STORIES OF THE
#MILLIONS MISSING

#ME ACTION

#MILLIONS
MISSING

Sarah

GERMANY


Missing since childhood

“My name is Sarah. I am 42 years old and I 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.”

#MILLIONS MISSING

Karen C.

SACRAMENTO

Missing since 1987

"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."

#MILLIONS MISSING

Lizzie

CHICAGO

Missing since 2015

"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 alllll the time. I miss seeing my friends, but I get too tired. – →

#MILLIONS
MISSING

Lizzie

CHICAGO

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."

#MILLIONS
MISSING

Lori B.


Missing since 2000

“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 →

Lori B.

..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.”

Jamie D.

CALIFORNIA

Missing since 2013

"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.

→

Jamie D.

CALIFORNIA

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.”

Heather E.

Missing since 1992

"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. I am not able to take on many counseling clients due to my symptoms."

#MILLIONS
MISSING

Shar

WASHINGTON

Missing since 2014

“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... →

#MILLIONS
MISSING

Shar

WASHINGTON

...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.”

#MILLIONS
MISSING

Amy E.

CALIFORNIA


Missing since 2003

“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... →

#MILLIONS
MISSING

Amy E.

CALIFORNIA

...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.”

#MILLIONS
MiSSING

David B.

CALIFORNIA


Missing since 2011

“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. →

#MILLIONS
MISSING

David B.

CALIFORNIA

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.”

#MILLIONS MISSING

Alana G.

VIRGINIA

Missing since 1999

"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... →

Alana G.

VIRGINIA

...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.”

#MILLIONS MISSING

Oihan U.

SPAIN


Missing since 2013

"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."

Lucy M.

WILTSHIRE, UK


Missing since 2003

"Today I am sicker than ever and I 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."

#MILLIONS MISSING

Henderson F.

SÃO PAULO

Missing since 2014

“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.”

#MILLIONS MISSING

Sigrid V.

NORWAY


Missing since 2014

“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.”

#MILLIONS MISSING

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. →

Nicola S.

LONDON, UK

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.”

#MILLIONS
MISSING

Sarah C.

CHICAGO

Missing since 2014

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... →

#MILLIONS
MISSING

Sarah C.

CHICAGO

→

…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.”

#MILLIONS MISSING

Allison M.

OTTAWA, CANADA


Missing since 1989

"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."

Marie

ÖREBRO, SWEDEN

#ME
ACTION

Missing since 2007

“My name is Maria and I am 47 years old. I have been diagnosed with ME for two years but have been ill for at least 10 years before that. I try to learn how to handle life with ME. I have to make choices all the time not to get worse. Where I live there are no doctors who canhandle ME. This means that I have to try and get worse on my own. It is a solitary disease.”

#MILLIONS
MISSING

Kathy I.

Missing since 2013

“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 bottomstretch, 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.”

#MILLIONS MISSING

Karin B.

OTTAWA, CANADA


Missing since 1994

"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!"

#MILLIONS MISSING

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.”

Laura V.

Missing since 2000

“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...

Laura V.

... 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."

#MILLIONS
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."

#MILLIONS MISSING

Jessica P.

MANCHESTER, UK

Missing since 2009

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

#MILLIONS MISSING

Blythe B.

INDIANA

Missing since 1997

"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."

#MILLIONS MiSSING

Nancy S.

"Missing the beauty of the world, nearby and in faraway lands. Missing just walking around the block with friends and family."

#MILLIONS
MISSING

Emma J.

UK


Missing since 2006

“I've been sick for 10 years. I very gradually went from mild ME to very severe ME. I miss traveling 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... →

Emma F.

UK

...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."

#MILLIONS
MISSING

Allison H.

MINNEAPOLIS


Missing since 2008

“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!”

#MILLIONS
MISSING

Claire P.

UK


Missing since 2013

“Missing... traveling, 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.”

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."

#MILLIONS
MISSING

Laural W.

Missing since 1994

"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!"

#MILLIONS MISSING

Marit O.

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

#MILLIONS MISSING

Debbie C.

DERBY, UK


Missing since 2013

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

#MILLIONS MISSING

Nina Y.S.

