



UNREST

Directed by Jennifer Brea

TRT: 97 mins

LANGUAGE: English, Danish

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LOGLINE

Twenty-eight year-old Jennifer Brea is working on her PhD at Harvard and soon to be engaged to the love of her life when she gets a mysterious fever that leaves her bedridden and looking for answers. Disbelieved by doctors and determined to live, she turns her camera on herself and her community, a hidden world of millions confined to their homes and bedrooms by ME, commonly called chronic fatigue syndrome.

SYNOPSIS

Jennifer Brea is a Harvard PhD student soon to be engaged to the love of her life when she's struck down by a mysterious fever that leaves her bedridden. She becomes progressively more ill, eventually losing the ability even to sit in a wheelchair, but doctors tell her it's "all in her head." Unable to convey the seriousness and depth of her symptoms to her doctor, Jennifer begins a video diary on her iPhone that eventually becomes the feature documentary film *Unrest*.

Once Jennifer is diagnosed with myalgic encephalomyelitis (ME), commonly called chronic fatigue syndrome, she and her new husband, Omar, are left to grapple with how to live in the face of a lifelong illness. Refusing to accept the limitations of bedbound life, Jennifer goes on an inspiring virtual voyage around the world where she finds a hidden community of millions confined to their homes and bedrooms by ME. These patients use the internet, Skype and Facebook to connect to each other — and to offer support and understanding.

Many ME patients have experienced uncertainty, confusion and even disbelief from the medical community and society as a whole. After all, it's easy to ignore a disease when patients are too sick to leave their homes. In *Unrest*, Jennifer shares her pain and the most intimate moments of her life in order to offer hope and visibility to those who suffer alone in dark, silent rooms.

Though Jennifer and Omar may have to accept that they will never live the life they originally dreamed about, together they find resilience, strength, and meaning in their community and each other.

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DIRECTOR'S STATEMENT

Unrest is a personal documentary. When I was 28, I became ill after a high fever and, eventually, bedridden. At first, doctors couldn't diagnose me and later began telling me that either there was nothing wrong with me or that it was in my head. As I began searching for answers, I fell down this rabbit hole and discovered a hidden world of thousands of patients all around the globe, many of whom are homebound or bedridden and use the internet to connect with each other and the outside world.

We were all grappling with a disease called ME, more commonly known as Chronic Fatigue Syndrome. This wasn't a disease I had ever really heard of, read about, or seen films made about, even though it is an extremely common condition. It's a story that's been flying under the radar for the last 30 years.

Unrest follows the story of me and my husband Omar. We are at the very beginning of our marriage, of our lives together, when this asteroid hits. And at the same time, I start reaching out to other patients and documenting their stories. We meet Jessica, for example, a young girl in England who has been bedridden since she was 14, and Ron Davis, a Stanford geneticist who is trying to save his son's life in spite of some incredible obstacles.

I made this film four times. At first, it was just an iPhone video diary. Those first few years, I could barely read or write but needed an outlet. And so I started creating these really intimate, raw videos.

Then I went online and met thousands of people, all over the world, living the same experience. Many were homebound or bedbound, isolated, without treatment or care, and often disbelieved. I thought, "How could this have possibly happened to so many people?" There was this deep social justice issue at the heart of it. An entire community had been ignored by medicine and had missed out on the last 30 years of science. A part of the problem is that many of us are literally too ill to leave our homes and so doctors and the broader public rarely see us. That is when I decided to make a film.

When we began shooting, I was completely bedridden, so I built a global producing team, hired crews around the world, and directed from my bed. I conducted interviews by Skype and an iPad teleprompter — a sort of poor man's Interrotron. We had a live feed that (when it worked!) allowed me to see in real time what our DP was shooting on the ground. Filmmaking allowed me to travel again.

As we started shooting, and I started to get to know these amazing characters, the film became about some of those burning questions that I had. What kind of a wife can I be to my husband if I can't give him what I want to give? How do I find a path in life now that the plan I had has become impossible? If I am never able to leave my bed, what value does my life have? And I started to become interested in what happens not only to patients but to our caregivers when we

or a loved one are grappling with a life-changing illness. These are questions we will all face at some point in our lives.

