currently back home with my parents in Norway working on getting better so I can get back to studying.

I am missing dancing all night, going to dance festivals and being part of the folk dance community.

BTW, I'm the blonde girl in the picture."

Missing since 2011:
Nicola S. | London, UK

I'm in the middle. I miss going to school and having friends.

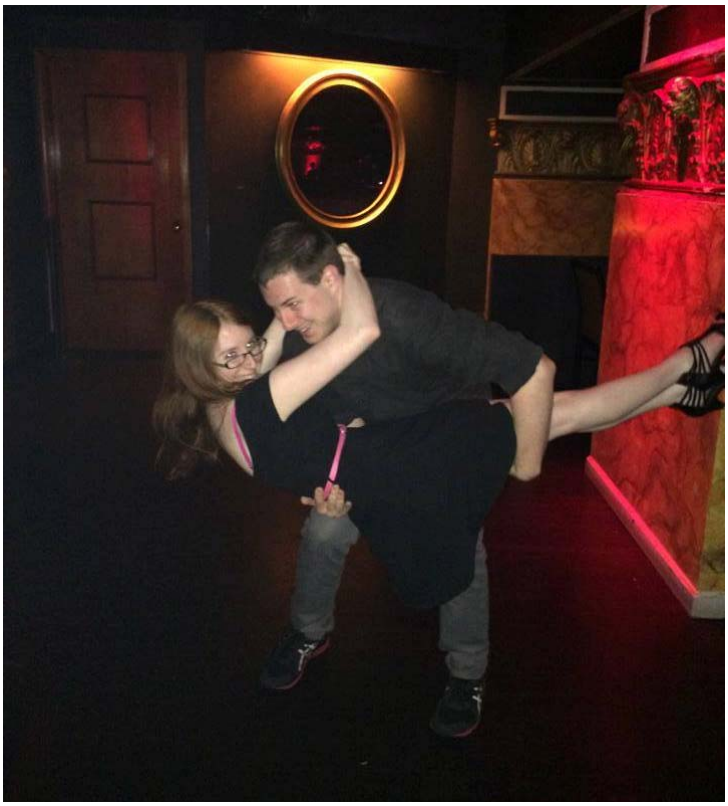
“I've had ME/CFS since 2011. I got glandular fever when I was 13 that wasn't diagnosed until 3 years later. As a result, I developed ME/CFS.

It took a year for that to be diagnosed at age 14. I had such bad tiredness and headaches I had to drop out of school and be home schooled.

My friends tried to be understanding but slowly I lost touch with all of them.

I've had ME for 5 years now and have still not been able to finish school so I can go to university. I miss hanging out with friends and socializing, not being alone in my room day to day.”

Missing since 2014:
Sarah C. | Chicago, Illinois



"I was getting my PhD in physics when I got ME/CFS. I went from graduate level physics, mathematics, and fluent French to having difficulty adding and remembering how to spell in English.

I went from being a teacher, a researcher, a student, a builder for Habitat for Humanity, a choral singer, and going dancing every weekend with my friends, to depending on my boyfriend to carry me if I needed to leave my bed.

While I have learned not to push, and can get round on my own, I now live with my parents as I can't work or study.

Join #MillionsMissing and help ME/CFS patients get back our lives and get back to the work we love."

Missing since 1989:
Allison M. | Ottawa, Canada

"I am missing being a happy active Mom.

My kids were only two years and one year old when I got sick, which was almost 27 years ago."

#MillionsMissing

Missing since 2013:
Kathy I.

“I miss riding my mountain bike so much....

I love going down a long winding dirt trail, total concentration, maneuvering bumps, rocks & turns, reaching the bottom stretch, yelling ‘towanda’!

This kind of total freedom was taken away
from me in September 2013.

Hoping to ride again someday but until then I'm painting, doing photography and connecting and supporting others with ME/CFS.”

Missing since 1994:
Karin B.| Ottawa, Canada

"I'm the tall one :)

I was diagnosed in 1994, when my son was a toddler.

I'm missing travel, social activities, being a 'mover and shaker', sleep, really living…

Thank you for helping to bring this insidious life-vampire into the mainstream!"

Missing since 2003:

Carollyn B. | California

Carollyn (standing) with chefs Julia Childs, Susan Feniger and Mary Sue Milliken

"Missing travel to distant cities.

Looking at my former self…
I miss her."

#MillionsMissing

Missing since 1997:
Laura V.

“Here is a picture of me before my health fell apart...
When I collapsed in 1977 at age 20 with "a mysterious debilitating illness" that remained undiagnosed for more than a decade, I had no idea what I was in for.

As it turned out, being struck down with ME marked my exit out of a fully functioning adventurous life into one that would often be reduced to a couch or a bed. For the next 39 years I have ridden an endless roller coaster of remissions and relapses, never reaching beyond 50% of my original level of functioning and maintaining usually at about 25% at best.

I miss skiing, hiking, swimming, traveling, performing music with friends, eating "forbidden" foods, staying up late, going dancing, sleeping deeply, feeling fully alive, and my career in Art Therapy that I was forced to abandon in 1989.

In spite of my illness I earned two degrees, produced a CD of original music in 2000, and a film about a local political issue in 2008.

I have crashed again & again & again from the effort expended on these accomplishments, but continue to paint, write songs, and make music, refusing to allow this dreadful disease to make me miss more and more and more than I already have.”

Missing: Emma C.

"I used to work as a hair and make-up artist, and have great fun going out with my friends.

Now I spend most of my time in bed, and use a wheelchair as I can't walk far.

I miss working, dancing, long walks."

Missing since 2009:
Jessica P. | Manchester UK

“A few of all the things I miss are...

I miss swimming and racing in pools all over the world...
as well as those dirty open water venues.
I miss tearing down a mountain on my skis.

I miss being active and running when I'm too impatient
for walking.”

Missing since 1997:
Blythe B. | Indiana

“This is a photo from my teen years. I got sick in 1997, when I was in high school.

I miss working with horses.
I miss being able to socialize and go out spontaneously without relapsing afterwards.

I am missing the ability to be self-supporting, have a career, and raise a family.”

#MillionsMissing

Missing: Nancy S.

"Missing the beauty of the world, nearby and in faraway lands.

Missing just walking around the block with friends and family."

#MillionsMissing

Missing since 2006:

Emma F. | U.K.

“I've been sick for 10 years. I very gradually went from mild ME to very severe ME. I miss travelling the most. The world is a gift we have been given the opportunity to explore. I can no longer do that.

For a year I couldn't even travel outside my bedroom & this year is the first time I travelled to the garden in 9 months. The garden is now my holiday.

This is me in Australia 2 years ago. A couple of weeks later I became completely bedridden. I had to drop out of university, move in with my mum. She had to leave her job because I needed 24-hour care.

Last year I became paralysed and spent time on a stroke ward. Around that time I applied for special funding to enter a severe ME ward in a hospital. The funding of £150,000 has been granted because my case is so severe. I'm now waiting to be admitted for a 3-6 month inpatient stay. My long term goal is to be able to travel again.

As soon as I'm well enough I will be jumping on a plane! Being isolated for 2 years because I've been too sick for visitors, means I miss people the most.”

Missing since 2008:
Allison H. | Minneapolis

ME/CFS in 2008; homebound since 2012

"I've missed traveling with my family, playing with my kids, being part of their school events, helping them participate in out-of-school activities.

I've missed doing yoga, running, walking the dogs, being a part of my life.

We need help!"

#MillionsMissing

Missing since 2013:

Claire P. | UK

"Missing... travelling, trekking for gorillas & exploring this amazing world.

M.E. sufferers are hidden from society, trapped in their own homes so that their needs and voices go unnoticed."

Missing since 2001:
Becca H.

This is quite an old photo… I'm on the left, at 11 years old, my last birthday before I became ill.

"I have been ill since I was 12; I'm now 27.

I missed all of my teenage years and education, my dream career of being a Veterinary nurse, social events, travel, relationships, playing the flute, independence, cycling, netball, running, walking and much more.

I still dream of the day I may get well enough to do some of these things... until then, I hold on hoping and praying that our suffering is not all in vain."

Missing since 1994:
Laural W.

"I miss travelling.

This photo was taken during the five years
that I was relatively well
after being on Ampligen for 1-1/2 years.

We really need to get Ampligen approved by the FDA!"

#MillionsMissing

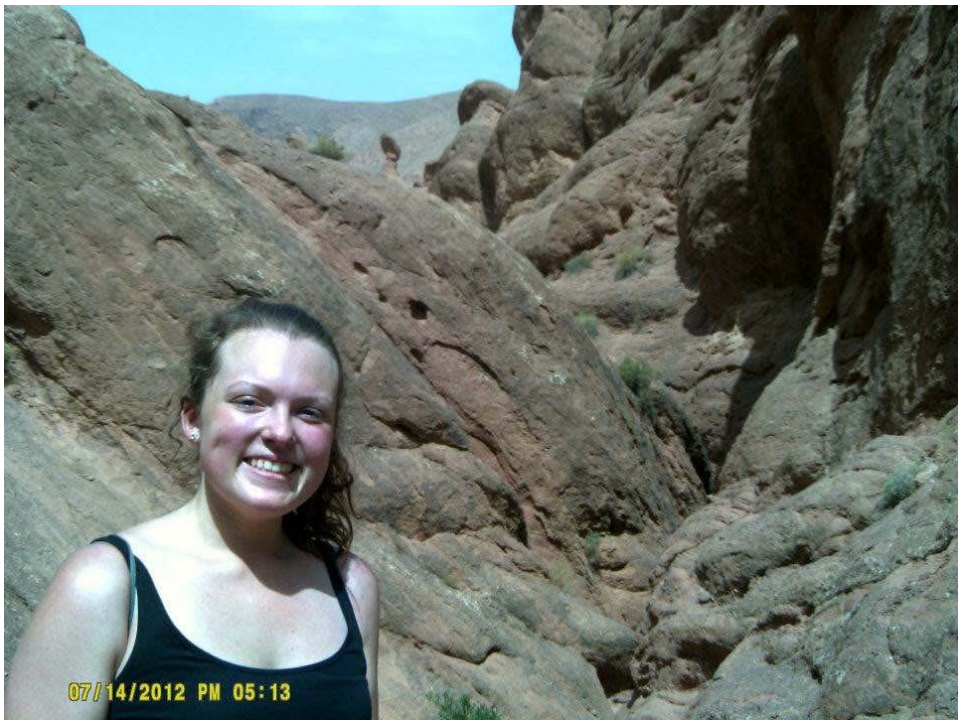
Missing: Marit O.

"I miss all kinds of physical movement,
but most of all,
I miss hugging my horse."

#MillionsMissing

Missing since 2013:

Becky C. | Derby, UK



"I'm missing hiking, traveling the world, working and socializing."

Missing since 2011:

Nina Y. S. | Berlin, Germany

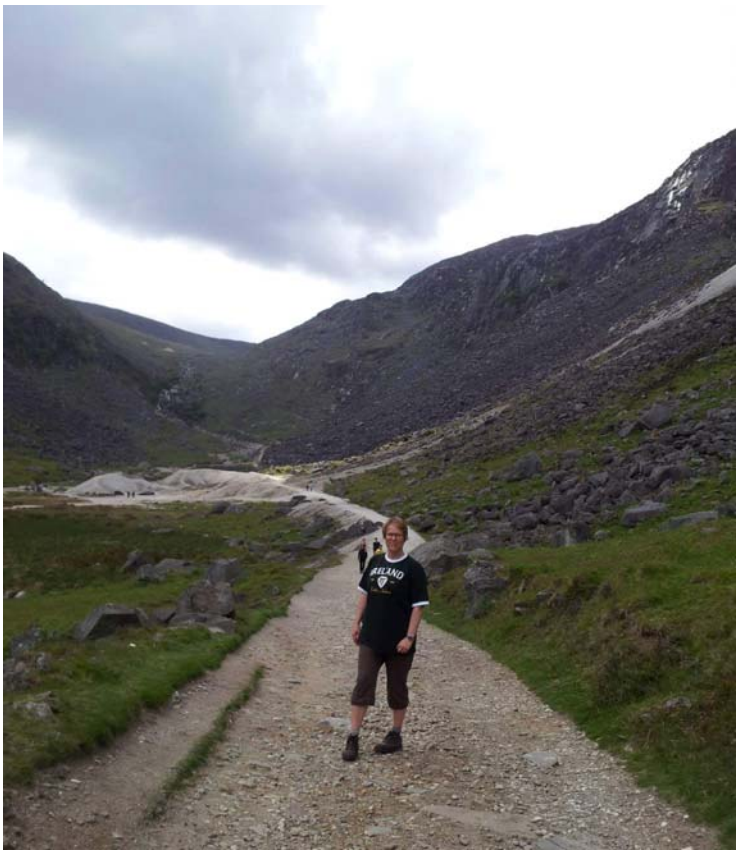
"Being a very social person and loving to travel, I was enjoying most to meet friends and family and go out. I was travelling to European countries, Africa, Asia and New Zealand. I enjoyed being with the locals, getting to know people, and savoring tremendously the foreign food and culture.

Five years ago, due to the travelling, my doctor recommended several vaccinations. I became bedridden for months, not even able to feed myself sometimes. I am now slightly better but still not able to go out for a walk, talk long to family and friends etc. most of the time.

I'm missing from friends, family, social life, travelling, eating, work, from the world outside my apartment, from life; this is partly the same for my boyfriend who is still with me, that angel.

Most of the time I'm very positive & do not think about what I'm missing, but more what I have."

Missing: Anna-Karin U.



"Missing going hiking.
Missing work since 2014.

Missing my social life, family life,
research funding for bio-markers and health
professionals with an understanding of CFS/ME."