BERLIN, GERMANY

Missing since 2011

"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... →

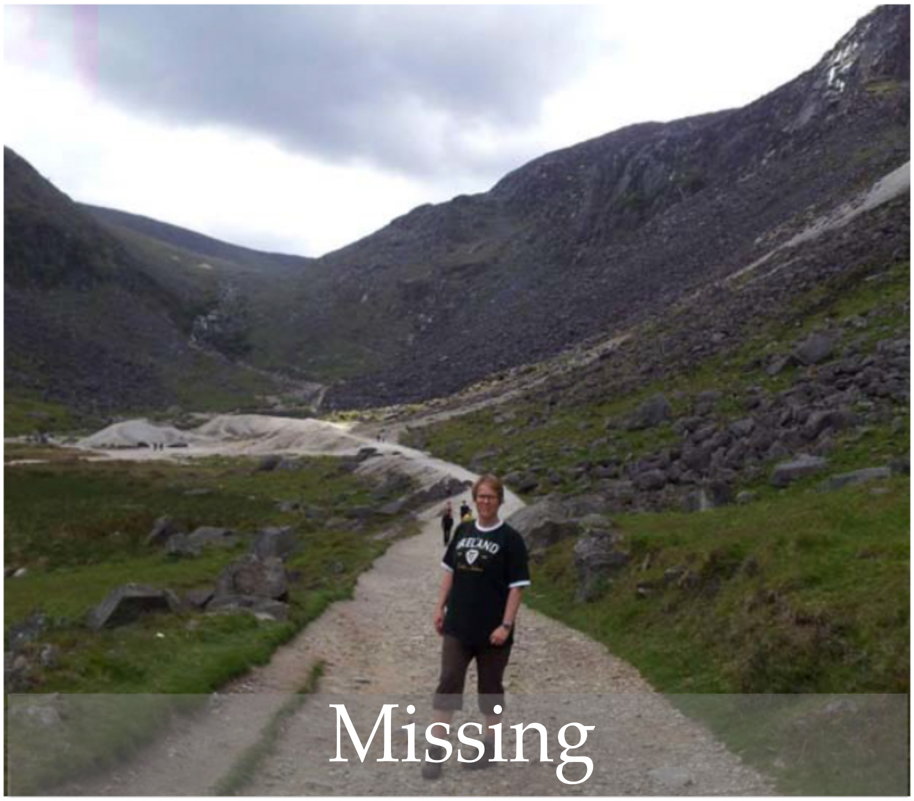
Nina Y.S.

BERLIN, GERMANY

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.”

#MILLIONS 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."

#MILLIONS MiSSING

Susan W.

SCOTLAND


Missing since 2013

"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."

#MILLIONS MISSING

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."

Siri S.

"I miss going hiking or bicycling with my husband.

#MILLIONS MISSING

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…"

#MILLIONS
MISSING

Mette H.

NORWAY

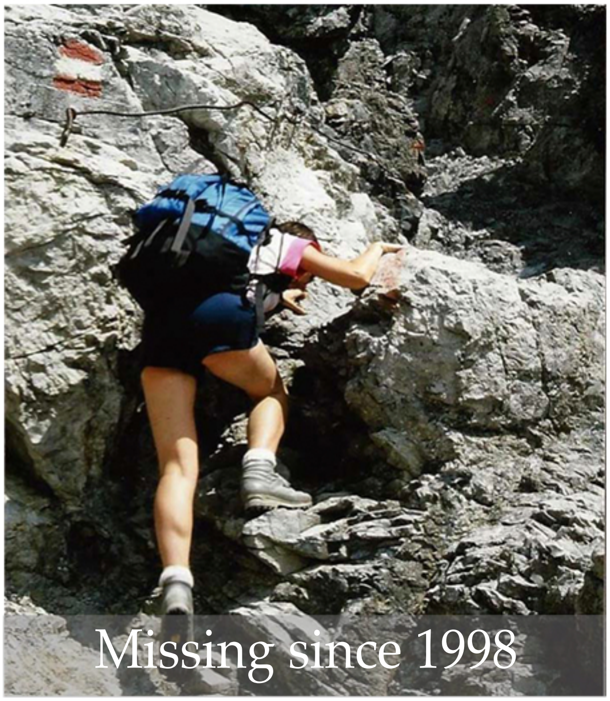

Missing since 2002

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

#MILLIONS MISSING

Kalee

ALBERTA. CANADA



Missing since 1998

“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.

#MILLIONS 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.”

#MILLIONS MISSING

A.

THE NETHERLANDS


Missing since 2003

“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!”

#MILLIONS MISSING

Mireille E.

GOTHENBURG, SWEDEN


Missing since childhood

“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!”

#MILLIONS MISSING

Tammy F.

MIAMI, FLORIDA


Missing since 2013

"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."

#MILLIONS
MISSING

Cedar S.

“I am missing hiking, camping, and working for the environment.”

:(

#MILLIONS
MISSING

Amy

NEWARK, UK

#ME
ACTION

Missing time with my children

“I’m Amy. I’m 33-years-old, and have been a mother for four years. For two of those years I’ve been suffering with ME. I never thought I would suffer from chronic illness. I never imagined living half a life due to an illness that my GP can’t tell me anything about. I never expected to be in a position where my health stops me from parenting in the way I want to parent my child. All of this came out of the blue. →

#MILLIONS
MISSING

Amy

NEWARK, UK

It could happen to you. My daughter will never be 2 or 3 or 4 years old again, those moments have passed. I can’t get them back. Don’t let another person miss out on parenting their child. We need funding now.”

#MILLIONS
MISSING

Helena

SWEDEN


Missing my work as a priest

“My name is Helena Andersson, I'm 55 years old and ill with ME since 5 years back. I miss my work as a priest, to be out in the woods, going for long walks, travel to other countries, to spontaneously able to do things without become worse and crash. I miss being able to take care of my home myself, and am sorry not to be there as a sounding board and practical help and support for my companion in the way I could before. I got sick with a bad cold one evening in June 5 years ago, and never got well.”