Lastly, there was a point at the middle of the edit when we had a very strong cut but I felt unsatisfied with just seeing us, these bodies, from the outside. I knew that there was so much about this experience that an external camera just couldn't capture. And so we started bringing in these elements of personal narration, visuals, and sound design in an almost novelistic way, to try to give the audience glimpses of our dreams, our memories. It was important to me to convey that regardless of our profound disabilities, we are all still fully human. That even laying in bed, we have these complex, inner lives.

It's my hope that in sharing this world and these people that I have come to profoundly love, that we can build a movement to transform the lives of patients with ME; accelerate the search for a cure; and bring a greater level of compassion, awareness, and empathy to millions upon millions of patients and their loved ones wrestling chronic illness or invisible disabilities.

—Jennifer Brea

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JENNIFER BREA'S STORY

The following is excerpted from a TED Talk Jennifer gave at TEDSummit 2016:

Five years ago, I was a PhD student at Harvard. And I loved to travel. I'd just gotten engaged to the love of my life. I was 28 and like so many of us when we are in good health, I felt like I was invincible.

Then one day, I had a fever of 104.7 degrees. I probably should've gone to the doctor, but I'd never really been sick in my life and I knew that usually, if you have a virus, you stay home, you make some chicken soup, and in a few days, everything will be fine.

But this time, it wasn't fine. After the fever broke, I was so dizzy, I couldn't leave my house for three weeks. I would walk straight into door frames. I had to hug the walls just make it to the bathroom.

That spring, I got infection after infection, but every time I saw my doctor, he told me there was nothing wrong. He had his laboratory tests, which always came back normal. All I had were my symptoms, which I could describe but no one else could see. I know it sounds silly but you have to find a way to make sense of things, so I told myself I was just aging. I remember thinking, "I guess this is what it's like to be on the other side of 25."

Then I started having strange neurological symptoms. Sometimes, I couldn't draw the right side of a circle. Other times, I wouldn't be able to speak or move at all.

I saw every kind of specialist: infectious disease doctors, rheumatologists, cardiologists, endocrinologists. I even saw a psychiatrist. My psychiatrist said, "It's clear you're really sick, but not with anything psychiatric. I hope they can find out what's wrong with you."

The next day, my neurologist diagnosed me with conversion disorder. He told me that all of my symptoms — even the fevers, the sore throats, and the sinus infections — were being caused by some distant emotional trauma I could not remember. The symptoms were real, he said, but they had no biological cause.

I was training to be a social scientist. I had studied statistics, probability, mathematical modeling, experimental design. I was uncomfortable with just rejecting the neurologist's diagnosis. It didn't feel true but I knew from my training that the truth is often counterintuitive — so easily obscured by what we want to believe. And, so, I had to take seriously the possibility that he was right.

That day I ran a small experiment. After the doctor's appointment, I walked back the two miles to my house, my legs wrapped in this strange, almost electric kind of pain. I meditated on that pain, contemplating how my mind could have possibly generated all this. As soon as I walked

through the door, I collapsed. My brain and my spinal cord were burning. My neck was so stiff I could not touch my chin to my chest. The slightest sound — the rustling of the sheets, my husband walking barefoot in the next room — caused excruciating pain. I spent most of the next two years in bed.

I was diagnosed with myalgic encephalomyelitis or ME. This is more commonly known as “Chronic Fatigue Syndrome.” The key symptom we share is that whenever we exert ourselves, physically or mentally, we pay and we pay hard. If my husband goes for a run, he might have sore muscles for a few days. If I try to walk half a block, I may end up bedridden for a week. It is a perfect, custom prison. I know ballet dancers who can't dance, accountants who can't add, medical students who never became doctors. It doesn't matter what you once were, you can't do it anymore. It's been four years, and I have never been as well as I was the minute before I walked home from my neurologist's office.

It's estimated that anywhere from 15 to 30 million people around the world have this disease. In the US, where I'm from, 1 million are affected, making it twice as common as multiple sclerosis. Many live for decades with the physical function of patients with congestive heart failure. 25% of us are homebound or bedridden. 75-85% can't even work part time. Yet doctors do not treat us, and science does not study us.

How could medicine ignore a disease this common and this devastating?