#MillionsMissing

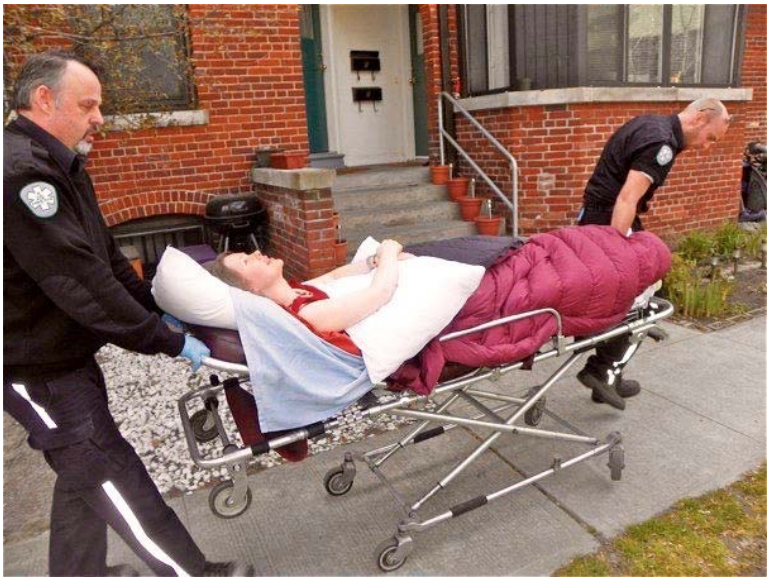
Missing since 2013:
Susan W. | Scotland

"I'm missing yacht racing in West Highland Yacht Week in Scotland since 2013.

There are lots of things I can't do just now but I miss the excitement and camaraderie of racing most."

#MillionsMissing

Missing since 2003:
Liisa L. | Toronto



"I have been in a hospital bed for 13 years.

I miss going to the bathroom.
I miss the outdoors. I miss my work.
I miss standing up. I miss walking.
I miss going outside for more than just ambulance rides.
I miss being outside for more than 45 minutes in the past decade.
I miss being able to wear clothes and shoes.

I miss the experience of living."

#MillionsMissing

Missing: Siri S.

"I miss going hiking or bicycling with my husband."

#MillionsMissing

Missing since 2015:

Clare S. | Surrey, UK

I'm second from the left!

"I'm missing freedom, human contact, family, friends and their children, teaching and helping my students, floating in the sea, views, hammering metal, the chance of motherhood…"

#MillionsMissing

Missing since 2002:

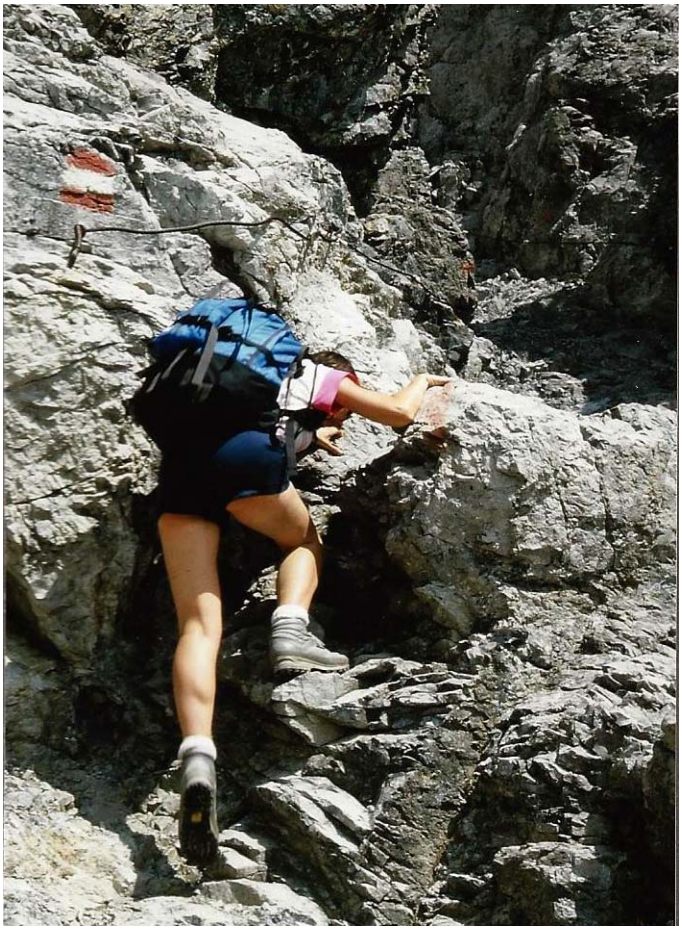
Mette H. | Norway

"I miss my work, my hobbies, my social life and my grandchildren.
Epstein Barr virus in 2002, out of work since 2010."

#MillionsMissing

Missing since 1988:

Kalee | Alberta, Canada



"This photo was taken almost 30 years ago while on our honeymoon in Austria & Switzerland. It was inconceivable that 2-1/2 years later, my active sporting life would be ended by an illness I'd never heard of – ME.

I'm one of the lucky ones – my husband has stayed by my side despite devastating lifestyle losses.

I'm missing: My active outdoor pursuits.
My husband is missing: His hiking partner."

Missing: Natasha F.

Australia

I am the one at the back with the blue fins.

"Missing diving, dancing, socializing, eating out and trips with friends since 2014."

Missing since childhood:

Mireille E.

Gothenburg, Sweden

"I've had ME since childhood but have been bed- and house-bound for 3 years.

I have not been able to travel since 2011.
I'm missing travel to Paris with my husband!"

Missing since 2003:
A. | The Netherlands

“Here is a photo of myself as a child;
I'm the blond one in the middle.

I’m missing out on my life,
a marriage, children,
and the nice job this little girl could have had –
if only governments, doctors, society had truly
invested in this illness, listened to patients, and cared
about ME!”

Missing since 2013:
Tammy F. | Miami, Florida

"I was a middle school teacher for 13 years, and a pianist. I had an active social life before I was struck down by ME in 2013.

I've lost my career, my home, my marriage, my friends, my freedom, my health, and my life as I knew it.

I miss living with no restrictions and experiencing life to its fullest! I had so many places left to visit and travel. This was a picture of me on my last trip to Hawaii."

Missing: Cedar S.

"I am missing hiking,
camping, and
working for the environment."
:(

#MillionsMissing

Missing since 2012:
Sheri P.

"It all started 4 years ago. I had had a flu shot, then a week later a respiratory illness.

The cough lessened, but my legs felt like they were made of cement, then my whole body felt heavy and numb, as if I had gotten a shot of Novocain from my shoulders down. The fatigue was extreme. I lay down to sleep and when I awoke, I couldn't move my body from the shoulders down. I couldn't sit up or roll over in bed. I couldn't hold a toothbrush. My head hurt like never before.

As I started to get a little feeling back, it was feelings of pain and nausea. I was totally dependent on my husband and children to take complete care of me--dressing, bathing, feeding me. My husband has to walk behind me with his hands around my waist to hold me up and use his own legs to move mine. The doctor did nothing for me but to refer me to a neurologist. No help there, no diagnosis either. I have now seen seven doctors with no diagnosis.

This disease has taken away my life. I was a very active mother, had just finished nursing school, volunteered at church and school, and worked part time.

Now, I can't even take care of simple household chores. I am too weak to stand to even do dishes. My goal of being a nurse has been stolen from me. Severity of the disease waxes and wanes but I am mostly couch bound. I can't leave my home alone because if I do, I may not be able to get myself back. I am not depressed, but I am not happy about being ill. May God help us find a cure!"

Missing since 2003:

Camilla C.

“13 years ago, ME was suggested to me by a GP when I was ill with extreme fatigue, palpitations, shortness of breath, etc., the year after I had my son. Blood tests showed nothing. I rested, ate healthy and after a year or so it eased. There would be periods I would "crash" and be very sick and bedridden for a few days. But then I would be normally active in between and recover fine. My friends knew me as the one always on the go. I liked to get out and make the most of life and enjoyed the outdoors with my two kids.

Three years ago, I noticed some weird symptoms, shooting electric pains in my hands, numbness, migraines, electric shock pains down my shoulder and arms, bladder problems, severe nausea, vertigo, dizziness, room swaying and IBS. The GP dismissed it as my being a stressed/depressed single mother--definitely not so! It got worse with muscle spasms, bone-crushing pain that I never thought possible and muscles that were on fire. I lost my sense of smell and taste for months, my fingers where hard to control, etc. It was horrific.

I had to insist the GP refer me to a neurologist. MRI and blood tests showed nothing, and the neurologist dismissed me, saying there was not much he could do. I cried my eyes out. I did get some medication to help with the spasms and ease the pain for a while, but it came back later.

Over the last three years, the ME has improved, then crashed and worsened every few months, each time leaving me worse than before, this time causing me to leave work. I will never forget the torture every day in that job of trying to put one foot in front of the other and keep working and not fall down each step--of collapsing and being wheeled out in a wheelchair. I would sleep for weeks comatose. I have gone to Emergency Services for help in desperation….none there. I cried my eyes out at being so sick and getting no help again. There are no specialists in Ireland, not one consultant. I had to become my own doctor and researcher on top of being horrifically ill. Eventually, a Facebook support group led me to an internal medicine specialist whose care I'm now in. I have to pay privately for this.

ME robbed my kids of a fun-loving mother in her prime, made me a prisoner in my body in my bed, has us on the breadline, makes me cry at times with a level of pain and sickness I only imagined one would experience close to death. How is it possible not to have any treatment after all these years? Throughout, I'm always strong and positive, but boy does ME test your limits.”

Missing: Lisa D.

"Losing my father was an abstraction until now. I've sent my share of sympathy cards to friends whose parents passed away, but only now is it possible to prepare for my own inevitable grief.

My dad is in a nursing home, bedbound, blind, dying a slow lonely death due to congestive heart failure and diabetes, but I can't be there with him. I can't hold his hand to comfort him or play CDs of his favorite Beethoven symphonies. I can't listen to him recount the stories I've heard him tell a million times or laugh at his corny jokes. Why not? Because I am too ill to travel cross-country due to CFS/ME. Even a brief phone call with him exhausts me.

I am a former Triathlete who worked full time, travelled, and climbed Mt. Kilimanjaro. Now, I am completely dependent on my husband to care for me. I feel isolated and lonely. It depresses me that research funding is so sparse when so many of us suffer. It adds to my hopelessness.

CFS makes a difficult situation unbearable. It is devastating to be so incapacitated that I cannot be present to help care for the remarkable man who loved his children unconditionally. Dad worked three jobs so that my siblings and I could get a college education. He always offered encouragement and gave sage advice. From day one, Dad put us first, and yet I cannot hug or kiss him one last time before he crosses to the other side due to a common, little-known, incurable, mysterious illness. A perverse illness that has drained me of all my energy and kept me housebound for 12 years. It torments me that I cannot say goodbye to my beloved father in person or attend his burial.

I told dad that I wished I could be there to help him and he replied, "I wish I could be there to help you."

Missing since 1986:
Anita P.

"In 1986, I came down with a sudden viral illness. Within 2 weeks, I was unable to walk. I was 24 and had been working full-time as a word processor for a law firm. I found myself completely disabled, bedridden, unable to work.

It was 11 years before I found a correct diagnosis and a doctor to help me, Daniel Peterson in Incline Village, Nevada. Dr. Peterson is a pioneer in the field of ME/CFS. His determination has never wavered from pursuing the cause and treatments for this horrible illness. I was one of the first five of his patients to be on the AMP-511 clinical trial and got Ampligen for the first time in December1997. I had a wonderful response and was on it continuously for eight years. I enjoyed increased energy and brain clarity. That allowed me to care for my family and advocate for fellow patients. I have never had any side effects from the drug.

I went from not being able to walk up the stairs to being able to exercise for 19 minutes on the treadmill. The joy that even a small improvement can give a person, to be able to do household tasks or get out of the house and take walks, is something that many patients do not have. The suffering is immense. **Many patients have to lie in bed for 18 hours a day,** as I did before Ampligen. Many patients have lost all friends and family.

Having any help is something to be grateful for. I only had that chance because of Ampligen. I became an advocate for ME/CFS. I took bike rides and hiked with my kids and was the mother I had always dreamed of being. I attended every baseball game and school performance and volunteered in their classrooms. It was like rising from the dead.

I watch the suffering of fellow patients and the heartbreak of many people that take their own life because they can no longer tolerate the years of suffering with no treatments or hope. There are no approved therapies for this illness and only one drug (Ampligen) currently in clinical trials, so I urge you to approve Ampligen in order to give others the hope and the chance to get well."

Missing since 1996:

Kelly S.

"I am 25 years old, unable to work, and live at home with my parents.

I started showing symptoms of disease around the age of five. Fatigue and pain have always been my top complaints. Of course, I have at least a hundred other symptoms, but I would take them all if I could just have a day with no pain or fatigue.

Over the years I have gradually worsened and I seem to get a new illness each year to add to the pile of diseases. I am mainly bedridden and have been for years now. I am always resting but getting no rest, never feeling refreshed. Trying to charge batteries that won't charge. I have thought about suicide more times than I ever could count. I live a very isolated lonely life, as most sufferers do.

Sometimes it feels as if my body is shutting down on me. I think about going to the emergency room, not even able to make it to the car if I decide to go. I rarely decide to anyway, because every time I ever have gone for my invisible illnesses, they have never once been able to help me in any way. I think there is one worse thing than actually dying, and that is feeling like you're dying repeatedly—just to live through it again and again.

My family has it much worse than I do. I can't imagine watching a loved one suffer as much as my family has had to watch me. I am a financial burden as well as an emotional burden to them, although none of them would ever admit it or even think it for that matter. And that's why despite these hands I have been dealt, I am still one of the luckiest people I know. I go to bed thanking God for each and every day and I feel blessed inside and out because I have people who love me an abundant amount. If I never find medicine that works, if there never is a cure, if I suffer until I'm 90 years old…I can still die happy and fulfilled because I have been blessed with angels in my life and not everybody can say that."

