UNREST

Directed by Jennifer Brea

unrest.film

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 bedridden and looking for answers. Disbelieved by doctors yet determined to live, she turns her camera on herself and discovers a hidden world of millions confined to their homes and bedrooms by ME, commonly known as chronic fatigue syndrome.

Unrest tells the first-person story of Jennifer and her husband, Omar, newlyweds grappling with how to live in the face of a lifelong illness. But it is also a global story about an international community of patients with a serious, life-altering illness — millions suffering invisibly and left at the margins of medicine and science.

Unrest world-premiered January in competition at the 2017 Sundance Film Festival, where it won a Special Jury Prize for editing. It has since screened at SxSW, CPH:DOX, HotDocs, River Run (Audience Award for Best Documentary Feature),

"A HIGH-GRADE EXAMPLE OF THE FORM"

- Variety

the Nashville Film Festival (Grand Jury Award for Best Documentary Feature), and at Sheffield Doc/Fest, where it won the Wellcome Trust's Illuminate Award for "vibrant and innovative filmmaking inspired by scientific understanding." *Unrest* also has a companion virtual reality piece, which premiered at Tribeca and won the Jury Award for best VR at Sheffield/DocFest.

In September 2017, *Unrest* will launch theatrically in cities across the US and UK, along with a global impact campaign, *Time For Unrest*, which aims to increase awareness, education, research and funding around ME. The campaign consists of community screenings to engage doctors, students, scientists, policymakers, and leaders in biotech & pharma around the world. In the US, the film will air on PBS's Independent Lens in January 2018.

For medical providers

With the lack of medical education or clear treatment guidelines, most doctors find ME difficult to diagnose. Patients spend on average five years seeking a diagnosis. *Unrest* brings medical providers inside spaces they are rarely able to go – their patients' homes and bedrooms – for an intimate look at a disease that leaves 25% of patients housebound or bedbound and often unable to even seek medical care.

It features interviews with doctors and scientists who have dedicated their careers fighting for patients with a disease once callously disregarded as hysteria. ME is on average more disabling and twice as prevalent as multiple sclerosis, but has no specialty home (patients

are left to be managed by their primary care providers) and no approved drugs. But there is hope – research groups across the US (Stanford, UCSD, Cornell, Harvard, Columbia) and in the UK, Norway, Germany, Japan and Australia are beginning to uncover basic mechanisms of the disease. In 2015, the Institute of Medicine proposed a new diagnostic criteria and the in 2017, the CDC updated their guidelines, although these guidelines have not been widely disseminated or used in medical education.

Ultimately, *Unrest* is a study on love and compassion. It invites medical providers to reflect how they can best support patients and caregivers grappling with any lifelong illness for which there are no clear answers and to reconnect with the reasons they first choose their healing profession.



"A REVELATION AND A CALL TO ACTION"

- Salt Lake City Tribune

For researchers

Rates of chronic, immune-related diseases have tripled to quintupled in the last fifty years and yet our systems of research and care have been woefully inadequate to tackling the epidemic. *Unrest* is in many ways a story about what happens when we fail to invest in science. Who

about what happens when we fail to invest in science. What role do our own biases play in the questions we choose to ask, the stories we tell, and the places we neglect to look?

Unrest features Ron Davis, a Stanford professor of genetics & biochemistry whose work was crucial to the success of the Human Genome Project, now caretaker to his son Whitney who is so ill, he can no longer speak. Scientists will come away from *Unrest* with a new understanding of how their work can directly impact people's lives and will be inspired by the detective story of a disease that appears to be infectious, environmental *and* genetic; sporadic and epidemic; implicates the immune, nervous, cardiovascular, gastrointestinal and endocrine systems; and may go to the very beating heart of what makes complex animal life possible – our mitochondria. With so much low-hanging fruit, we hope *Unrest* will inspire new researchers to investigate a fascinating and challenging disease.

For government officials

It's estimated that at least 1 million Americans and anywhere from 15 to 30 million people around the world live with ME. (For comparison's sake, that means it is two to three times as common as MS.) ME patients score more poorly on quality of life surveys than those with multiple sclerosis, stroke, diabetes, renal failure, lung disease, heart failure, and various cancers. 75% of patients are left unable to work, costing the U.S. economy \$17 to \$24 billion in lost productivity each year. In spite of the profound individual and social impact of the disease, there are no FDA-approved treatments, no diagnostic tests, and an annual federal research investment of \$6-\$7 million per year – about what we spend studying hay fever.

Unrest shows the profound consequences of this neglect by our public health, medical, and research systems on patients and their families, who are left impoverished and often without any support to confront a life-changing illness. It also speaks to their incredible resilience and the global social movement they are building to finally end the stigma and inspires elected officials and policymakers to think about how they can be stronger allies and support a better future for all.