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Q&A WITH DIRECTOR JENNIFER BREA

1. Why did you begin filming?

There are so many reasons I picked up my camera. First, because every time I went to my doctor and tried to describe in words what was happening to me at home, I was dismissed. I tried to be as precise as I could. I used metaphors, I used examples. I tried to describe what I was experiencing in brutal detail, yet my extreme and life-altering neurological symptoms were invariably translated into “headache.” It was hard for my doctor to understand that when I was able even to make it to the doctor’s office, it was because it was a day when I was feeling uncommonly well.

I started filming myself on my iPhone at those moments when a doctor is never around — when suddenly I couldn’t speak, or when I’d have to just lay down in the middle of the floor, unable to lift my head. When I brought these videos into the consult room, it changed the conversation completely. I saw the looks of concern, shock and horror on my doctor’s face. Suddenly it was, “Get an MRI, get a spinal tap, go see this specialist.”

I also turned to filmmaking as a way to make sense of things. I’d always been a writer, but I lost my ability to read and write when I became bedridden. So my iPhone became my diary. The film began as a form of private, personal expression simply because I needed that outlet to stay sane.

2. How did the film morph from a personal diary to a documentary feature?

I started to learn my disease wasn’t rare or new, but that it had a long history. There were millions living with ME who had been forgotten because of the way the disease was harmfully and inaccurately branded as “chronic fatigue syndrome” in the 1980s. I began to uncover the layers of misogyny and assumptions that medicine and society have about female patients being unreliable narrators of their own stories. I couldn’t countenance the prospect of spending the rest of my life in bed. But more than that, I couldn’t countenance living in a world where we allowed this to happen. What I saw angered me, and I knew this was a compelling story. I believed that if the world could see what the experience of this disease was really like, if we could share our most intimate and painful moments, then things might begin to change.

3. How were you changed by the process of working on *Unrest*?

Filmmaking became a way for me to transcend the limitations of my body and connect to other people and other worlds. Through the powers of technology, I got to be inside bedrooms in different countries, to travel to devastatingly beautiful landscapes, to build relationships and find community. Working on this film kept me connected to the world and let me start to regain a piece of who I used to be — a journalist, a world traveler, constantly seeking.

I also had this intense experience of mirroring: I heard stories that sounded exactly like my story. I heard people describe symptoms no doctor had ever heard of that were not recorded in medical literature that were exactly the same as mine. Realizing that other people were experiencing these things helped my husband, Omar, and me to feel that we weren't alone.

In time, the camera took on an almost transformative power. Each moment we were recording was a moment that now had the potential to mean something. It imbued otherwise useless, meaningless, random pain with the hope that one day, if shared, these moments could help others. It took many conversations with my husband and with all of our DPs to make them understand: "If you see me screaming, do not try to help, do not back away. Get closer. We already know there is very little you can do for me. In those moments, the camera is the greatest act of love and care you can provide."

Through making this film, I have found that we as human beings are more resilient than we know. When faced with unimaginable obstacles, we can find resources within ourselves we didn't know we had. I think that is especially true if you're lucky enough to have people who profoundly love you, or if you're able to come together and find a community.

4. How long did it take to make the film?

I first started documenting myself in the spring of 2012 after I was diagnosed with conversion disorder. In February 2013, I decided that I had to make a film after a really bad crash — I showed up at the emergency room barely able to walk and was sent home with an aspirin. For funding, I launched a crowdfunding campaign, which ended up raising well over four times my initial goal. The success of the campaign proved there was a networked, passionate, eager audience for this film.

The new budget suddenly allowed me to imagine making a totally different kind of film. I started doing scouting shoots and trialing different forms of remote directing. We used a Skype teleprompter (a poor man's Interrotron) to conduct interviews, and eventually, I found a way to stream our onset camera to my computer. Gradually, I built a global team. Our Danish co-producer Anne Trolldoft Hjorth and DP Christian Laursen joined in February 2014. My producer Lindsey Dryden joined me in May 2014. Producer Patricia E. Gillespie came onboard in summer 2014. We completed post-production in December 2016, so the whole process took four years. One patient has called it "an uprising from our beds."