Missing since 1997:
Sophie K.

"May 1997, a flu that didn't really want to be become a flu. During my time in bed and on the couch I decided I wanted to go to college after all so I, after what seemed like an eternity (2.5 weeks) went back to my temp job and told them the good news. The not-flu kept lingering on so even my last few weeks on the job were spent at home.

In September, school started and I managed fine the first month or so, then "it" came back and from November on I was practically housebound, perhaps once a month crashing on a friend's couch after a measly trip to the mall. Sore throat, feverish, "fatigued" (worst description of every cell in your body yelling NO to movement), aching bones and an indistinct pain in the middle of my head (and my dad) drove me to the doctor's office.

Blood was drawn, results came back negative. After a while he allowed me to go to the internal specialist at the hospital. A virus, Coxsackie B, was to blame and within a year I should be up and running, sailing, shopping, learning.

The year passed silently. Fully counting on the specialist's estimate, I enrolled for a second (and next year's third and fourth time) in college but even trying to go was out of the question. I spent my days on the couch, behind the computer chatting to friends or staring at the wall or TV.

It became a family project; my mom would choose an (alternative) doctor or buy a book describing cures and we'd decide on where to go next. My dad would transport me to wherever the antibiotics, reiki or energetic healer was located. Most didn't work or made me worse, some helped. Things stayed pretty much the same. A real doctor with a degree and everything gave me antibiotics for Mycoplasma, which I barely made through to the end, I got so sick. Since all else had failed I went back to the hocus-pocus lady, and all brain-hell broke loose. For weeks I couldn't walk a straight line from dizziness and needed a bathroom within drunk-walking distance in case of returning meals. My brain, eyes, even teeth started trembling and slowly parts of me seem to be working again.

Will I indeed be well soon??"

Missing since the 1980s:
Carol H.

"I am one of the fortunate ones.

I was knocked down by what I now know was ME in the 1980s, when I was in my 30s. Very little was known about this odd thing that happened to me… I was exhausted beyond anything I had ever experienced, and for no apparent reason. I had a debilitating headache, 24/7 for months on end. My throat was always sore. But the utter exhaustion was the worst. There was no amount of willpower that would allow me to function normally. At its worst, the goal of my day was simply to take a shower.

For roughly four years, this disease dominated my life. I was unable to work for several months, and had several years in which my entire being was focused on resting every possible moment so that I could continue to work and be self-supporting. Friends, hobbies and fun fell away.

Doctors didn't believe that I was sick. Friends and family did not understand. And I plugged on through it, with no idea when, or if, it would ever end.

It was a difficult and humbling time — realizing that the dreams I had had for my life might not ever come to be — the simple dreams like having children, playing sports, going out to dinner with friends, doing satisfying work. When we're young, we think we know the troubles that may lie ahead. I would never have anticipated being sick with something that few believed was real, no cures or treatments and which caused people to question my integrity.

I am fortunate that I got better. Slowly. Over the course of many years. I say that I'm 95 percent well now. The truth is that I always have a consciousness of how much energy I have expended and when I will be able to get enough sleep. But these are minor troubles. I dodged a bullet. A significant, awful bullet. And I don't know why or how I dodged that bullet. My heart breaks for the millions who are not so fortunate and who continue to suffer, day after day."

Missing since 2003:
Sharon S.

“My illness struck just as I was finishing high school. I remember waking up the morning of my SATs and finding that numbers seemed like strange hieroglyphics. I bombed. I was so ashamed! (I later realized that every time I relapsed, numbers would be a problem for me. I still don't understand why.) For the other symptoms, I found self-deprecating excuses: lazy, clumsy, forgetful, lacking discipline, etc. I told myself--and anyone else who might have noticed something off about me -- that I was "just coming down with something."

As years went by, I found it more difficult to do everyday things. Sure, there were times of near-normalcy when I was able to fool myself and my friends; but more often, I struggled with being able to make and keep dates or appointments. Old interests--hiking, skiing, cycling, paddling -- were given up. I just couldn't keep up with my friends, and the cost of the exertion in the days and weeks afterward was too steep. Housework and hygiene suffered. Relationships were neglected. Eventually, I had to give up working.

When I married, my husband knew I was ill; although neither of us knew what I was sick with. During the year leading up to our marriage, I was reeling from the effects of a bout of strep throat and flu. He was understanding, and since he didn't want me to work anyway, I was able to slowly regain ground lost to my last job.

We began a youth ministry. At one point, a close friend pointed out that it "wasn't normal" that I consistently needed days in bed after every event. She urged me to get medical help. I had been in denial for so long. The doctor first diagnosed me with mononucleosis. When the mono hadn't improved after a year, she re-examined my full symptom roster and changed the diagnosis to CFS.

She referred me to a specialist who gave me advice that I dismissed at the time as too simple, but have now come to appreciate for its practicality: proper sleep hygiene; avoid alcohol, caffeine and soda; rest when tired (I scoffed under my breath, "when am I NOT tired? I'll be resting all the time!"); eat a healthy diet; keep a journal of activity levels....etc.

Thirteen years have passed since that diagnosis. I am still learning how to pace, to read my body's signals to avoid most crashes and use mobility aids. My family and friends have joined my husband in supporting me and encouraging me to rest and not over-exert. There are good days when I can socialize, pursue hobbies or work around the house; and there are bad days when I hang on and hope to survive.”

Missing since 1991:

Lisa E.

"I suddenly became ill on January 27, 1991. I was an active woman—a wife and the full-time working mother of two sons, a 3-year-old and a 6-week-old. I wrote the following poem two years later as it expressed the raw emotions I felt living with ME/CFS. It has truly been a roller coaster ride, with the "peaks" less than 50 percent of the "person I used to be" pre-illness.

I am now in my 26th year of living with this illness. This last year has been brutal, leaving me mostly homebound. I could have sat down today, this many years later, and written this same poem. Other than the change of name from CFIDS to ME/CFS, the feelings are the same.

My life is forever changed and continuing on, with a purpose for each day, is my goal. I have learned to rely on faith, gratitude, mindfulness and grit.

ROLLER COASTER RIDE

Riding on the crest of the Roller Coaster –
On track with a loving family and rewarding career,
Looking forward to accomplishing more of my life's ambitions,
Living for future glories to become happy memories,
Everything is at an accelerated pace.
Right when my life seems at its peak; the ride takes a dip.
CFIDS.
Oh, the anxiety, the exhaustion, the pain, the fright, the isolation.
Anger surfaces and bursts out at every opportunity.
Self-esteem plummets—where are all my pillars of pride?
Today stretches into a thousand tomorrows in snail's-pace motion.
Existence becomes a day by day, minute by minute effort.
Relinquishing independence, fighting for an ounce of energy; rest and more rest.
Regaining momentum; Reflecting on my life; Searching my soul for gems of truth,
Inching my way forward, ever thankful for small shifts—both mind and body.
Determined that I will conquer this illness, whether cured or not;
Ending one cycle only to catch another Roller Coaster Ride."

Missing since 2009:
Melani S.

"The first week of graduate school was only a few weeks away when I suddenly became very sick and mysteriously didn't get better. I was poised to take on a fulfilling career in health sciences research, filling my leisure hours with running, cycling, hiking and other outdoor adventures. But it quickly became apparent that school was not going to be feasible, and neither was my laboratory job. I essentially had to drop out of life and try to figure out what had taken over my body so violently.

That was just over 7 years ago. I've managed to adjust my expectations dramatically since then in order to lead as satisfying and meaningful a life as possible. I've endured a great many changes over the years: returning to part-time work, taking a few college classes, getting married, opening my own businesses, losing my job again, suffering a major relapse, getting divorced and moving to a new area. Each day brings a new set of feelings, both physical and emotional, and I credit my yoga and meditation practice for keeping me afloat in this often-turbulent sea.

I've learned a lot about radical self-care and have had to learn the hard way how to prioritize my needs so I don't get sicker, even at the expense of career opportunities, friendships, social invitations and vacation plans. It's frustrating being so young (I'm only 29) living with an invisible illness. When I walk down the street, nobody suspects that I have a debilitating disease that prevents me from doing half the things I want to do. Every time I get to know someone new, I feel like I have to "come out" over and over again, which only compounds the feelings of isolation that I deal with.

Luckily, I've had the privilege of good health insurance and have worked with a group of great doctors over the years. But no matter how amazing they are, ME/CFS still remains a mystery; a mystery that robs me of sleep, energy, cognitive function and a "normal" young woman's existence. I'm managing fairly well right now thanks to a combination of prescription medication, dietary intervention and alternative healing. Building on my background in health sciences, I hope to get certified as a holistic health professional, and work with other young women affected by chronic and invisible illnesses.
As well as be a voice for change, for education, and for research funding!"

Missing since 2003:
Madaline F.

"I can't say I had an easy, stress-free childhood, but I knew I was loved. I was an only child at home with older parents. Mom had bad heart condition, and died while I was still a teen. She was my world. I managed to have a pretty normal life. Married and raised four beautiful kids.

Kids were grown. I came through a horrible divorce and some crazy relationships.

I was under a lot of stress, newly remarried. I was working a stressful job and living with my new husband and his teens, who were raised very differently than I raised my babies.

I was 50 years old when I found out I had fibromyalgia. Always waking up in pain. A couple of years later, I caught the flu. I couldn't get out of bed. I went downhill pretty fast from then on. Went to part-time work to no work. Went from going to parties, card games and lunches with friends to staying in bed. Hurting all over my body, especially my neck. And completely, utterly exhausted.

I said to my doctor, I think I have CFS. He said Oh yes. And perhaps MS. Well, the MS never came, thankfully, but I was completely bedbound for three years.

When I found a pain doctor and also received Cortef for the exhaustion. It changed my life. I was out of bed to do minor chores.

I do not get any help from anyone around here. No one believes in CFS. But I do get help from my pain doctor for the fibromyalgia. She is about to retire, and I am so scared. What am I going to do without the help of pain pills and Cortef? I can get out of bed with those. I can't do a lot of things still, but I don't want to go backwards. Here in Oregon, they have made pain medicine sound like it is evil. I know it saved my life. I would have ended my life if I would have had to go forever with that pain. I was becoming so extremely depressed and at the end of my rope. When I found my pain specialist and I read as much as I can and found out through the Solve ME/CFS Initiative and other groups that I am not alone, I feel less afraid.

I am 63 now. My husband still does much of the work and shopping. Sometimes I can go do a little bit of shopping, but I usually pay for it by being in bed for days afterwards. "

Missing since 2001:
Stephanie S.

"Many ME/CFS patients are forced into the inescapable but necessary isolation of solitude, longing for the face-to-face connection we felt with loved ones and the world. Even short visits come with the inevitable post-crash**.**

Now at 62, I was "lucky" enough to be 47 when ME/CFS descended on me like a thief, robbing me of…."me." I grieve that young sufferers may never get to live full lives.

Growing up, my health was more fragile than others, but I managed. In my 20s I owned a business, sold it and traveled to Ecuador as a missionary. Then I embarked on a music career and later worked my way up in a Fortune 500 computer company. At 40 I married the love of my life.

At 47 I was feeling increasingly more ill and, after a bout with an infection followed by a flu that lasted weeks, became an invalid, so weak I could hardly move, and with debilitating nausea. Then came the "Electrical Storm."

If you've ever touched an electric fence, that awful residual tingling is what courses through seemingly every nerve and muscle in my body…. for 14 years. My heart continuously beats forcefully, electrical current shoots out into all extremities and my head, even affecting my vision as though I'm seeing the world through the screen of a bad 1950s snowy TV set. Triggers can make it worse: bright light, noise, frenetic TV shows, more than a few minutes on the computer, talking on the phone. No medication makes it better.

I spend about 12 hours a day in bed, 12 in my recliner, getting up for a few minutes at intervals, jokingly calling it "my 5 minute life," grateful that I can bathe myself and make food. Having POTS makes it difficult to stand even with Florinef.

Over time I spent tens of thousands of dollars seeing dozens of doctors in grueling appointments, from homeopaths to tropical disease specialists. I realized that I had severe ME/CFS. Five years ago, after a fruitless week in a Houston hospital, I made the decision that I would no longer subject myself to any more torturous tests or dismissive physicians. I knew in my heart that I was neither crazy, "clinically depressed," nor trying to garner attention. Who would choose this disease?

The best advice I can give is this: You have to make a decision to live, taking each day at a time, finding SOME joy in the day or the moment. There are millions of people around the world with ME/CFS and we are 'together in our isolation.'"

Missing: Sarah L.

"I played trumpet, sang choir, captained the hockey team, sailed and climbed mountains. I traveled the world, and I achieved degrees and was busy and always managed to keep going, no matter what. And that was the problem. Because I kept feeling more and more like I was wading through treacle and then I would start to feel like I was blacking out—so bad was the intolerable exhaustion that would make me unable to get out of bed.

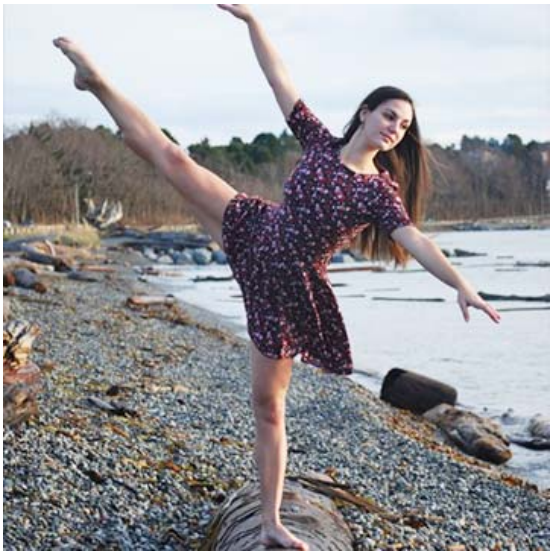
Way back I discovered that the stress of academia was not good for me so I became a yoga and meditation teacher. I was told I had PTSD. So for years I struggled and tried to make myself swim and do zumba and yoga four times a week and teach six yoga classes and I got the initial high from the exercise but then would wake up in the night feeling like I had been savagely beaten up. Migraines started in 2006, the same year I began to be bullied by my boss.

