A Shella Films and Little By Little Films production
In association with Impact Partners and Chicken & Egg Pictures

UNREST

Directed by Jennifer Brea

97 minutes / Cert tbc
In English and Danish

Winner:
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Sheffield Doc/Fest, Illuminate Award supported by Wellcome

http://www.unrest.film/

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UNREST

Directed by Jennifer Brea

Director, Writer - Jennifer Brea
Producers - Jennifer Brea, Lindsey Dryden, Patricia E. Gillespie, and Alysa Nahmias
Co-Producer - Anne Troldtoft 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
Cinematographers - Sam Heesen, Christian Laursen
Editors - Kim Roberts, Emiliano Battista

Unrest is a co-production between Jennifer Brea's Shella Films, based in Los Angeles, and Little By Little Films, a boutique production company based in Gloucestershire, UK, founded by Lindsey Dryden.

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UNREST

Directed by Jennifer Brea

FEATURING:

Jennifer Brea

Omar Wasow

Jessica Taylor

Leeray Denton, Randy Denton, and Casie Jackson

Karina Hansen, Ketty Hansen and Per Hansen

Ron Davis and Whitney Dafoe

UNREST

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LOGLINE

Twenty-eight year-old Jennifer Brea is working on her PhD at Harvard and months away from marrying the love of her life when she gets a mysterious fever that leaves her so ill she becomes bedbound, often in excruciating pain, 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 Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome *Unrest* is, at its core, a love story. How Jen and her new husband forge their relationship while dealing with her mysterious illness is at once heartbreaking, inspiring and funny.

SYNOPSIS

Jennifer Brea is a Harvard PhD student soon to be married to the love of her life when she's struck down by a mysterious fever that leaves her so ill she becomes bedbound, often in excruciating pain. She becomes progressively unwell, 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 life stuck in bed, Jennifer goes on an inspiring virtual voyage around the world where she finds a hidden community of millions who have disappeared from their own lives, 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.

UNREST

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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, totally 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 had disappeared from their lives and used the internet to connect with each other and the outside world.

We were all grappling with a disease called ME (Myalgic Encephalomyelitis), also 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. At the same time, I start reaching out to other patients and documenting their stories. We meet Jessica, for example, a young girl in Kent, England who has been confined to her bedroom 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.

I met thousands of people, all over the world, living the same experience; 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 confined to bed, 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 DoP and producers were 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 lying 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 the millions upon millions of patients and their loved ones wrestling with chronic illness or invisible disabilities.

–*Jennifer Brea*

UNREST

Directed by Jennifer Brea

Q&A WITH DIRECTOR JENNIFER BREA

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 lie 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. 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.

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 confusingly branded as “chronic fatigue syndrome” in the 1980s. (The name CFS misleadingly implies that tiredness is the main, indeed the only, symptom. Around the same time, the illness was nicknamed ‘yuppie flu’ in the press.) 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.

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 traveller, 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 DoPs 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.

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', suggesting that symptoms could be traced back to a psychological trigger that she could not remember. In February 2013, I decided that I had to make a film after a really bad health 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 over $200,000, 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 Troldtoft Hjorth and DP Christian Laursen joined in February 2014. My producer Lindsey Dryden joined me in May 2014. Producer Patricia E. Gillespie came on board 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."

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 in my bed for 99% of the time, 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 time zones 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.

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 patients' 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.

UNREST

Directed by Jennifer Brea

"*When faced with uncertainty we must be willing to say "I don't know" — because "I don't know" is where discovery starts.*"
~ Jennifer Brea

THE FOLLOWING IS EXCERPTED FROM A TED TALK JENNIFER GAVE AT TEDSUMMIT 2016, "WHAT HAPPENS WHEN YOU HAVE A DISEASE DOCTORS CAN'T DIAGNOSE".
https://www.ted.com/talks/jen_brea_what_happens_when_you_have_a_disease_doctors_can_t_diagnose

"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 also 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 in bed 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?”

SUBJECT BIOS

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

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, USA)

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-Bearman (Kent, UK)

24-year-old Jessica Taylor-Bearman 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 Kent, England with her new husband Samuel, her sister and her parents. She 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, USA)

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, USA)

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 tolerate light or sound, nor communicate.

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FILMMAKER BIOS

Jennifer Brea - Director, Writer and Producer

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. Her feature documentary, *Unrest*, premiered at the Sundance Film Festival in January, where it won a Special Jury Prize. She is also co-creator of *Unrest VR*, winner of the Sheffield Doc/Fest Alternate Realities VR Award. An activist for invisible disabilities and chronic illness, she co-founded a global advocacy network, #MEAction, launched a global day of protest, #MillionsMissing, and is a TED Talker.