5. What challenges did you face during the making of *Unrest*?

Unrest was made in a totally new way, technologically, which brought a lot of challenges. Throughout much of the production of the film, I was 99 percent bedridden, conducting interviews on Skype and directing remotely with my producers and crews around the world. The film is an unusual combination of professionally shot vérité, self-filmed iPhone videos, and interviews conducted via Skype. My producers were on location across the world — Patricia in the US, Lindsey in the UK, and Anne in Denmark — relaying the shooting environment to me using live feeds and text messaging. Managing an ever-expanding production team remotely, and collaborating across timezones and cultures, was also a challenge.

I don't know that anyone would choose this method to make a film. However, now that I see the possibilities that exist, I believe that no matter what happens with my health, I will continue making films. That's an incredible thing — the fact that we succeeded in making *Unrest* shows that even living with profound disabilities need not necessarily be a barrier to telling our own stories.

6. What do you hope audiences will take away from the film?

I want people who watch the film to understand that ME is a serious, life-changing illness with a long history, and that it has been seriously neglected because of sexism and because of ignorance and biases within the medical community. I want people to know that there are millions suffering invisibly because science and medicine do not see us, because our disabilities are invisible, or because we are trapped in homes and bedrooms and therefore invisible to our communities. I want people to see and experience people living with disabilities as complex and fully human. And I want people to walk away with a sense that life is fragile, life is precious. We are all temporary, but that when faced with unforeseen obstacles, we all have the potential to find resources within ourselves we didn't know we had.

We need to realize that science and medicine are profoundly human endeavors, and that doctors, scientists and policymakers are not immune to the biases of the rest of the world. We also need to think about women's health in a more nuanced way — our immune systems are just as much a battleground for equality as the rest of our bodies. Finally, we need to listen to patient's stories, and when faced with uncertainty we must be willing to say "I don't know" — because "I don't know" is where discovery starts.

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SUBJECT BIOS

Jennifer Brea (Los Angeles, California and Princeton, New Jersey, US)



Jennifer Brea is a filmmaker, writer, and data wrangler. She was a PhD candidate in the Department of Government at Harvard University, studying political economy and statistics, before getting sick. She earned her AB in Politics from Princeton University, and is a TED Fellow. Prior, she was a freelance journalist in China and East and Southern Africa. Jen was born in Long Island, New York, raised in Central Florida, and now divides her time between New Jersey and California. She is married to Omar Wasow, co-founder of BlackPlanet and a professor at Princeton.

Omar Wasow (Princeton, New Jersey, US)



Omar Wasow is an Assistant Professor in Princeton University's Department of Politics. His research focuses on race and politics. His co-authored work on the challenge of estimating effects of race was published in the *Annual Review of Political Science*. His research on the political consequences of nonviolent and violent protests has been featured in *The Washington Post*, *Vox*, and *The Week*. Before joining the academy, Omar served as a regular on-air technology analyst and was the co-founder of BlackPlanet.com, a social network he helped grow to over three million active users. In 2003, he helped found a high performing K-8 charter school in Brooklyn. He is a recipient of the NSF Graduate Research Fellowship and the Aspen

Institute's Henry Crown Fellowship. He received a PhD in African American Studies, an MA in Government, and an MA in Statistics from Harvard University.

Jessica Taylor (Kent, UK)



Jessica Taylor has been bedbound with severe ME since she was 15, which she developed after a flu-like illness. After spending four years in hospital, she now lives at home in a village in England with her sister and parents. Shocked to be spending her teens lying flat in bed in the semi-dark, Jessica created a blog called [The World Of One Room](#) to help her survive. She also founded, from her bed, a charity called ShareAStar which does outreach to severely disabled and terminally ill children.

Leeray Denton, Randy Denton, and Casie Jackson (McDonough, Georgia, US)



When Leeray Denton got sick in the 1980s, she saw 15 doctors. “They all told us it was all in my head,” she says. Her husband, Randy, was overwhelmed by the responsibilities of being a single parent and, putting his faith in experts who told him his wife wasn’t really sick, he left his wife and two teenaged daughters behind. Ten years later, Leeray and Randy’s daughter, Casie,

develops ME shortly after giving birth. As, decades apart, Leeray and Casie face the same diagnosis, Randy realizes how wrong he — and the doctors — had been, and sets out to understand this illness and win back his wife and daughter.