June 2009 I was verbally attacked several times in front of my colleagues by my boss causing a total breakdown where I continued working but was inwardly fracturing with the strain, pain and stress. Three years later I could no longer even stand to work. All my symptoms were put down to PTSD. November 2015 I was diagnosed, to my surprise (duh!) with ME/CFS, which suddenly made sense of the confusion that my life had become. Now I try to find a baseline and go out to a choir once a week and have given up all aerobic physical stuff as I just can't bear the beaten up sensation that follows it.

I do sail though. I get my husband to haul several sails up and then I rest for several hours looking at the sea and the sky whilst the boat sails along happily. Perfect. And I write more. I write poems and short stories. And I keep reminding myself that Churchill wrote from his bed and so did Florence Nightingale, and so I keep abreast of the topics I am interested via my laptop sitting propped up in bed. I research and study mindfulness, self-compassion and neuroplasticity.

I am still astonished how physically debilitating ME is. I could rush out of the house right now if one of my kids was in danger. But I would be in pain all over and feel that awful blacking out feeling quite soon after the exertion. And I hate that. But you know, I am trying to learn to be kind to my condition and still find ways to live an interesting and fulfilling life. I have had to learn that my little energy is precious and should be used well."

Missing since 2009:
Siobhan B.



“I am 23 years old, and I've just been diagnosed with ME after being sick for nearly six years. I was a professional ballet dancer, dancing with the Royal Winnipeg Ballet when I started to feel ill.

There were a few instances where I can imagine this all began. I had a few bouts of infection from various illnesses and surgeries. From then on, I began to feel weak and ill. I was dancing my little heart out and couldn't cope after a while of pushing myself to my limits.

It got to the point where I had pushed myself too far and things got out of control. I was hospitalized and had to return home to British Columbia. I thought my body was just telling me to rest and recuperate and that I could return to Winnipeg after a few weeks off.

Two years later, I found myself still ill with no answers. I went to countless doctors and naturopaths and never found myself bouncing back. I would explain how I gained 40 pounds in what felt like one day. I felt dizzy, nauseous, had vision disturbances, menstrual issues, gut issues, almost no energy, which caused anxiety, mood swings, depression. I felt like I had lost my identity. I decided to audition for the Canadian College of Performing Arts in Victoria, BC. I was accepted and started in September 2012. I thought perhaps getting back into dancing and exercise and being in an environment that I loved again would help me feel better. It did to some degree, as I was running off adrenaline. However, I would crash like I'd never crashed before. Between each year in the summer holiday, I would come home to my family and hardly do anything all summer to recuperate for the next year. This was a three-year program, and I graduated in February. I am so glad I attended the college as I now have a potentially promising career in Musical Theatre.

Since February however, I have felt worse than ever. I had a big crash just after graduation and didn't get out of bed for about three weeks. In June, I got a call from the Complex Chronic Diseases Program at B.C. Women’s Hospital to say I will be starting at their program. I've since started the program, started a treatment plan and got a supportive set up at home with a flexible job to allow me to rest, but still save some money. I will be here for a minimum of a year, but looking forward to entering remission and starting my career in Toronto or even London! I have hope that we will raise awareness and all live happily ever after!”

Missing since 1990:

April T.

“I've been sick with ME/CFS now for 26 years. It all started for me with a case of mono on my 19th birthday back in college. I never felt the same after that.

When I look back through the years, I realize I did learn to pace myself through most things, even though I wasn't fully aware of that right away. Despite being ill, I did receive my bachelor's degree, eventually got married and have a beautiful daughter that truly inspires me every day.

I've learned to prioritize what's most important in my life. Due to the major limitations I have (energy being the most), I am currently a stay-at-home mom. I am very fortunate that I have this as an option. This way, I have more to give to my family with my limitations. I'm lucky to have a kind, supportive husband who helps me out with many daily tasks. Besides being the sole breadwinner of our family, he also cooks and helps out so much with our daughter. I am very grateful and blessed to have my family. They are truly my inspiration and what keeps me going.

It truly has been a daily challenge over the years to try to keep my mind focused on the positive. There are so many times I tend to think "if only" I could work and help out with the finances, play more with my daughter, have a clean house, cook more and the list goes on. I do mourn the loss of my life that could've been if I hadn't been ill all these years with such a misunderstood illness such as ME/CFS. I try not to compare myself to healthy individuals. Some days are easier than others. I didn't ask for this, so I know I shouldn't feel guilty.

I've also learned many things about myself over the years in dealing with ME/CFS. I've learned who I can count on. It seems as more years go on there's less people, but I've accepted that and know that I do have supportive people in my life thankfully. I've learned how to be my own advocate when it comes to taking care of myself (since **the majority of medical professionals do not understand ME/CFS** or really try to). I've learned to listen to my body and rest when I need to if I can. Some days are better than others, of course. I've also learned to not care about what other people think.

Living with ME/CFS has definitely been life-altering in almost every way possible. My greatest wish is that those suffering with ME/CFS get the respect they deserve from the medical community, along with everyone else. This by far has been the hardest part of living with a devastating illness such as ME/CFS. I'm hopeful this will change.”

Missing since 2005:
Kate S. | Philadelphia

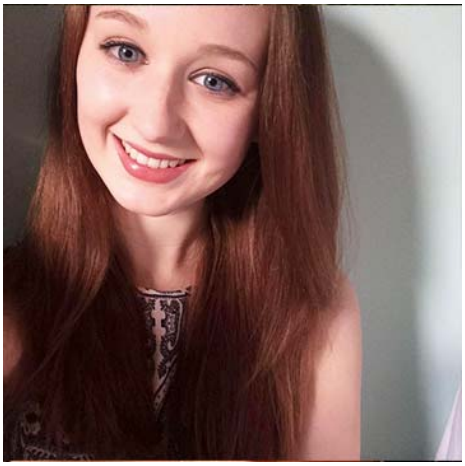
"I spent the first 20 years of my life riding horses on my family's farm, playing field hockey, spending time with family, studying poetry, cartwheeling and singing everywhere I went. Life was effervescent and kind. However, for the past 11 years, I have spent every second pushing mentally, spiritually and physically through CFS, an illness that chocked me to the sidelines.

From this new vantage point, I have learned the value of spiritual evolution, and my mind has become muscular in its determination. My body, however, has not learned how to reclaim its former vigor. I suffer through immense pain and fatigue each day. In order to teach a night class at a community college three days a week, I must sacrifice my entire day to the bed, the bathtub and the yoga mat.

My husband prepares my meals and massages my body so that I can rest and walk without a limp. At 5 p.m., I walk the one block to Community College of Philadelphia to hold office hours and teach a night class. Upon return, my body is aching for sleep and my head pounding with a migraine. Yet, I do this because the alternative means a figurative death.

If I don't have the opportunity to contribute to the world, to teach, to encourage, then my illness would vanquish me. I push and struggle, and it exhausts me. But I must continue forward, sacrificing my long list of ambitions for the tiny moments of joy and gratitude, casting extra burdens upon my husband and family and friends. This path is mentally treacherous, but I'm the kind of woman who will keep hiking to the top, as long as hope dangles like a rope from the precipice."

Missing: Pippa S.



“When I was 15 years old, I started to experience a general decline in my health. I felt fatigued, lightheaded and experienced pain in my legs and feet. Every doctor I saw attributed this to “being lazy” and “just hormones.” Even though I was a ballerina in training, an active volunteer and on my feet for 10+ hours a day, I was told that I needed to improve my fitness and just “try a bit harder,” and then I would feel better.

Over the next four years my health continued to decline, though I managed to gain good marks in my exams, get into my top-choice university and have an amazing first year of being a student. However, during the summer following my first year as I was volunteering abroad, I experienced a huge relapse and became severely unwell.

It was this massive loss of functioning that finally made the doctors take notice, and I was diagnosed with ME/CFS. During that time I was unable to walk, struggled to talk and felt utterly miserable for about a month. However, I made gradual improvements and have been lucky enough to continue with my studies.

I am now about to enter my third year of university, and I'm no longer the active, fun-loving student that I once was. I have significant muscle weakness, which makes walking difficult, along with memory difficulties and impaired cognitive functioning which make studying a challenge, sensory impairment which makes leaving the house painful, and post-exertional malaise, which means I have to strictly pace myself to avoid “crashing” and being confined to bed.

It's not an easy life, and every day is a struggle. However, after about a year of grieving for my old life, I'm starting to feel like myself again. I have some good laughs with my friends about the awkward, embarrassing and just plain ugly situations that have arisen from being ill, and I do joke about my situation a lot. I'm hoping to use my own experience to work with chronic illness sufferers in the future.

The one thing that's been most influential in my illness journey so far is how much the little things matter. This led me to create my fundraising initiative Spoonie Survival Kits (“Spoonie” being the slang word for a chronic illness sufferer). The kits are little bags of happiness that remind people that somebody cares, funded off donations and my own money, and then sold online to raise money for chronic illness charities. We're currently reaching thousands of people in 41 countries! ”

Missing: Suzette B.

“My spirit floats off the couch, gracefully. But she has to turn around, gesture at me to get up. “Can’t you show me how to levitate?”

“No,” she scolds. “Not until you’re dead, and then only if you’re nice to me.” My body rolls, grunts. There’s nothing graceful about it.

Or, I ask her, “Remember the story about my husband’s graduate seminar? How the professor’s back pain forced him to teach lying down on the seminar table, the students sitting around him. Do you think they’d let me move my couch into the classroom? And bring some pillows for my neck and for under my knees??

“Your legs still work, and your back pain isn’t that bad. Get up.” I do. “But will I get dizzy driving to school? Will my legs go numb walking across campus? Will the floor move in the classroom again? To distract her and myself, I think about that woman I met in the CFS/ME doctor’s office when I was finally diagnosed. Curly, blonde hair, attractive, she didn’t look sick, but I could see the pain etched around her eyes and hear it in her soft voice as she mentioned the skull-crushing headache. I knew that pulling in of her body to steady herself against all the movement and noise around us. It was the first time I understood I wasn’t alone and invisible, that if you looked closely enough, the act didn’t really work.

The problem, I try to explain to my spirit, is bearing your own weight. She doesn’t get that. “My bones, muscles, they all feel like lead, and when did the air around me become a raging river current I have to drag my body through?” "Your last day of cycling,” my spirit answers. I returned home after just a half-hour on a level road. I couldn’t imagine my light frame moving easily through air ever again.

“Some of those antidepressants fooled me into feeling light, again. There was that one making my pupils huge.” When the doctor asked how I was doing at the follow-up, I told him, “Great!” He laughed, seeing my pupils and took me off the med immediately. Another med gave me soaring nightmares. They could have rivaled the Romantics’ night of drugs and stories like Frankenstein, but I wanted my sleep back, wanted to wake normally, without gasping.

One med works, and yes, my pupils are normal. It’s not prescribed to help with the dizziness with driving, but it’s made that go away. My students, the cats needing feeding, my husband getting me off the couch, although he can sometimes look as impatient as my spirit. The memory of being the oldest and taking care of things when his mother had cancer isn’t a good one. I catch him checking my breathing.

And a horse bears my weight, the instructor telling me last week we looked good—all three of us—graceful.”

Missing since 2013:
Janda K.

“I had just returned from traveling in March 2013 when I came down with what felt like the flu. After three weeks in bed, unable to even sit up most days, I thought it might be mono. Tests revealed we were close: Cytomegalovirus, which is a virus in the mono/Epstein Barr family. While I seemed to recover somewhat by April, I managed to drag myself through the motions of work through the summer, but by September it was clear that my recovery was going backwards. I was given a diagnosis of "Post Viral Syndrome" and told by my infectious disease doctor that some people are just “never the same.” (What!?)

Still unable to get out of bed, my career came to a grinding halt. My social and family activities stopped completely. My husband became sole caregiver to our two young sons. I spent the next 18 months lying in a dark room, sleeping, unable to even move my limbs some days, struggling with disjointed thoughts and confusion, what I would later hear described as brain fog, but doesn't come close to explaining what it is or how it feels.

There are moments of the day where things feel almost normal for an hour or two—where I am lucid and my thoughts follow a normal and clear succession—but then that deteriorates into a jumbled, chaotic mess of disjointed thoughts that don't follow clear logic or understanding. I struggle to follow simple current events, plots of TV shows or stories that family and friends share. I just don't follow the conversation. It’s like cobwebs that slow down your synapses so that it feels like the "Get Smart" doors slamming down in your brain. Nothing is getting through.

Year 2 of my illness I still primarily spend my days in bed. At least I am out of my pajamas now, but not much else has changed. I gave up my career in PR, gave up volunteering in my kids’ classrooms, gave up socializing and traveling. I've had to sit on the sidelines and watch my friends celebrate their birthdays while I am too sick to join in. I've missed too many family adventures to count.

"Fatigue" is another word that just doesn't fit the bill. It feels like I have lead in my veins. Sometimes I can't speak; it requires too much energy. That isn't "fatigue." There is just nothing “in the tank” to fuel standing up or talking. My son asked me the other day what I did "before you were sick", and it broke my heart to realize he may never get to see who I was before this illness rewrote my life.”

Missing: Sean S.

“Illness has unraveled me. I have lost nearly everything. Yet, I am one of the lucky ones. Most of my 20s I had little energy for family, friends, hobbies, relationships, education or career flexibility. And yet, while I am still grieving watching life pass me by, I continue to be reinvigorated and healed only by what I can describe as pure grace.