Deborah Hoffmann - Executive Producer and Creative Advisor

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 *Mullholland'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 on the Independent Spirit Awards, and Gotham Awards. She is a member of the documentary branch of the Academy of Motion Pictures Arts and Sciences.

Lindsey Dryden - Producer

Lindsey Dryden is an award-winning creative producer and director, and founder of British production company Little By Little Films. She was one of the earliest to join the *Unrest* film team and is also a co-producer of *Unrest VR*. She began her career in British TV documentaries (BBC, Channel 4, History Channel) before Associate Producing hundreds of shorts at Current TV, and then moving into independent films for cinema. Her acclaimed work as a director includes *Lost and Sound* (SXSW) and *Close Your Eyes And Look At Me* (True/False), and as a producer *Unrest* and *Little Ones (*dir: Joanna Coates). She has made films with and for BBC, Channel 4, Wellcome Trust, Tate, Royal Court Theatre, Royal Shakespeare Company and Hyundai, and her work has premiered at SXSW, True/False, Sundance, Sheffield Doc/Fest, CPH:Dox, DocsDF, MIFF and Art Of The Real. As an impact producer, she is a passionate advocate for creative bespoke distribution, and has worked on films including *The Man Whose Mind Exploded* and *Angels and Ghosts*. A proud member of Queer Producers Collective, Lindsey is a frequent mentor and guest speaker at film festivals, a Lecturer in Film Production, a recent Filmmaker-In-Residence at Jacob Burns Film Center, a resident at Somerset House Studios and a Fellow of HotDocs Forum, IFP and Guiding Lights. She is currently making art films for Tate (the latest of which appears in the Queer British Art exhibition at Tate Britain), and directing a new fiction/doc hybrid mystery film, about an incredible jazz musician and gender outlaw.

Patricia E. Gillespie - Producer

Patricia E. Gillespie is an award-winning documentary filmmaker and Sundance Fellow. In addition to producing UNREST, she served as Line Producer on Sabaah Folayan's WHOSE STREETS, and is currently in production on her directorial debut, AMERICAN MONSTER, a non-fiction series exploring the intersection of poverty and violence in the American South produced in concert with Morgan Spurlock's company, Warrior Poets. In her spare time, she produces commercial content for clients like Johnnie Walker, Nike, and Adidas.

Alysa Nahmias - Producer

Alysa Nahmias is an award-winning producer of documentary and narrative films. Her debut feature documentary about Cuba's revolutionary architecture, *Unfinished Spaces* (2011), was broadcast on PBS, HBO Latin America, and Al-Jazeera "Witness," won a 2012 Independent Spirit Award, numerous film festival prizes, and was selected for Sundance Film Forward. She recently produced the fiction feature *No Light and No Land Anywhere* by director Amber Sealey with executive producer Miranda July, which won a Special Jury Prize at the 2016 L.A. Film Festival. Her documentary producing credits include the Kino Lorber and PBS American Masters release *Afternoon of a Faun: Tanaquil Le Clercq* directed by Nancy Buirski with creative advisor Martin Scorsese (New York Film Festival, Berlinale, 2013); *Shield and Spear* by director Petter Ringbom (Hot Docs, Sheffield Doc/Fest, 2014); Academy Award-nominated director Jennifer Redfearn's ITVS/PBS feature *Tocando La Luz* (Full Frame Jury Prize,

2015). Nahmias was a 2013 Film Independent Fellow. Her work has been shown at festivals and exhibitions worldwide, including the Venice Biennale and MoMA.

Anne Troldtoft Hjorth - Co-Producer

Anne Troldtoft Hjorth began working in film production after receiving a grant from the Danida Grant Committee, founded by the Danish Foreign Ministry. She has been involved in *Unrest* as co-producer since February 2014, focusing on the film's production in Denmark, but also working on production in the US and UK. Anne holds a Master's Degree in Journalism and has several years of experience in TV, radio production, and broadcasting, with primary experience from The Danish Broadcasting Corporation. She also has a Master's Degree in Middle East Studies, and has lived and worked in the Middle East for several years. As sub-editor at Arab Reporters for Investigative Journalism (ARIJ), she was based in Amman, Jordan, and most recently she was based in Ramallah, West Bank, while working for a Danish NGO. Documentary production continues to bring her back to the region.