Karina Hansen (Holstebro, Denmark)



Karina Hansen in Denmark became ill at 16 after an acute case of mono. After her case was assigned to a psychiatrist who considers ME a form of “Bodily Distress Syndrome,” police appeared at her family house with a battering ram. Her parents Ketty and Per were told that Karina’s illness was psychosomatic, and that by caring for her (for example, by protecting her from exposure to sound and light, often a problem for ME patients), they were supporting her “false illness beliefs.” For three and a half years, Karina was forcibly institutionalized and denied contact with her parents. In October 2016, she was allowed to decide her own care and asked to go home.

Ron Davis and Whitney Dafoe (Palo Alto, California, US)



Ron Davis is a Professor of Biochemistry and Genetics at Stanford University and Director of the [Stanford Genome Technology Center](#). He, along with colleagues from Stanford and Harvard, — including several Nobel Laureates — are collaborating to find the cause of ME, exploring existing drugs for potential treatments, and working to develop a cheap, commercially viable test. In October, 2013, Davis was listed in [The Atlantic](#) as one of the greatest innovators currently working. His son, Whitney, is an ME patient who is so ill he can no longer communicate with his family.

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FILMMAKER BIOS

Director, Writer, and Producer: Jennifer Brea

Jennifer Brea is an independent documentary filmmaker based in Los Angeles. She has an AB from Princeton University and was a PhD student at Harvard until sudden illness left her bedridden. In the aftermath, she rediscovered her first love, film. She is a Sundance Fellow and has been supported by the Sundance Documentary Edit and Story Lab, Sundance Institute Catalyst Forum, IFP's Filmmaker Lab, and the Fledgling Lab. *Unrest* is her film debut.

Executive Producer and Creative Advisor: Deborah Hoffmann

Deborah Hoffmann received an Academy Award nomination in 1995 for her documentary *Complaints of a Dutiful Daughter* and again for *Long Night's Journey into Day* in 2000. She is widely acclaimed as editor of such classic documentaries as the Oscar®-winning *The Times of Harvey Milk*, *Ethnic Notions*, and *Mulholland's Dream*. She has received two National Emmys, a Peabody, a DuPont Columbia Award, and a Rockefeller Fellowship. Deborah has been a lecturer at the UC Berkeley Graduate School of Journalism since 2000. She has served on juries for the Sundance, San Francisco, and Mill Valley Film Festivals, and for the Independent Spirit Awards and Gotham Awards. She is a member of the documentary branch of the Academy of Motion Pictures Arts and Sciences.

Producer: Lindsey Dryden

Lindsey Dryden is an award-winning British producer and director who began making creative documentaries with a focus on the body and the arts, after starting her career in British television documentaries (BBC, Channel 4, History Channel). Her films, including *Lost and Sound* and *Close Your Eyes And Look At Me*, have shown at numerous festivals worldwide, including SXSW, True/False, Sheffield Doc/Fest, and Film Society of Lincoln Center's Art of the Real. She has been supported by IFP, IDFA DocLab Academy, and the Hot Docs Forum. Lindsey is a regular mentor at festivals, a film lecturer, a recent Filmmaker-In-Residence at Jacob Burns Film Center in New York, and a proud member of the Queer Producers Collective. She is currently working on *Unrest* and *Billy*, a hybrid music mystery film and interactive experience about an incredible gender outlaw.

Producer: Patricia E. Gillespie

Patricia E. Gillespie is a Wasserman Award-winning filmmaker and Sundance Fellow based in New York City. In addition to her work on *Unrest*, Patricia also served as Line Producer on Sabaah Folayan and Damon Davis' *Whose Streets?*, and is currently the Creator/Director/EP of *American Monster*, a non-fiction crime thriller produced in partnership with Morgan Spurlock's Warrior Poets and Preferred Content.

Producer: Alysa Nahmias

Alysa Nahmias is an award-winning director and producer of nonfiction and narrative films. Her documentary *Unfinished Spaces* won a 2012 Independent Spirit Award and numerous festival prizes, and was selected for Sundance Film Forward. Her producing credits include *Afternoon of a Faun: Tanaquil Le Clercq* directed by Nancy Buirski with creative advisor Martin Scorsese (New York Film Festival, Berlinale, PBS's *American Masters*); *Shield and Spear* by director Petter Ringbom (Hot Docs, Sheffield Doc/Fest); *Tocando La Luz* by Academy Award-nominated director Jennifer Redfearn (Full Frame, PBS); and the narrative feature *No Light and No Land Anywhere* by director Amber Sealey with executive producer Miranda July (Jury Prize, Los Angeles Film Festival 2016).