Coping with the stigma of an invisible, misunderstood illness has gifted me with a nourishing connection to self, soul and planet and a ferocious compassion for all life.

My earliest memory of being different is not having the energy to run and holler on the playground like other kids. Socially, delayed cognitive processing and ADD-like brain fog made adolescence excruciating. I grew up playing outside in a haze of pesticides sprayed on the cornfields around my house.

A Type A personality, I pushed through. I went into deep denial in high school when my blood pressure and adrenal fatigue was so bad I would black out standing up too quickly or close my eyes to rest when walking down the halls. I almost didn’t make the last few months of high school even though I amassed achievements a mile long.

It was in college that I completely lost control. Life felt like a death match game show I could not win. Cycling through severe stomach pain, exercise-induced blackouts, muscle pain, amnesia, neuropathy, insomnia, nausea and depression was the norm. I should have dropped out. Chronically flu-like, I blamed myself. I chose to hide and overcompensate and graduated with honors.

I had a burst of almost-normal energy followed by another decline, and this cycle continued until I was housebound on and off for years and then six months straight in 2013. At one point, my depression became severe, and I was fighting for a reason to "be here."

While I still experience relapse and down cycles, I am now healthier at a core level than I have ever been. After a lifetime of illness, I have made a 65 percent recovery by engaging in therapies to heal CNS dysfunction, naturopathy, somatic work, and most importantly, taking up a strict diet of rebellious self-love and self-advocacy.

I am now successfully self-employed helping others reckon with chronic illness.

I wouldn’t change the agonizing soul lessons that have brought me here for a thousand carefree years in the sun. Little by little, as I let go and listen to the whisperings of guidance within, I am regaining more than I could have ever lost. I am unspeakably blessed.”

Missing: Becky W.

"I am a major disappointment to everyone I know. I am a worthless human being. My existence has no meaning. Why? Because Fibromyalgia, Chronic Fatigue Syndrome and chronic migraines have robbed my life of any meaning it ever had.

I'm married and have five children. My interactions with them consist mainly of when they stop by my bedroom to see me. My husband has to wait on me. Our relationship has lost all intimacy. We merely coexist.

My career ended when I could no longer make it through a day in the classroom. Teaching was my passion. It rewarded me in ways that are indescribable. I received awards and was recognized by our governor for the compassion I put in to my teaching. When a student entered my room, they were not only my student, but my child. I taught, encouraged, counseled, listened and most of all let them know there was someone in their life that cared.

What rewards do I get now? Having enough energy to take a shower. Seeing my children do well in spite of their circumstances at home.

Pain, exhaustion, and most of all incredible loneliness is all I know. I've lost my friends. They stopped calling when I kept canceling. I can't tell you how many times I've been told, "well, you look all right". These are invisible illnesses that need to be recognized. Not swept under the rug.

My poor family lost their mother. I feel so guilty to burden them. They certainly didn't ask for this either. The sadness and despair I feel is all they see. Happiness? It's a fond memory. I cry every day. I cry for the person I used to be and so desperately want to be again."

Missing since 1988:

Tracy B.

“I received my first flu shot back in November 1988 in San Diego, Calif. After that, it just seemed like I was sick all the time with something. I was stressed at my job on top of that. Then a friend of mine found a good deal on flights to Europe for the following spring. I kept hoping to get better from all these sicknesses I was incurring by the time April came. I had a stomach bug as we were flying over there. I pushed myself to backpack going from hostel to hostel.

When I returned back to work my body just crashed and I was bedridden for a week. I worked, but never felt good, and it was a huge struggle day to day. I went from doctor to doctor trying to find out what was wrong with me. Finally one doctor said I had Chronic Fatigue Syndrome. My labs were positive for Epstein-Barr virus. I got a little better but never fully recovered from the symptoms of a flu-like illness. Twenty-four years later I still suffer.

I stayed in an unhappy marriage, so that I didn't have to work and that I could raise our two daughters. A huge challenge! Now I am divorced and working part-time in the school cafeteria, which has become very difficult lately as I have been having heart exertion, pain and palpitations. I am on a beta blocker now, but the fatigue and sick feeling is still overwhelming.

I'm afraid I have to finally submit to this chronic illness and apply for disability if I make it that far. I truly just want to make it to my daughter's high school graduation in 4 years. All these years have been just plain scary. Yes, I've been through the friends not believing me thing, saying it's all in my head to losing jobs all because of it. Every person I encounter in my life, I think to myself, they are so lucky not to have this! Thank all of you working toward a cause and cure. ”

Missing since 2009:
Tatiana A.

“I always was healthy, I felt pretty and happy with a lot of energy plans. When I came to US from Cuba 15 years ago, I wanted to get the world for myself. I wanted to enjoy the life I was pursuing. I worked very hard, trying to fit within this new country and I feel I got it!! However, about seven years ago, I started feeling tired and after many doctor visits and lab tests completely negative I ended with a diagnosis of depression. Even my husband and family members didn’t believe I was sick.

It was very frustrating and sometimes humiliating and misunderstood. My life changed from shining gold to wet charcoal, from white to black, no more happiness, cannot enjoy my son's activities, I had to quit work, and it has affected all my dreams and my life. I always said "I am not ill because I am depressed, I feel depressed because I am ill." Now, I mostly live confined to my house with the terrible sensation that soon I will be also confined to bed.

It seems nobody could understand, at some moment I believe that everything was in my imagination and went to the psychiatrist, yet things were worst. I also considered suicide, but decided to fight for what I considered best: HOPE.

Recently, at Florida NOVA SE center for the immune diseases, they found real evidence that my immune system is working wrong, my pain and general illness is REAL, not imaginary. Previously, I saw many doctors and specialists who told me CFS/ME does not exist, "It is a name given when nobody can tell you what you have." Whatever the name is, it is REAL, and we need help.

Here at US, family doctors are not prepared for this situation, they don't know about this sickness and then, they cannot diagnose it. We need to fight for funding for research and support from media and press. We need to fight for the insurance to cover the treatment even if it is not a definitive cure because being ignored and isolated is the most terrible thing a human being can face.

Ignorance is obscurity, we need help from our family, friends, doctors and community to be able to float while a cure is found. I want to be happy again.”

Missing: Sue C.

“Before CFS, I was an outdoor girl who loved walking in the mountains, swimming, gardening, cycling, and dancing. I still am; I just can't do those things much anymore.

I sang in choirs, played the piano and was very sociable. I had just done a Master’s degree in writing, seen my first grandchild born, and rebuilt our home after an earthquake. I was 58.

I am so grateful that I had those 58 years. Grateful, too, that I was never bedbound for more than a week at a time.

Now I live in a way that no one without CFS can understand. Each day, there is a very limited amount of energy available—sometimes more, sometimes less. I find creative ways to enjoy the most satisfying life possible, whilst trying never to overspend energy. I know if I do overspend, I run the risk of being bed-bound for a week, a month or years. There is no easy way back.

I live in five-minute portions. I do things I love for five minutes, or three minutes, or one minute. I do jobs in five-minute stages. I rest in between. I play with grandchildren for 10 minutes. I drive up the mountain and walk for three minutes. I do outdoor jobs on good days. In public buildings, I sit and close my eyes and cover my ears for five minutes—or even lie on the floor to recover.

I am getting better. But I can never plan my energy in advance. So I can rarely be with people.

I get ill indoors from mild chemical housecleaners, damp, mold, carpets, perfumes. I get ill outdoors from rotting vegetation after rain, from wind, pines, sea breezes.

I get ill from noise, loud voices, machines, music, vibration in cars; from talking and from listening to people talk; from strong sunlight and electronic signals.

CFS, by its very nature, makes for a totally solitary life with truly massive limitations. It's slower. It's boring. It's without much hope. It calls for huge reserves of spiritual strength, self-compassion and optimism at a time when the brain is often fuzzed up with fog, and the body is crying out for healing.

We often can't even socialize with, or talk to or phone each other, as low energy and brain fog limit all those ways of communication. And yet, we continue in complete intelligence and avid interest in life from the sidelines.

Missing: Cheryl B.

“ME/CFS is an invisible disability. When you look at me, you won't see my broken aerobic metabolism that has cost me my muscle strength, flexibility and endurance.

You won't see that taking a shower or preparing a simple meal causes me to exceed my anaerobic threshold, creating lactic acid build-up, exhaustion and pain.

You won't see how my sleep is disrupted every night, restless and unrefreshing. You won't see the chronic and debilitating muscle and joint pain, headaches, sore throat. Or the intolerance to noise, bright lights, chemicals and foods that were easily tolerated before ME/CFS.

You won't see my lost sense of productivity, accomplishment and contribution that I got from career that I loved and was so much of my identity. Or my lost sense of connection with others because socializing exceeds my energy limits. Or that I can no longer be counted on to help family or friends in need, or be an equal partner and companion to my husband.

You can't see my uncertainty about the future. You can't see my heart yearning to live fully, while my body and brain deteriorate.

But it's real, and it's my ME/CFS story. ”

Missing since 2010:

Jean B.

"ME/CFS started six years ago, after I was poisoned when my house was treated for termites. I was so sick and almost died from it. I got better from that after feeling really awful for a month, but I couldn't do much and had a lot of infections. I had to quit working at the store where I was employed. I have had to limit my activities greatly.

My husband is my only financial support. I went to medical doctors when I first got sick, but I didn't get much help … I was told to go see a shrink. My only help has been my chiropractor and a doctor that does comprehensive and integrative medicine and some research on my own. Insurance doesn't cover anything that I have found to be helpful! It is a very frustrating disease which steals away your life. It also costs us so much money in doctor visits and tests. I have good days and bad days and good weeks and challenging weeks with this disease. I am able to function at home and do most things I need to do, but anything that causes me a lot of stress and pushes me beyond my strength to do it will put me down for a few days. I don't have many activities outside my home.

At first when I got sick I had to be in bed and had no energy to take care of myself and even showering or fixing a meal was very hard to do. Before I got sick, I exercised every day for one to two hours. I don't have the energy anymore to exercise so my body is getting more unhealthy and out of shape. I am getting more injuries from my lack of exercising. I experience a lot of heart pressure and tightness. I have gone through many tests on my heart and nothing shows up. I have also been to the ER a few times.

I try and eat very healthy. I also try and do things that keep my mind occupied. I have found meditation helpful, and serving others as much as I feel able to do makes me feel happier and takes my mind off of my health challenges."

Missing since childhood: Jenna M.

“I was diagnosed with CFIDS/Fibromyalgia at age 14. I went from dancing five days a week and cheerleading to being nearly bedridden for a couple months. I'm so fortunate to have found a few diamond doctors and I am so much better now, five years later. It's definitely still a struggle some days, and I push myself probably harder than I should, but that's just who I am.

I now attend a university and have been doing very well. My fatigue is minimal, and the worst things that act up are my trigger points, currently my hands and wrists. But I have come so far. Besides being a full-time student, I work in child care (which I absolutely love!), work for a princess company (one of the best jobs ever), and model (also awesome). I also dedicate as much time as possible to giving back to others: I run my own service events and volunteer when I can.

Of course with my busy life, I sometimes get very anxious or overexert myself and have to take a step back, but I accept (most of the time) that my body is not like other bodies. Other people might not see nor understand what I am going through, but that's ok; they don't have to. One of my biggest sources of pride is how strong I have stayed throughout this whole process.

I feel like my life changed over the course of a day when I first had a bout of CFS, leaving me nearly bedridden for months. My body has not been the same since. And it's hard. I can't do everything I want. But I do everything that I can. I have never let my illness get the better of me. I do my best to keep my head up and keep a positive attitude, reminding myself that my relapses will pass, and some days are just not as good as others.

I acknowledge my illness but do not allow myself to be sick; sickness is a mindset that I withstand from accepting. CFS/FM will always be a part of my life, and I constantly have to work around them, but they're not stopping me.

Missing since 1983:

Suzy Dee D.

"I fell ill in 1982 after a bout of glandular fever. I was 15 years old and little did I know that the future I had planned in my mind was now irrevocably changed.

I tried so hard to conform to what my school wanted, I was accused of malingering. I was sent to a psychiatrist. I doubted myself, but my wonderful parents never did.

I eventually left school, lost most of my friends and along with it a huge chunk of my self-esteem. So now I was ill, lonely and getting depressed. Yes, depressions is part of this illness but rip a 16-year-old life apart and try not to be a little sad about it.

I happily met a caring young man whose mum had long-term health issues who could see the me beyond my ME, here we are 31 years later. He has been my rock, my salvation, my friend, my lover, receptacle of all my anger and frustration but never, ever my detractor.

I did get better (I use that term lightly) I managed to conform to society's rules. I went to evening classes. I found a job. I lived an outwardly normal life. What the rest of the world didn't see was the girl who was in bed by 8 every night, who slept much of the weekend all to enable her to do the 9-5 thing that we are supposed (!) to do. Did I have a balanced work/life? Hell no, but what else do you do in a world who doesn't believe you are sick?!

I eventually went part time at work because we wanted to get pregnant and my tired body just wouldn't cooperate whilst I was working to the point of constant exhaustion. I'm delighted to say that in 1996 I had a baby, but how many mums have to let their three week old go to stay at their own mum's house one night a week so that this tired and hurting body could sleep and recover? My reality versus yours.

My health has had ups and downs over the ensuing years but after a bout of swine flu in 2010 it's been on the decline again. I had to give up my little part time job - a whole eight hours a week - because I was just exhausted and feeling ill all the time.

Pacing is my middle name but the energy envelope with which I can juggle is getting smaller and as a consequence my concern over my future is growing. There is nothing I can do to change it, maybe one day there will be a better treatment than that that lies within our own hands. We pace, we boom and bust just so we can have moments of snatched normality. I know the price I have to pay and sometimes it's worth it."

Missing since 1983:

Phil C.