Kim Roberts - Editor and Writer:

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 an Eddie award 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 '06); *Made in L.A.* (Emmy winner '09); *The Fall of Fujimori* (Sundance '05); *Lost Boys of Sudan* (Independent Spirit Award '04); *Daddy & Papa* (Sundance), and *A Hard Straight* (Grand Prize, SXSW). Kim received her Masters Degree in Documentary Film Production from Stanford University, where she won a Student Academy Award.

Emiliano Battista - Editor
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.

Sam Heesen - Cinematographer
Sam Heesen was born in Sydney, Australia. When he was ten days old he moved to Bangladesh, where he lived for four years. From there he moved to Costa Rica, Indonesia, and India. At the age of 14 he moved to California and began working on films and thinking about light. He now works as a cinematographer in Los Angeles.

Christian Laursen - Cinematographer
Christian Laursen is a Director of Photography based in Denmark, whose credits include *Unrest* (Sundance 2017), *Forever Now* (SXSW 2017), and commercials for clients including Renault and Welum. He was nominated for the Filmkraft Best Photography Award for *Velkommen Til Paradis*.

Bear McCreary - Composer
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 *Blacks Sails*, *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.

James LeBrecht - Sound Designer and Mixer
James LeBrecht is a well-known film and theatre 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.

Emma D. Miller - Associate Producer
Emma D. Miller is a producer and programmer. She was previously the programming manager at the Full Frame Documentary Film Festival in Durham, NC, where she oversaw all submissions to the festival and managed the film selection process. She has screened for several international film festivals and consulted on festival strategy, distribution, and outreach for documentary films, including serving as an associate producer on *Knife Skills*, a short documentary directed by Oscar winner Tom Lennon, currently in post-production.

Emma has worked with Netflix, National Public Radio, PBS's *POV*, and WNYC's *Studio 360*, and she has contributed to NPR.org, *Documentary Magazine*, North Carolina Public Radio, and other outlets as a writer and radio producer. Emma holds a certificate from the Center for Documentary Studies and B.A. from Duke University, where she was a Robertson Scholar.

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

Co-Executive Producers
Mitch and Debbie Menaged
Mona Eliassen
Jenny Raskin

Co-Producers
Leslie Berriman & Nion McEvoy
Michael J. Thies
Reid Hoffman & Michelle Yee
Mara Sandler

Associate Producers
Yvonne Huff Lee & Jason Delane Lee
Alex Usborne & Justin Edgar for 104 films
Alison Brewer
Blake Ashman
Els Bakker
Joanna Kerns
Li Lu
Mona Eliassen

Unrest – Facts about ME / Chronic Fatigue Syndrome

The award-winning cinema documentary *Unrest* explores the stories of people living with ME / Chronic Fatigue Syndrome. Here are some facts about the disease.

What is ME / CFS?

- ME (Myalgic Encephalopathy or Myalgic Encephalomyelitis) is a medical condition characterised by reduced ability to function after exertion
- Other names used for ME may include:
    - Chronic Fatigue Syndrome (CFS)
    - Post-Viral Fatigue Syndrome (PVFS)
    - Chronic Fatigue Immune Dysfunction Syndrome (CFIDS)
    - Systemic Exertion Intolerance Disease (SEID)
- According to current estimates, over 250,000 people in the UK have ME / CFS[1] (more than double the number of individuals with HIV or Multiple Sclerosis)
- 80% of people with ME go undiagnosed, due to a lack of education and awareness[2]
- Lab findings for individuals with ME show:

    - Changes in immune function, including low natural killer cell function[3], increased autoantibodies[4], and significant elevation or depletion of inflammatory chemicals in the blood[5]
    - Changes in cellular metabolism that limit energy availability for patients
    - Neuroinflammation and increased lactate in the brain, and MRI changes post-exercise
    - Alterations in the autonomic nervous system, including issues with temperature regulation, high variability in heart rate and blood pressure, and ability to maintain

[1] ME Association 'What is ME/CFS?' http://www.meassociation.org.uk/about/what-is-mecfs

[2] Griffith, James P., and Fahd A. Zarrouf. "A Systematic Review of Chronic Fatigue Syndrome: Don't Assume It's Depression." Primary Care Companion to The Journal of Clinical Psychiatry 10.2 (2008): 120–128. Print.