Lorraine

UK

Missing decades of my life

“I was a single mum working two jobs to bring up my two children. Working hard. I had lots of friends and a pretty good social life until I was knocked out with glandular fever in my late thirties. I took 3 months off work trying to recover. I returned to work even though I knew I was not ready. But doctors, family and friends encouraged me it was for the best. I continued to work but knew there was something terribly wrong. →

Lorraine

UK

I would crawl up the stairs to bed every day after work to bed to rest. Then get up to make kids dinner, do the washing, clean the house then bed. I could not understand why I was so sick. Doctors said it was because of my age when I got glandular fever. Younger people recover quicker. I would get better in time. Three years later, I married a lovely man who understood I needed rest and was very supportive.

As years went by I continued to push and push myself everyday. Thinking why am I not getting better? I finally got diagnosed with fibromyalgia, then CFS. Still pushing through working hard. Fast forward 8 years. I'm divorced. Haven't worked for past 4 nearly 5 years. I've lost my independence, dignity and pride, friends and my world as I knew it was over. I'm now becoming more severe. I've tried everything put to me. Two years ago I tried to take my life and woke up in ICU on life support. I had had enough.

#MILLIONS MISSING

Lorraine

UK

I don't want to die but I don't want to live like this. It's the dealing with people who are ignorant to this disease, the pain, exhaustion physically and mentally. The judgement. The sarcastic digs. It's like I'm being punishedfor being sick. It's 13 years since I got glandular fever and my life changed forever. I'm now 50. I cannot and will not do another decade of this life. Doctors have been rude, unsupportive and I have felt so alone with this. My kids are older now. But I've lost so many precious years with them. My 24-year-old son has been showing sign of having it too. He has left the house a handful of times in two years for doctors appointments. He stays in a darkened room 24/7. Doctors say he has anxiety and depression. But I see the signs.

I'm sure he has ME. So I try my best to look after him. It breaks my heart to watch this. He was such a active boy. He's lost all his friends. No one speaks to him, and his life...

#MILLIONS MISSING

Lorraine

UK

...as he knew it is gone. We are left to our own devices. It's not right and it's so cruel. Early treatment and proper advice is so crucial. I pray thing change soon. Not just for me and my son but for the millions missing."

#MILLIONS
MiSSING

Nina

LONG ISLAND, NY


Missing my career as physician

"I had a wonderful, rewarding career as a physician. I worked hard and spent long hours researching everything I could for my patients. During my time off I gardened, went hiking, enjoyed karate and kick-boxing. I loved photography, diving through the waves at the beach, and traveling with my family. A few years ago I began to notice some intermittent fatigue. "Bad days", I called them. I researched causes of fatigue and spent...

→

#MILLIONS MISSING

Nina

LONG ISLAND, NY

...a lot of money on supplements and holistic providers. I wasn't able to exercise anymore - I suddenly had no "wind" and afterwards crashed instead of feeling rejuvenated. But rest was not restorative - it did nothing. I stopped tending my garden. I struggled to get through work just to come home and lay on the couch. I cut back my hours and reduced my patient load. The fatigue became profound, and I couldn't do it anymore. I became unable to drive. I couldn't walk or stand for long. My husband took on all the shopping, cooking, and cleaning.

Although I am never "normal", there are times when that feeling of being miserably sick lets up a little. We take advantage of these "ok times" to get me out of the house for a short period, and this is, of course, when I run into former patients and co-workers who tell me how great I look! I've apparently never looked...

Nina

LONG ISLAND, NY

...so “fabulous” as when I got sick. The hardest thing, though, is my interaction with other doctors. I don’t look “ill”. It pains me to see the look of disbelief on their faces when I explain the crushing fatigue, the weakness--the feeling of constantly being sick. A once- esteemed, well-respected and hard-working physician, I am now looked at dubiously by my own peers. This truly is an “invisible illness”.
My new “life”.

#MILLIONS
MISSING

Noa

HAMBURG, GERMANY

Missing since 2004

“I‘ve always been a jack of all trades, interested and gifted in many areas. If ME didn’t happen, I‘d be a trauma psychotherapist by now. I would probably lead at least one choir, sing in another two and have fun being active in several sports. And I think, I might be a mom as well. I was 27 when I became severely ill following an infection. This led to me being single, in need of benefits and unable to continue my studies.

I will be 42 soon.

→

#MILLIONS
MISSING

Noa

HAMBURG, GERMANY

My life now is way less colourful, even though my substitute carer has covered the wall I‘m looking at with a beautiful, weaved duvet, striped in warm colours. My life is mostly horizontal. I no longer see the life as one big potential for good things to happen. That doesn’t mean I’m depressed. It is an evidence based worldview I’d gladly trade in for a more hope and joyful one. With more research, a treatment option will evolve one day and make this situation less bleak. I will be lying here, welcoming it with open arms.”