"In 1983, at 22 years old, I was diagnosed with spondylolysis and spent 11 months in a back brace. After a few months, I began having bouts of fever, sore throat, diarrhea, bronchial and sinus infection. Because the back brace limited my physical activity, my doctors believed this to be some form of metabolic/immune system adjustment to a more sedentary lifestyle.

After a year, it was evident that no such adjustment was going to happen. I was spending about a week of every month bedridden and most of my remaining time managing intense muscle pain, fatigue and brain fog. I consulted dozens of health providers to no avail. Many were troubled by their inability to understand why I was experiencing these symptoms. Some were dismissive. One explained that I was malingering and referred me to a psychiatrist. In 1987, I was diagnosed with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) by Dr. Anthony Komaroff.

I served as librarian and telephone counselor for the Massachusetts CFIDS Association for several years following my diagnosis. I continued to work full-time, married and had children, struggling constantly to manage the effects of my symptoms on our family life and in my work. We lived through hundreds of crashes, made accommodations in every aspect of our lives and simply trudged through the day to day, fighting off the despair for lack of any effective treatment. Between 1998 and 2000, my symptoms became milder and the need for bedrest less frequent. Eventually, my family and I began to talk about the illness in the past tense. Bewildered yet grateful, it would remain a mystery how, after 17 years, it just went away.

Twelve years later, in 2012, it returned following a bout of pneumonia. Now in 2015, at 55 years old, the physical and cognitive challenges are more debilitating than they were in my youth. I am able to work only part time.. I've stopped all community and social activity. My wife, who has retired, spends most of her time managing our family affairs and helping me manage my medical care. I am fortunate to have a team of healthcare providers that communicate with one another and are committed to my care. The research of the past decade has helped me identify promising options for symptom relief and to pursue diagnostic and treatment methods accordingly. This has been expensive and arduous, but has helped me to remain functional and optimistic.

Missing: Rona L.

“It was during my mid-20s that I became unwell. ME/CFS was my initial diagnosis—much to my surprise. I didn't believe in the diagnosis so ignored it and carried on with life. My health deteriorated over time, though I continued with all my usual tasks. At age 28, the glands swelled up throughout my body, and the doctor thought I might have glandular fever. I was used to ignoring symptoms at this point, and only went to see the doctor because my right thigh had swelled up so much it couldn't fit in my pants any longer. Within weeks, I was flattened and serious unwell.

Firstly, I was diagnosed with overactive thyroid, but my levels returned to normal unusually fast. Because I was still seriously unwell despite normal thyroid levels, further testing was carried out, and I was diagnosed with dysautonomia along with the CFS/ME.

It's been nearly six years and I am classified as permanently disabled now. I miss the weekend adventures with my husband and daughter. Taking walks. Being able to go out by myself—and being able to go out when I choose or need to. Soon I will have been disabled for half of my daughter's life. There were so many adventures for us to share that will never happen. That's the thing about this illness. We get stuck, almost in stasis...but time marches relentlessly on. Children grow up; children we might have dreamed of are never born. Marriages and partnerships are changed forever. Sometimes, we become people we don't recognize. Who is this disabled person? I still feel propelled, internally. I am still driven to live my life, to get out in the world.

Only in more recent times, after a fortuitous stabilization of my symptoms (no hospitalizations for about two years—whoop whoop!) have I been able to see the value in my life once more. I've started reading again (difficult, but practice is paying off). I found a course to study at home, and the teacher even visits me here. Because I can no longer get up to play the piano with ease, I did what I never thought I'd do; I'm learning a string instrument--the ukulele. I've heard it said that a person can never be sad whilst playing the ukulele. I've managed it once—but mostly, I'd say this assertion is true.

There is a lot of living, learning and loving left for me to do. I hope that if I ever become extremely unwell again, I'll keep believing that. But I just don't know. At my worst, the GP said mine is one of the cruelest illnesses she's ever seen. Life excites me, though. I enjoy my responsibilities and working toward goals. Please help us escape the confines of this illness.

Missing since 2008:

Chris W.

"I became ill with ME/CFS after an acute, viral, flu-like illness eight years ago. I was 56 years old and had a responsible position in the federal government. With accommodations from my employer, I was able to work for 2-1/2 more years until I was eligible to retire. But— I had to stop traveling, eliminate public speaking, work from home frequently and reduce my workload in order to remain employed.

In the four years since my retirement, my health has gotten worse. My Post-Exertional Fatigue puts severe limits on my physical and cognitive activities. I did not expect to spend my 60s lying on the couch.

My friends are fully engaged in active lives while I am on the sidelines feeling sick most of the time with swollen glands, headache, sore throat—**it's like having the flu 24/7.**

I want some effective treatments in my lifetime."

Missing since 2013:
Peter Y.

I came down with what I thought was the flu in February of 2013. I never really recovered from it though, feeling tired and having frequent headaches and joint pains.

At first I tried exercising more, eating better and getting more sunlight, all to no effect. In April of that year, I finally went to the doctor about it.

Long story short, after seeing several healthcare professionals and being prescribed the usual drugs such as steroids, antidepressants, antibiotics, etc., nothing helped. I had more blood tests than I can remember, a sleep study, X-rays, full body scan; all they could find was high titers of Epstein-Barr and a slightly elevated white blood count. Finally, after some two years of this, my rheumatologist diagnosed CFS.

I am now on disability. I have tried all the various supplements and vitamins that people mention on blogs and websites, too numerous to account here, and none helped. I am encouraged by the stories of those who have gotten better or improved, and equally discouraged by the stories of those who haven't.

I try now to eat healthy, nap as needed, and pace myself. Minimizing stress is important as well. One day at a time is how I have to live now, and I hope for the future to be different. I got sick at the age of 52, and I am grateful that this didn't happen earlier in my life."

Missing: Elisabeth R.

"I got ME when I was 15 after a Meningococcal B vaccine trial in Norway. (There are over 300 people in Norway that have now come forward about getting ME after receiving this vaccine).

I was a very sporty kid, but after I got the vaccine, I was unable to attend any sport or school. I got continually worse, but no doctor believed me to be ill.

It took me 15 years and a change of country to get a diagnosis, by a very well-known doctor who knows this illness well: Dr Rosamund Vallings in New Zealand. She gave me all the latest information and great support.

I am still fighting for my diagnosis to be respected and to get treatment in the medical and social field 24 years on in Norway.

Serious biomedical research is paramount."

Missing: Jill M.

“A disease called TTP began my descent into the world of SEID. In 1998, I was hospitalized for over two months with TTP. I would have 13 bags of plasma exchanged through my body daily in an effort to put the disease in remission. I came out of that with constant fatigue, swollen glands and sensitivity to stress, light and noise and a foggy brain that began interrupting my work. Although I had a mild case of SEID, I really didn't know or understand what was happening. Every doctor I saw had nothing to say.

In 2006, I came down with Valley Fever, and it wreaked havoc on my endocrine system, giving me my third auto-immune disease called Schmidts Syndrome. This gave me the more moderate case of SEID with episodes of severe. I lost my health, my career, my relationship and had to leave my home of 35 years to be near my family for support. I am disabled from SEID, CFIDS, ME. It doesn't matter what you call it, it remains a debilitating and severely isolating disease. It is long past due that the whole medical community and government acknowledge this disease for what it is.

Prior to these devastating diseases and the permanent SEID, I was a healthy, hard-working, vivacious individual. I loved life. Although I still love life and am grateful for what I have and what I can do on a good day, I still grieve the loss of life. I also grieve the lack of funding and the ignorance of the numerous doctors that have traumatized me with a lack of validation and care or a willingness to look into this disease.

On a daily basis I struggle with debilitating fatigue and joint pain. I have to use what energy I have like a commodity. Some days I trade showers for doing my dishes or visiting family or friends. Some weeks are spent in bed recovering from PEM. Some days I can shop and hangout with my family but I always, always end up back in bed with PEM. The smallest of things can trigger—noise, smell, light, talking. Sometimes it’s a sensory overload, which is a new symptom this year. What I may be able to do one day leaves me obliterated the next. ”

Missing since 2013:
Katherine S.

"On Feb. 5, 2013, I began to notice that I was feeling unusually tired. I was a fit, healthy 21-year-old. Within days, I developed what I thought was an ordinary viral infection, albeit a particularly nasty one. My whole body was in pain, my throat was sore and swollen, and I could barely keep my eyes open. I expected to be better in a few days, a week at most, but a few weeks later, I was no better, and a blood test confirmed glandular fever. I was in my final year of university at the time.

Over the coming weeks, the worst symptoms faded, but I was still exhausted, barely able to walk without feeling faint, and my head felt like it was filled with sludge. I battled through and finished my degree, even accepted a job offer, not even considering that recovery was not on the way. I struggled at work, and after a full day in the office I would collapse at home, sometimes just about managing to feed myself and do a few basic tasks. Other times, I would just sleep until it was time to go back to work in the morning. I felt like I had no life. Several times I went to my GP about how tired I was feeling, and was repeatedly told to come back if it didn't get better. Blood tests all came back normal.

More than a year had passed when I decided to go back to university. I felt desperately unhappy in my job. I continued to struggle there, and the doctors I saw decided I was simply "depressed." When I tried to insist that my mood was low because I was so tired that I couldn't do anything I wanted to do, one even told me I was "in denial." I was in tears because I felt like no one believed me, which only seemed to confirm their assumptions. They didn't seem to understand that I had plenty of motivation and enthusiasm for life (unlike a depressed person), I just didn't have the energy. I was put on antidepressants, which not only failed to treat my fatigue, but caused all kinds of unpleasant side effects.

It was only due to luck that I finally received help. A doctor new to me recognized what she was seeing, and referred me to the specialist chronic fatigue service. Two and a half years after becoming ill, I received a diagnosis. You wouldn't think being diagnosed with a debilitating chronic illness could be a good thing, but it was a relief to finally feel like I had been understood. A diagnosis hasn't been the end of my struggles, but it's been so long now that I have learned how to pace myself, limit my activities to a sustainable level and come to terms with living this way.

I am hopeful that I will yet recover."

Missing since 1971:
Maryann R.

“I have been the face of **ME/CFS for over 45 years.** After graduating from nursing school in the mid-1960s, I moved to Hawaii. During visits to my family in Indiana, I came down with the flu and meningitis. That is when it all started. By the time I married in 1970 and set up a permanent home in Hawaii, this "monkey-on-my-back" was well established.

In the early years, the relapses were only two to three times a year. The overwhelming fatigue and malaise would abate, and life resumed in a normal way. But over the years, the symptoms came more frequently, lasted longer and could be triggered by even minimal exertion. During exacerbations, I have always felt exactly the same since day one. The only variable to the fatigue and malaise is the severity: sometimes mild, sometimes severe and everything in between.

The story of my search is like everyone else's—dozens of doctors, hundreds of appointments. The same old refrains: "**Well, it's not killing you,"** or, "If it's serious, **something else will show up**," or the most repeated, "**Are you depressed?"** I waited patiently over the years, still am. I keep abreast of the research and information that is known so far. And as I enter into my seventh decade of life, I contemplate if the cause and cure will ever be known in my lifetime.

ME/CSF resulted in abandoning my professional goals of career advancement, obtaining a degree and working full time. I was forced to retire at age 62. My marriage ended after 40 years, and although my illness was not the cause, I'll never know how much it played into the disintegration of the relationship.

It has severely limited my social life. It causes the disappointment and embarrassment of yet another cancellation. Do I make the commitment, the plans, the reservations, knowing full well that there is a very good chance that I will have to cancel and disappoint not only myself, but the people to whom I've made the commitment? If I'm lucky, I will be able to participate and enjoy and will probably exert myself. But do the memories of those good times outweigh the consequences that may put me in bed for the following days, weeks, months? It's always a gamble.

Missing since 2002:
Melanie P.

"Prior to ME/CFS, I was an active mother who loved running her kids.. I worked as a preschool dance teacher and a motivational speaker and writer. When I first got sick, my long time PCP searched everything she could for a cause. I remember the day I looked in her eyes and said "Don't tell me I have Chronic Fatigue Syndrome... I don't believe in it." It was so stigmatized in the 80s, I was sure it was just a psychological problem for overworked people.

Fourteen and a half years later, I've been to four out-of-state doctors, the Mayo Clinic and Vanderbilt University. I am unable to work; I rarely leave the house and sometimes have several daytime hours in bed. My cognitive abilities have declined so much that even writing this short story took days. I do everything right. I pace, have a supine exercise routine and treat every symptom possible, but I continue to get sicker. **I feel like I have the flu all of the time,** We need research for ME/CFS because it's the antithesis of physicians' knowledge and typical training. My gastroparesis requires that I eat low fiber and stay away from most fruits and vegetables. My POTS requires a high salt diet, more than I can stomach. Both are the opposite of "proper" nutrition. My body is intolerant of all physical exertion—I feel so much worse 24 hours later, and it can last for days or even weeks. Doctors always tell their patients to exercise.

My body is so sensitive to stimulation, that I have to use noise canceling headphones, and visits with groups of people have become impossible. Doctors would label this anti-social. I am sleepy all day and fight to not nap according to "proper sleep hygiene," but in the evening, as all stimulus decrease (lights, sound, activity), my body becomes more alert, and I can't fall asleep. I am not depressed. On the contrary, I am a positive person always searching for new things I can do in the midst of this horrible illness.

Doctors want me to take antidepressants. Doctors want me to take stimulants to fight the fatigue. My body reacts to stimulants with no high, and all crash. They make me so sick. On the other hand, medications that depress my ANS wake me up and make me feel more able to be active. And yet, if I do, I cycle back to the exertion reaction—only it's stronger and longer because I was tricked by the meds to be more active. Everything about my illness is opposite of what doctors are trained to say and do to help me. Everything they tell me to try makes me sicker. I have become very weary of their ideas. This is why we need research. The things this illness does to my body do not fit into any currently understood illness. "

Missing since 1995:
Chris W.