Editor and Writer: Kim Roberts

Kim Roberts, A.C.E. is an Emmy-winning editor of feature documentaries. Her recent work includes *The Hunting Ground*, *American Revolutionary: the Evolution of Grace Lee Boggs*, *Waiting for "Superman"* (Paramount), *Food, Inc.* (nominated for a 2010 Oscar®), *Autism the Musical* (HBO), and *Inequality for All* (Radius). Kim won an Emmy for *Autism the Musical*, her third nomination. She was nominated for Eddie Awards for *Food, Inc.* and *Waiting for "Superman"* from the American Cinema Editors. Her other films include Oscar® nominees and Sundance Grand Jury Prize winners *Daughter from Danang* and *Long Night's Journey Into Day*; *Last Call at the Oasis* (Participant); *Two Days in October* (Peabody and Emmy winner, 2006); *Made in L.A.* (Emmy winner, 2009); *The Fall of Fujimori* (Sundance 2005); *Lost Boys of Sudan* (Independent Spirit Award, 2004); *Daddy & Papa* (Sundance 2002); and *A Hard Straight* (Jury Award, SXSW 2004). Kim received her Master's Degree in Documentary Film Production from Stanford University, where she won a Student Academy Award.

Editor: Emiliano Battista

Emiliano Battista is a London-based film editor of award-winning feature documentaries, dramas, and television programs. His films include *3 ½ Minutes, Ten Bullets* (Special Jury Prize Sundance 2015, HBO); *How is your Fish Today?* with Chinese novelist and film-maker Xiaolu Guo (Sundance 2007); *The Intimacy of Strangers*, *The Solitary Life of Cranes*, *Black Out*, and *Night, Peace* with Eva Weber; *Elvis Pelvis* (Berlin Film Festival); *Dolce Vita Africana*, a portrait of Malian photographer Malik Sidibe; *The Runner* by Saeed Taji Farouky; and *The Auction House*, a tale of two brothers about the oldest auction house in India. Emiliano has also worked on multi-screen art installations shown in major exhibitions and museums worldwide: *All That is Solid Melts into Air* and *No Permanent Address* with Mark Boulos.

Composer: Bear McCreary

Bear McCreary studied composition and recording arts at USC, where he was the last protégé of film music legend Elmer Bernstein. McCreary landed his first scoring job out of college with *Battlestar Galactica*, which earned him a spot on *Io9.com*'s "Ten Best Science Fiction Composers of All Time." He currently scores AMC's *The Walking Dead* and ABC's *Marvel's Agents of S.H.I.E.L.D.*, among others. McCreary won an Emmy for Outstanding Main Title Theme for *Da Vinci's Demons*, and also received Emmy nominations for his work on *Blacksails*, *Outlander*, and *Human Target*. Some of McCreary's film credits include Focus Features' *The Forest*, Lakeshore Entertainment's *The Boy*, and a recent collaboration with producer J.J. Abrams on *10 Cloverfield Lane*. With numerous projects in the works, McCreary has validated

Bernstein's instincts, proving himself as one of the most versatile and in-demand composers in the industry.

Sound Designer and Mixer: James LeBrecht

James LeBrecht is a well-known film and theater sound designer and mixer, author, producer, and disability rights activist. He is the founder of Berkeley Sound Artists (BSA), an audio post-production house. BSA was the sound house for *The Blood of Yingzhou District*, the 2006 Academy Award® recipient for short documentary. Other credits include *The Force*, *Unrest*, *The Waiting Room*, *The Devil and Daniel Johnston*, *Daughter From Danang*, *We Were Here*, *Bang: the Bert Berns Story*, and *Audrie & Daisy*.

Jim's work as an advocate for the rights of people with disabilities began in high school as a member of Disabled in Action, a pioneering disability rights group. He helped found the Disabled Students Union at UC San Diego in the mid-1970s. Currently, LeBrecht is a board member at the Disability Rights Education & Defense Fund, a leading organization working for the rights of the disabled through education, legislation, and litigation.