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[4] Loebel M, Grabowski P, Heidecke H, Bauer S, Hanitsch LG, Wittke K, Meisel C, Reinke P, Volk HD, Fluge Ø, Mella O, Scheibenbogen C. (2016 Feb). Antibodies to β adrenergic and muscarinic cholinergic receptors in patients with Chronic Fatigue Syndrome. *Brain Behav Immun. 52*: 32-9. doi: 10.1016/j.bbi.2015.09.013. Epub 2015 Sep 21. PubMed PMID: 26399744.

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Severity and symptoms

- The majority of patients tend to see a fluctuating pattern of symptoms including . Symptoms vary considerably over time.[6]
- Symptoms can be mild, but in 25% of cases they are severe enough to leave patients housebound.[7] Individuals may be confined to bed for months or years.
- Common symptoms of ME include:
    - Significant physical or mental fatigue
    - Profound loss of muscle power
    - Muscle pain that may include tenderness and swelling
    - Reduction in ability to function, after even minimal exertion
    - Debilitating pain
    - Difficulty sleeping
    - Cognitive dysfunction
    - POTS (postural orthostatic tachycardia), which prevents patients from maintaining an upright or seated position

Causes

- The cause of ME is unknown. However, it is confirmed that many patients contract ME after a viral infection, and some infections are more associated with onset than others.
- Other triggers may include an operation or an accident, although some people experience a slow, insidious onset.

Who is affected?

- Men and women, and people of all races, creeds and colors, can contract ME. Both children and adults can have ME.
- However, women are four times as likely to have ME than men[8].
- The myth of "yuppie flu" has been discredited. Studies show that people of all socioeconomic classes have ME.[9]

Diagnosis and treatment

- There is no single test that can diagnose ME and it often takes several years for patients to receive a diagnosis
- There is no cure for ME and no universally effective treatment. Treatments which help some patients are often ineffective or harmful in others.[10]
- The aim of much care is to reduce symptoms, and treatment can include drugs and complementary therapies.
- Controversially, the official NHS treatment for ME involves a combination of CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy).

[6] ME Association 'What is ME/CFS?' http://www.meassociation.org.uk/about/what-is-mecfs

[7] Pendergrast, Tricia et al. "Housebound versus Nonhousebound Patients with Myalgic Encephalomyelitis and Chronic Fatigue Syndrome." *Chronic illness* 12.4 (2016): 292–307. *PMC*. Web. 8 Sept. 2017.

[8] ME Research UK 'ME/CFS in women and men', 19 Aug 2015 http://www.meresearch.org.uk/news/sex-differences-in-mecfs/

[9] Bierl, Cynthia et al. "Regional Distribution of Fatiguing Illnesses in the United States: A Pilot Study." Population Health Metrics 2 (2004): 1. PMC. Web. 8 Sept. 2017.

[10] ME Association 'What is ME/CFS?' http://www.meassociation.org.uk/about/what-is-mecfs

- However, the government funded PACE trial – the 2011 research that formed the main basis of the recommendation – has been featured on Retraction Watch and PLoS has placed a 'Notice of Concern' on the study.
- Patients have found that CBT is ineffective and graded exercise therapy can make their condition worse. Furthermore, the PACE trial methodology has been shown to be flawed by many clinicians and academics. The ME Association is calling for an independent review of the trial. [11]

UK Research and service provision

- ME is a stated priority for the Medical Research Council, but research activity remains "chronically" low according to ME Research UK.[12]
- Grants from the largest funders for ME / CFS are worth an estimated £17 million in the UK, a twentieth of the amount available for Multiple Sclerosis Research

Economic and societal costs

- In addition to the 250,000 people directly affected, ME has an impact on carers and family members. Family life, education, and ability to work can all be severely disrupted.
- At a societal level, ME has a major impact on health and social care services, as well as productivity in terms of working hours lost
- The economic cost of ME/CFS was estimated at £6.4 billion per year in the UK in 2004 and the cost is likely to have increased since then .[13]

[11] Shepherd, Charles 'PACE trial claims for recovery in myalgic encephalomyelitis/chronic fatigue syndrome – true or false? It's time for an independent review of the methodology and results' Journal of Health Psychology, Vol 22, Issue 9, 2017

[12] ME Research UK 'ME / CFS Research Funding' 29 Sep 2016 http://www.meresearch.org.uk/news/mecfs-funding-report/

[13] Reynolds K, Vernon S, Bouchery E, Reeves W. The Economic Impact of Chronic Fatigue Syndrome. *Cost Effectiveness and Resource Allocation* 2004:2(4):1-9.