“In 1995, I began to experience a deep aching in my forearms. I tried to ignore it as I went through my day, which, at that time, was as a stay-at-home mom who was homeschooling her two sons.

The thrumming pain kept me awake nights for about three weeks. Shaky and sleep-deprived, I saw a rheumatologist who diagnosed me with Fibromyalgia. During that visit, I would have the first of yearly Nuclear Antibody tests, which test for autoimmune activity. This test always comes back positive.

Just when I thought I'd gotten the Fibromyalgia under control, in 2001 I lapsed into a bone-deep fatigue, accompanied by flu-like symptoms, which turned out to be Mononucleosis. This kicked off my Chronic Fatigue Syndrome. I was 41. I was in bed for three months.

My life has never been the same since. I've gone from doctor to doctor, only to be treated symptomatically for everything from Acid Reflux Disease, migraines, insomnia, deep muscle and joint pain, depression and so on. At 50, I determined that I would go back to college to finish my undergraduate degree in English. I did so, taking one or two classes at a time. Somehow, I pushed myself through the fatigue and was filled with pride when I walked across the stage in 2012 to receive my diploma. Only a handful of people knew what I'd gone through to earn it.

Since then, I've longed to work outside the home, but have been unable to as my CFS continues to dominate every aspect of my life. Even so, I am blessed with a deeply kind, resourceful and loving husband. My faith helps me immensely, and the love of my family is also a precious gift. However, unless a miracle occurs, I fear that living with the debilitating fatigue and other painful symptoms of CFS will be the thing I live with until I leave this earth.

I'm not sure that any major scientific breakthroughs will be made in my lifetime, and it's sad to see so little federal funding go towards research.

Missing: Lisa Z.

“Before I got married, I was a very active, healthy, social person with plans to open my own business, get married and to start a family. I was diagnosed in 1991, only months after getting married. When we took our vows, we never expected to have to deal with "the worse" part of "for better or worse" for quite some time, but we had no choice. I tried to continue working, but had a miscarriage and then trouble conceiving, so I was told it was either a career or a family, so I chose family.

I had two hard, complicated pregnancies, but was blessed with two healthy children. I wish I could've shown them my strong, energetic, hard-working, fun side. But I was only able to show them my loving, weak side...baking for them when I had the energy, reading and playing games with them inside, instead of running around and playing with them outside, and hardly ever being able to have them invite friends over because it would be too much for me to handle without extra help.

I still to this day don't talk or tell many people that I have ME/CFS because it's too difficult to explain or defend. Except for my immediate family (and even they don't understand it always), I really don't have any support. I don't have a special doctor to treat me and have survived solely on pacing myself and trying to live as healthy of a lifestyle as possible, within my limits.

I know I am much luckier than many people with ME/CFS, I am not bed- or chair-bound, but I still mourn the life I could've had, the income I could've had and the friends that I've lost along the way since I've had to live a very unsocial lifestyle. I am very angry that ME/CFS is not more recognized and that I'm embarrassed to tell people that I have it because I'm afraid of how they will react and I don't have the energy or brain power to explain and defend my illness to them. If only people (and some doctors) would understand and treat us the same as they would if we told them we had MS or Lupus, or any other recognized illness...”

Missing: Connie F.

“As a former letter carrier, I know that not getting enough exercise is not the reason why I came down with CFS/ME. Feeling like I had the flu for weeks, then months, while doctors kept telling me nothing was wrong continued until I was led to a rheumatologist who could diagnose me properly. Although that same doctor was able to prescribe what I call my miracle medicine several years later, the Buspar I am now taking regularly has not cured me. Life is more bearable, though, as I struggle to keep a part-time job to supplement my disability income.

Since I have always been single, I am solely responsible for taking care of myself. This is especially hard when I come down with seasonal colds or flus, seeing as I still have to do all my own grocery shopping and cleaning. It is so hard to not be jealous of others who have husbands who let them stay home in bed to take care of themselves. I often wish that this life would be over already, as it is so difficult. But I do have many friends and family who help to make it worth living day to day. Also, there is always hope that someday someone will find a cure during my lifetime. If that happens, I would not want to have missed it!

Probably the hardest part of managing this illness is dealing with the attitudes of many of those around who think you have it made working part-time, believing that you are healthy enough to work full-time. Many times, I come home from work, feed myself something for dinner, even if it is just cereal and collapse for the night. Since people only see me at my best, being that I only come out when I am feeling well enough, they think I am like that all day. The reality is that much of my time is spent recuperating from being out and about.

I was thin and in excellent health when I became ill. Now I am overweight and seem to always be dealing with something attacking my immune system.. It is very hard to keep smiling when you never feel really good, but I certainly do keep trying.

I continue to make plans for my future, all the while knowing that those plans could change in a heartbeat due to how I am faring on any given day. In the end, though, isn't that what all of us must come to grips with? I just have to deal with it daily. ”

Missing since 1994:
Susan R.

"My story begins in 1994. I was 29 at the time. I was a mother to a beautiful daughter and married to my high school sweetheart. I worked full time in the healthcare industry and instructed aerobic classes at the local YMCA. I loved the outdoors.

I awoke one morning in April with a high fever, swollen glands, chills and "brain fog." I thought I had the flu, but it never left. I was exhausted all the time. For months I sought the help of numerous doctors who checked me for everything from Cat Scratch Fever to Lupus, Lymphoma, MS, Thyroid Disease, ...the list goes on. Needless to say, they never figured out what was wrong, and I was finally diagnosed with CFS in 1996. My doctor was useless in helping me with my symptoms.

I had disability insurance that declined to pay my benefits if I did not submit to neuropsychiatric testing because of my CFS diagnosis. I was forced to work part-time and give up my aerobic instructor job. I was ultimately discharged from my employer whom I gave 20 years of my life to.

We almost lost everything we worked so hard for. And the impact was worse for my family, who didn't understand this illness, watched me suffer and could do nothing to help me. The psychological impact on me was almost unbearable. Many people I loved questioned my debilitating illness. I felt like a failure and as my doctor said "well, you won't die from it." No, I have not died from it but at times, I wished I would have, even now.

In May 2000, I suffered a rt. thalamic stroke. I have deficits that affect my left side. In 2006, I discovered a positive Lyme test performed during my hospitalization for the stroke in 2000. I was never treated for the Lyme Disease. So, I have two highly controversial diseases. I believe that we will find a link between CSF and a chronic, untreated viral infection (ie: Epstein Barr virus, Mononucleosis, Lyme Disease, etc).

I want people to understand that we are not lazy — this is not all in our heads or fabricated—this is real and not made up. We have such a difficult time getting through our day. We need advocates to speak for us because we are too sick to fight and speak for ourselves."

Missing since 2005:
Paris A.

“Imagine that you have the flu. You're so exhausted that walking feels like you're moving through quicksand. Your whole body aches. Your mind is foggy, and it's hard to concentrate on anything. Every system in your body is off in some way—joints, muscles, brain, digestion—everything.

Even though you're not well, you have a meeting today so you have to go to work. You drag your exhausted, aching body out of bed, and by some miracle you manage to get to the office. All day you shuffle along, secretly praying the day will go faster so you can go home and go to bed. The refreshing sleep you need to feel better becomes the thing you daydream about all day long. Finally you go home. But when you get to bed, you can't fall asleep—the ultimate irony. You lie there knowing if you could only get some sleep you'd feel so much better, knowing tomorrow you have to get up and do it all again, and wondering how you'll manage. **Now instead of one day, imagine that is your entire life. Every day.**

That's my life. It's been that way for 11 years. **My life went from active, social and hopeful to sedentary, isolated and lonely.** Some days are better than others. Since I first got sick I have come a long way because I've learned how to live within my energy envelope and manage my symptoms.

But every day I am sick. Every day I deal with fatigue that pulls me down. Every day I am in pain. Every day I mourn the life I could have had, should have had. My entire life revolves around this disease. And the accompanying depression makes it hard to imagine that it will ever get better. ”

Missing: Tiffany L.

“It's hard living with an invisible illness that not many people understand (let alone believe), has no known cause or cure, and no effective treatments. Before CFS, I had giant goals: get my PhD, have a baby, gain tenure at my university, make a name for myself in my field, etc. I completed my PhD and gave birth to my sweet little girl just before getting really sick, but I've had to adjust everything else.

This disease has robbed me of lots of things like a clean house, an active social life, advancement in my career, hobbies and much more. But I've learned to re-prioritize, and I've come to a place of deep appreciation for the things I can still do. I teach at a university, but I'm no longer seeking tenure. That means I make a little less money but I have a lot of flexibility in my schedule and overall much less stress. Many of my classes are online, so it's very manageable with this disease.

And I truly love my job. And I have my beautiful daughter and a sweet wonderful man who is very understanding and never makes me feel guilty about not doing enough around the house. And pets! The three of us are animal lovers and spend lots of time living our sweet pets. Yes I have challenges, daily pain, heavy fatigue and a whole host of other symptoms that have forced me to slow down to a snail's pace, but I have a life full of love. And I am grateful. And I am happy.

When things get really hard, I remind myself to "look for the love." Because it's everywhere. I can always find it in my child's eyes, in a warm hug, in a cat's purr, and in my Facebook support groups. I can find it at my daughter's school when I see children hugging their parents goodbye each morning. I can find it on TV when I watch an inspiring documentary or good indie film. It's in music and art. There it is again when my neighbor waves to me and offers a kind smile. Love is simple, it's everywhere, and embracing it is a powerful defense against the darkness of this debilitating disease.

For many years, I was depressed. Severely depressed. Depression is a dark and scary place to which I never want to return. With the right antidepressants, the use of medicinal marijuana and finding a good therapist, I was able to pull through. It's strange how life works. I hate this disease, I hate my chronic migraines, and I hate depression. And yet it's 100% because of this journey that I have so much gratitude and love and joy in my heart. I've boiled down my priorities to only what is absolutely most important. And that's how I always want to live life, with or without chronic illness.”

Missing since 1980:

Bill J.

"I came home from work on Dec. 8, 1980, feeling sick from a flu-like virus. I was out sick for two weeks, before limping back to work for the last of the month, but **never felt the same again**. By May of 1981, I developed a full blown case of what later became known as CFS. I was bedridden for a solid week until the debilitating fatigue let up.

I later lost my job, and struggled to find some kind of work I could still do, even going to a business school for training. Afterwards, I got a job in the composition room at our daily newspaper, but lasted less than two months until I became too tired to do the job and was let go. At that point, I needed to apply for Social Security Disability.

First, I had to try to find out what was wrong with me physically. I had to go to a local community hospital clinic to start the tests, since I had neither money nor insurance. As there was no name for the malady at that time, Social Security kept turning me down, and I had to keep appealing my case. It took four years of testing until I was finally diagnosed with CFS, and I could get approved for disability, though my appeals went all the way to the U.S. District Court of Appeals, just short of the U.S. Supreme Court level.

During this time, I had to move in with friends for a year. After that, I managed to find an apartment that was income-based, and my "income" from welfare was so low that not only did I not have to pay rent, I would go to the apartment office each month to receive utility payment assistance.

Being able to finally qualify for Social Security Disability payments has been a blessing, but it took SO long to get them. I'm now going on 62, and haven't worked since the 1980s."

Missing since 1986:
Anne B.

"I have been suffering from CFS for almost 30 years. I'm alone in life and have to support myself, so pretty much any energy I can drum up in a day is spent on working, with little or nothing left for those things that make life wonderful—family, friends, hobbies, love. I used to sew and make most of my own clothes. No more. I used to act and sing in community theater, opera and bands. No more. I used to draw. No more. I used to take evening classes in languages, art, and astronomy. No more.

My evenings are now spent watching TV, reading and doing puzzles. I'm bored with so little stimulation. Weekends are the only time I'm able to do errands or chores; I have to triage them very carefully. Buying groceries gets done because it has to. Vacuuming does not. I shower (sitting down) no more than once a week .

Since I look fine, people are reluctant to believe that I'm sick and will tell me, "everyone gets tired!" They don't understand—I don't "get tired." **I'm never NOT tired**. Think about a typical day for most people: You're up at 6, make breakfast for the family, get the kids off to school, go to work, take the kids to soccer/piano/dance in the afternoon, come home and make dinner, help the kids with their homework, get them off to bed, throw in a couple of loads of laundry, and finally, finally, fall onto the couch exhausted. Think about how you feel at that point. That's how I feel when I wake up in the morning, except now I have to get through an entire day.

Oh, yes, I've applied for disability, unsuccessfully. I just need to keep applying until approved, but it's a lengthy, energy-consuming process, and I'M TOO TIRED! **I think about suicide every single day. What's the point of continuing, when life is all struggle and no reward? Yes, I'm depressed. Wouldn't you be?**"

Missing since 1993:

Tammi R.

"When I was in my mid-20s, my family went on a Florida vacation. We had a great week of swimming, shopping and eating seafood! On the way home, I started feeling very ill. Over the next four days, I got sicker and my fever rose. Doctors discovered that my colon was swollen twice its normal size, and I was hospitalized for several days. They deduced that I had an unidentified intestinal virus. I didn't feel well for a long time and whenever I experienced stress I felt exhausted. After a couple days of bedrest, I seemed to recover.

At age 30, my illness became chronic, and I was either bed or couch-bound for a year, unable to even ride in a car. Thankfully, my health improved after a year and I was able to work part-time for three years. I really enjoyed this position and was able to work because I lived at home, and my mom did most of the cooking and cleaning. I attended a Bible study during this time and met my husband. We married in 1996. My health decline again after three years of working part-time, so I quit my job. I have been a homemaker for almost 18 years.

In 2000, after my second relapse, I became mostly housebound. I was unable to drive or cook . **I crawled around our house wearing my husband's volleyball kneepads for 10 months because I didn't have the energy to walk.**

In 2001, I qualified for a study with the experimental drug Ampligen. Someone drove me to Charlotte twice weekly for three years. I went from 10% functioning ability and in a wheelchair to 65% and being able to walk again for short distances by 2003. My health stayed at this level for a few years and then began to decline again in 2007.