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ABOUT ME/CHRONIC FATIGUE SYNDROME

“The treatment of today’s ME/CFS patients is comparable to that of lobotomy patients decades ago. When the full history of ME/CFS is written one day, we will all be ashamed of ourselves.”

–Prof. Dr. Ola Didrik Saugstad, Professor of Pediatrics, WHO Advisor, Norway

Myalgic Encephalomyelitis (ME) is a systemic neuroimmune condition characterised by post-exertional malaise (a severe worsening of symptoms after even minimal exertion). It causes dysregulation of both the immune system and the nervous system. The effects of ME are devastating enough to leave 25% of patients housebound or bedbound. In many parts of the world, it is commonly known as Chronic Fatigue Syndrome.

An estimated 17 million people around the world are suffering from ME. Approximately 75-85% of them are women and 80-90% of them are undiagnosed. (Estimates vary depending on the diagnostic criteria used.)

In 1984, an outbreak of a mysterious disease in a small skiing town on Lake Tahoe left hundreds ill. The CDC was slow to respond. When it did, without testing any samples or examining any patients, investigators dismissed the event as a case of mass hysteria.

There were experts, then and now, who believed outbreaks in Lake Tahoe, New York, Florida, and elsewhere in the 1980s were instances of a devastating, post-infectious neurological condition. It has gone by many names since the 1930s: atypical polio, Icelandic Disease, Royal Free Hospital Disease, Myalgic Encephalomyelitis (ME) and most recently, Chronic Fatigue Syndrome — a name that has inflicted its own sort of iatrogenic harm.

Researchers believe ME is triggered by a virus, but that there is unlikely to be a single viral culprit. Environmental toxins may play a role, but not in all individuals or outbreaks. Like polio or multiple sclerosis, it occurs both in clusters and sporadic form. Its hallmark symptoms include profound cognitive and neurological impairment, tachycardia that prevents many from maintaining an upright or sitting position (“POTS”), immunological dysfunction, and an abnormal response to ordinary exertion.

Despite decades of science documenting profound abnormalities, for the first months and years of illness many suffering from ME meet with doctors who do not believe they are really ill. This is because in America, the disease is taught in just 6 percent of medical schools. Patients are told to go about their lives, to exercise or maintain a level of activity that, due to the metabolic dysfunction that is central to this disease, can lead to permanent disability. MS receives \$115 million per year in public research funding. Chronic Fatigue Syndrome, which affects over one million Americans and is three times as common as MS, receives \$6 million a year. There is no FDA approved treatment, no drug in the pipeline, no big push for a cure.

The human cost of medical and policy neglect is tremendous. At the “mild” end of the spectrum, even patients who still work may lose 50 percent of their previous function. Others are forced to abandon careers they loved. Twenty-five percent of patients are shuttered in their homes or trapped in bed. At the most severe end of the spectrum, patients may live the rest of their lives in darkened rooms, unable to tolerate light, sound, or human touch. Only 4-8 percent fully recover.

The physical devastation is compounded by social harm. ME results in an estimated US \$20 billion (2004) in medical costs and lost productivity each year. In the US and the UK, there have been numerous cases of children being taken away from their parents and placed in foster care. In Europe, some severely ill patients have been forcibly institutionalized and made to exercise. They receive psychiatric diagnoses: “bodily distress syndrome” (an excessive concern for their symptoms) or “pervasive refusal syndrome” (for refusing to exercise and get better). This story is not unique to this disease: 40 percent of patients with a recognized autoimmune condition are initially diagnosed with hypochondria or a psychosomatic disorder.

Some ME patients, after many years of stigma, isolation, and severe physical disability, commit suicide. Many more stories never come to light. Eighty-five percent of patients who have ME are undiagnosed. Contrary to popular perception, people of color and the working class are at *greater risk*.

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Director - Jennifer Brea

Producers - Jennifer Brea, Lindsey Dryden, Patricia E. Gillespie, and Alysa Nahmias

Co-Producer - Anne Trolldtoft Hjorth

Executive Producer & Creative Advisor - Deborah Hoffmann

Executive Producers - Ruth Ann Harnisch, Lisa Gunn, Donna Fairman Wilson,
Dan Cogan, Ian Darling, Regina K. Scully, Lynda Weinman

Editors - Kim Roberts, Emiliano Battista

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