I am currently still on this drug. ME/CFS and Postural Orthostatic Tachycardia Syndrome (POTS) have largely taken away many things I enjoy in life; anything involving concentration or brain energy is improving from Ampligen, but is still very limited. For the last several years, my travel has been limited to within a two-hour radius of our home. Thankfully, the Ampligen infusions are slowly helping my cognitive and energy symptoms, however**, the hardest part is getting people to believe how ill I am because I look so normal. I have suffered with ME/CFS for 23 years now**. "

Missing since 1968:

Merry S.

"My last two years of high school—1968-1970—I was unwell all the time and in and out of the hospital for tests. At one point, I was diagnosed with esophagitis, later with a severe kidney infection.

During the second year, after a month of headache and fever every day, I consulted a doctor again. He was so sure that I had a terminal disease of the connective tissue that he ran the test five times. Every time the test was negative. I was sent home with a diagnosis of a viral infection—virus unknown—and a prescription for an antidepressant.

So my illness, which years later I came to know as ME/CFS began when I was a teenager. My experience with ME/CFS began, however, much earlier than my teens, because mother was ill. Although she was never diagnosed, I have absolutely no doubt that she suffered from ME/CFS. I don't remember my mother as ever well. She spent much of her time asleep on the couch.

M my health did improve after high school, and I thought of myself as generally healthy, but in retrospect I realize that I dismissed symptoms and cut back on activities. My circle of friends was smaller than it had been in high school. I didn't participate in extra-curricular activities. I didn't respond to the invitation to enroll in Honors College.

The year after graduation from college, I worked in a factory, and although the job was light packing, it was too hard for me. I felt more and more run down. Finally I got sick with a terrible sore throat, aching joints, etc.

Symptoms waxed and waned during the next couple of years. Some days, weeks even, I actually felt ok. My health declined again when I tried to go to graduate school and after that when I was working as a technical writer.

Then the summer of 1988 I was very ill. Later I would think that I must've had hepatitis. I don't know. One day as I lay in bed, I thought I saw Death sitting at my computer. **Since that summer I have not been well one day.**

In 1990 I got a diagnosis of CFS. My health has continued to decline as the years have gone by. Since a major crash in the fall of 2009 I've had to spend most of my time in bed. I am now 63 and close to the age my mother was when she died. I hope my life is almost over."

Missing since 2008:
Helen K.

"Eight years ago, I became ill with mono at the age of 52. After six months of exhaustion, my doctor stated I had chronic fatigue syndrome. Six months after that I was told I have fibro. I missed so much work. I am an RN. I am out on disability as I was not able to work enough. We lost our home because we couldn't pay the mortgage. Our income is about a third of what I was making prior to becoming ill! I can't clean my apartment the way it should be, I can't cook the way I used to.

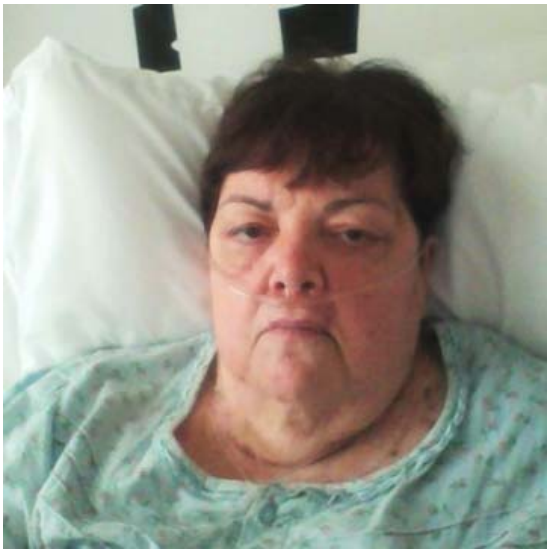
We have very little intimacy as I have no desire. I have sensitivity to lights, sound and some materials and scents. I also have IBS, I cry easily. I have trouble sleeping, which affects my awake time. This past winter I was in bed for over two months as my body crashed again, and I came down with bronchitis. And I could not fight it off. I also have COPD.

I am not the grandmother I want to be. I often don't want to see the babies or the older ones. I don't bake for them like I used to do, simple things. I have no desire. And don't let me forget the simple things like remembering to shut the stove off when I take the pots off. Or how to make a meal that I've made a thousand times. Or driving to the grocery store and forgetting where or how to get there. Very frightening. Or walking across the room and looking like I've been drinking alcohol all day, I wobble and lose my balance daily.

I get out daily in the summertime the pain is much more manageable for me in the summer. The winter can be intolerable for me with the constant changes in the barometer. I also have trouble concentrating, if I am on the phone with someone, after a few minutes, it's as though I don't hear them, I am blank. This makes me not speak on the phone. And I isolate. I feel like I am not a good friend or wife of mother to my family and friends. Most understand, but then they really don't. So to say my life has changed is an understatement. I miss myself, my job, my life..."

Missing since 1981:

Jan B.



"I am 63, a 35-year survivor of ME/CFS. I am homebound, only leaving home for medical appointments. **I belong to the 25% of people with ME/CFS in the severely affected range**. Prior to becoming ill, I had a busy fulfilling life as a single mother. I worked two jobs: a 20-year career in the mental health field and a part-time job. I volunteered in my community. I enjoyed water aerobics and played softball and basketball at the local recreation center. I also swam, played tennis and rode horses.

In 1981, I couldn't seem to recover from a particularly severe bout of flu. I was exhausted, had to quit my part-time job, stop volunteer activities and curtail my life to bare necessities. I spent most of my time away from work in bed. The symptoms have waxed and waned since, never completely disappearing. Especially hard to deal with are the: constant muscle/joint pain, post-exertional malaise and cognitive difficulties (word finding), short-term memory loss, extreme exhaustion after mental effort, neuropathy, severe pain/numbness in my feet and hands, loss of sensation, photosensitivity, very poor balance. I use a cane or walker. I have orthostatic intolerance, only able to stand upright for two to three minutes at a time.

The term fatigue is inadequate to describe the weighted inability to move or function that I feel every moment of my life.

My life since having CFS has been cycles of relapse and remission. With each cycle, relapse has extended and worsened. I tried cognitive behavior therapy (CBT) and graded exercise therapy (GET) treatment that accelerated the progression of ME/CFS and caused loss of functioning that I never regained.

By 2006, I was housebound and almost completely bedridden. I wasn't able to consistently keep medical appointments. Over time, I have improved enough to take care of my personal needs and attend doctor appointments. I require assistance with grocery shopping and house cleaning. I need oxygen 24/7 (never smoked) and use a walker or cane for mobility.

I left my career in 1995 and was approved for SSDI in 1999. My poor health caused me to sell my home of 33 years. **I was once told by a woman that watching me worsen was like watching me fade into a ghost before her eyes, a Technicolor picture fading to blurred black and white."**

Missing since 1992:

Brie A.

“As a youngster, I was a musician, **won two bronze medals in Junior Olympic Nationals for swimming** and was a good student. I was happy and playful. As a licensed psychotherapist, I had a successful private practice.

I became ill with a flu-like virus at the age of 24. I developed unrelenting fatigue, joint pain, swollen lymph glands and severe headaches. I ended up on short-term disability for a year. I would sit on the floor and try to hold a hair dryer, but my arms couldn't hold it for more than a minute. I was diagnosed with CFS, but everyone thought it was just in my head. I have a very strong will and began to feel better, though never felt as good as before my illness.

For many years, the symptoms would wax and wane. I accommodated and hid my illness fairly well. I worked part-time and would sleep on the weekends. Giving up was never an option. I was raised with the mantra "Whatever the mind can conceive and believe, it can achieve." My partner started doing more and more. Pretty soon, she was doing all the cooking, cleaning and errands. I was using what little energy I had to keep working. I had to take a "sabbatical" for eight months in 2003. We couldn't afford for me to quit working part-time, so I returned to my private practice. I had stopped socializing because I never had the energy.

I've had this disease for 24 years. The symptoms have changed a bit, and I've gotten really good at hiding it. I even learned how to detach from my body so as not to feel the pain. Last year was IT for me....I couldn't continue working. Nothing I tried helped....I finally reached my breaking point. I never knew this was a progressive disease, but it is. I now have a neurological disorder. Testing revealed severe abnormalities.

At the age of 47, I sometimes get lost going to familiar places, can't find the right word, and have difficulty with calculations/puzzles/or simply understanding what someone says. My CPET testing shows that on a cellular level, I don't have enough energy to do simple tasks (washing the dishes, vacuuming). I went on disability in October 2014. I tried to return to work in January 2015, but only lasted six weeks. I now receive long-term disability, but the company says I have to prove I am still disabled after two years. I don't have good medical care because there are no doctors in my area that are even interested in learning about this disease.

Patients like me really need two things: 1.) Understanding and acceptance of this disease by the medical community and the public (a new name too); 2.) Research to invest in treatment. Please Help!! ”

Missing: Donna W.

"We had a wonderful life. We were raising two active girls with busy schedules every day of the week. When I first got ME/CFS, I did not know why I did not feel well any longer. As my children grew, each year become more difficult to keep up with working, taking care of our home, attending all the girls' sporting events, cooking, volunteer work, attending church and having energy to enjoy life with my family. I went to the doctor, but received no answers.

After 10 years of living this way, I became even worse. The day I was finally forced to admit to my husband that I needed help with our household was embarrassing for me. I am blessed that he understood that I was pushing with all my might to be a good mother, wife and contributing member of society. We have now had to pay for home help for the past 10 years. The part that hurt the most was when I got so bad that I could no longer leave the house to do things with my children. They were robbed of so many things that they deserved to experience with their mother.

ME/CFS slowly stole our lives. There were no longer family outings or physical outdoor play together. My girls missed my presence every day. By 2003, I had to stay in bed every afternoon and most of the evening. This was how I lived every day, and my family missed me as much as I missed them. In 2009, ME/CFS rendered me completely bedridden. My amazing husband had to help bath me, dress me and blow dry my hair so I could collapse in bed when he was done.

We feel like we have lost everything. Normal life does not live here. No more eating out as husband and wife. No more entertaining or enjoying friends. The only way my family or anyone could see me is to briefly visit my bedside. This year I missed the births of my first two grandchildren. I cannot even hold them. Living this way is heartbreaking for everyone in our family. Funerals, birthdays and holidays, for each one my family is there, and I am stuck here in bed ALONE. Eating Christmas dinner alone should not happen. Please help all of us who are living in isolation with no hope for a future or a life."

Missing since childhood:
Aimee L.

"For as long as I can remember, I have struggled with depleted energy levels. I used to lose concentration in school far too easily and could sometimes find the smallest amount of physical exertion exhausting. Of course, I was just labeled by those around me at the time as lazy; the fact that I have always been overweight did not do much for me either, if I am honest.

It took over two years, various tests, and failed medication for me to finally get the diagnosis I had been searching for: I was suffering from myalgic encephalomyelitis (ME).

It has only been 10 months since I got my diagnosis and in that time my health has plummeted. I had to go off sick from my job, only to then have to leave all together which was heartbreaking. The pain in my joints has worsened; I cannot walk without using my walking stick, and I need a perching stool to help me carry out simple tasks. This illness has severely lowered my quality of life and it makes me so angry that it has managed to do it so easily.

I used to walk everywhere. **Now, I am lucky if I can make it to my local supermarket 2 minutes down the road.**

I love to read; I am a massive bookworm. **Now, I cannot make it through a paragraph anymore without having to go back to reread it because the information is just not going in.**

And, I used to sing. My God, did I love it! My way of escaping anything and everything was to sing. **Now, I barely have enough breath in me to form a coherent sentence – and that is without having to stay on my feet for 3-5 minutes.**

I think the most heartbreaking part for me is that the illness has stolen what my marriage should have been. My husband and I were supposed to go out into the world, experience things, and live to the fullest. **Now, we are lucky if I have enough energy or the pain has subsided enough for me to be able to get off the sofa to help with tea.**

My big wake-up call was falling trying to get out of the bath. **I am not the able bodied 26-year-old I should be and that is a devastating thing to come to terms with.**

Missing since 2000:

Mary B.

"I was diagnosed with ME/CFS in September 2004. Six years prior to that, I had pneumonia and was in the hospital for a few days. I stayed home for three months with intense and overwhelming fatigue. Eventually, I got better and went back to work. But two years later, I went through the same exact scenario. I got a bad infection and took antibiotics. This time, the fatigue came and did not leave.

I tried working for a year; my Director of Nursing was so amazing and willing to work with me as much as she could. Eventually, I was down to 4 hours/week and even that was too much. **My personal physician said it was time to stop. That was one of the most difficult days for me in my life. I loved nursing and having to give it up was heartbreaking.** I kept up my license because I thought I would get better. The changes were life-altering.

My husband took over most chores. It changed his life as well, obviously. All my kids were grown by now and out of the house but very supportive.

This is such an isolating disease. I am alone most of the time. I pace myself throughout the day. Mornings are better for me so that is when I try to get out to grocery shop or run an errand or two. I can load and unload the dishwasher or washer and dryer. I can cook easy meals and make the bed. Besides that my husband does everything else.

If a trip is planned, it needs much advance planning and rest ahead of time. Naps are incorporated into each day. Upon return, it takes weeks to catch up to where I was before the trip. If I become ill, I am really down and out; it takes much longer to recover due to this disease. I try so hard not to get ill. During flu season I try not to go out at all. My husband does the shopping and errand running. I know fairly well what I can and can't do, but there are days that I try to push and do more… and pay the price.

I get 'brain fog'. My words do not come out right. My husband John is my lifesaver, along with my incredible doctor who understands this disease. I count on her and know she will help when I need it. This disease has totally changed our lives and I pray for a cure someday soon!