

A close-up, low-angle shot of a woman with dark, curly hair lying down. She is looking upwards with a contemplative expression. Several EEG electrodes are attached to her forehead and temples, with colorful wires (red, blue, yellow, green) extending from them. The background is a plain, light-colored wall.

docimpacthi5

2019

HI5 IMPACT CASE STUDY:

UNREST

**Building a global movement
to fight for people living
with ME**

Film Still *Unrest*



THE FILM

Jennifer Brea is twenty-eight years old, working on her PhD at Harvard, and months away from marrying the love of her life when a mysterious fever leaves her bedridden. When doctors tell her it's "all in her head," she picks up her camera as an act of defiance and brings us into the hidden world of the millions of people that medicine has abandoned.

In this story of love and loss, newlyweds Jennifer and Omar search for answers about the disease Myalgic Encephalomyelitis (ME). As they explore possible treatments and face unexpected obstacles, they encounter others who are dealing with similar challenges. So Jennifer sets off to tell their stories, too.

Traveling by Skype from the space of her bed where she is confined, Jennifer crafts intimate portraits of four other families suffering similarly in the US, UK and Denmark. Their bedrooms connected by Skype and Facebook, these patients teach Jen how to make a life of meaning when everything changes.

Jennifer Brea's Sundance award-winning, Emmy-nominated documentary *Unrest* chronicles her personal journey from patient, to storyteller, to advocate.

WHO SAW IT?

International:

22 COUNTRIES

34,000+
ATTENDEES
570+ COMMUNITY
SCREENINGS

TRAILER VIEWS:

Facebook Official Trailer:
1,069,499 ViewsYouTube Official Trailer:
335,854 ViewsVimeo Official Trailer:
80,900 ViewsIN THE US: 13 THEATERS
in NYC, LA, Chicago, SF,
Berkeley, Seattle, Baltimore, Palo
Alto, Grand Rapids, Atlanta,
Portland, Princeton, Tucson
Box office total: \$40,081Held over for 2 weeks in
NYC & BerkeleyIN THE UK: 57 THEATERS
Box office total: \$47,144

Online:

PBS Video: 37,271 streams
in the United States (over 14-day
window 1/18/18 to 1/22/18)Vimeo: 4,354 on-demand
plays globallyAmazon: 650,294 minutes
streamed in United States,
United Kingdom, GermanyNetflix: No streaming figures
available (global release)

iTunes: 8,371 transactions globally

Google Play: 1,423 transactions in
United States, Canada, United
Kingdom, IrelandVudu: 306 transactions
in United States

Indemand: 927

DirectTV: 99

PRESS HITS:

229 reaching an estimated
14,348,498 peopleWEBSITE PETITION FOR ME EQUALITY:
9,573 signatures

SOCIAL MEDIA:



• Unrest Facebook:

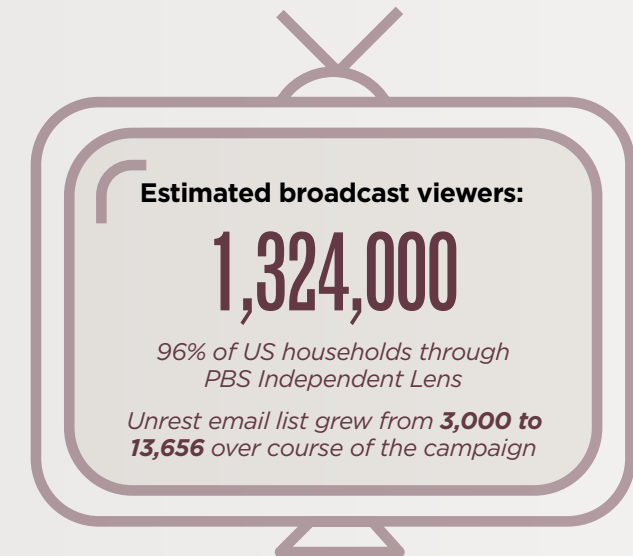
30,519 Followers
+ 29,844 Likes

• Unrest Twitter:

9,258 Followers
2,653 Tweets with
the #UnrestPBS hashtag

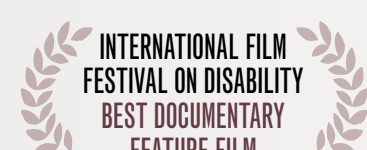
• Unrest Instagram:

3,993 Followers

*ALSO EMMY NOMINATED FOR
OUTSTANDING DOCUMENTARY
EDITING AND SHORTLISTED FOR
AN ACADEMY AWARD FOR BEST
DOCUMENTARY FEATURE

Estimated broadcast viewers:

1,324,000

96% of US households through
PBS Independent LensUnrest email list grew from 3,000 to
13,656 over course of the campaign40+ festivals internationally, including:
Sundance, SXSW, CPH:Dox, Sheffield Doc/Fest,
HotDocs, MIFF, RiverRun International,
International Film Festival on Disability

THE TEAM

FILMMAKERS



Director/Writer/Producer
Jennifer Brea



Writer/Editor
Kim Roberts



Producer
Lindsey Dryden



Producer
Patricia E. Gillespie



Producer
Alysa Nahmias



Editor
Emiliano Battista

CINEMATOGRAPHERS

Sam Heesen
Christian Laursen

COMPOSER

Bear McCreary

A co-production between **Shella Films** and **Little By Little Films**

EXECUTIVE PRODUCERS

Ruth Ann Harnisch
Regina K. Scully
Mona Eliassen
Ian Darling
Dan Cogan
Omar Wasow
Lisa Gunn
Lynda Weinman
Donna Fairman Wilson

EXECUTIVE PRODUCER & CREATIVE ADVISOR

Deborah Hoffmann

CO-EXECUTIVE PRODUCERS

Jenny Raskin
Mitch & Debbie Menaged

DENMARK CO-PRODUCER

Anne Trolldtoft Hjorth

ASSOCIATE PRODUCER

Emma D. Miller
Laura Hess

IMPACT TEAM

Laurie Jones, Global Director of Impact, Shella Films
Jessica Edwards, Impact Strategist
Erica Ales, US Impact Producer
Hannah Bowlus, US Impact Co-ordinator
Lucy Wilson, UK Impact Producer
Film Sprout, Community and Grassroots Distribution
Together Films, UK Impact Distribution
Regina Clemente, Managing Director

IMPACT TEAM

MEAction is the organization that Jennifer Brea launched two years before *Unrest*. They are an international organization that develops and supports a network of country affiliates, affinity groups, city, state, regional, and other local chapters, and individual advocates. They are building a global movement to fight for recognition, education, and research so that one day, all people with ME will have access to compassionate, effective care.

Open Medicine Foundation
Solve ME/CFS
American Medical Women's Association
The Massachusetts ME/CFS & FM Association
ME Association
ME Research UK
Action for ME
Emerge Australia
Danish ME Association
ME/CFS Foundation SA

TRADITIONAL DISTRIBUTION

US Theatrical Distribution:
Shella Films (self-distribution),
in association with the Sundance Institute
Creative Distribution Fellowship

Broadcast Distribution:
PBS's Independent Lens (US)

SVOD:
Netflix

VOD & DVD:
Shella Films (self-distribution)

IMPACT CAMPAIGN

IMPACT DISTRIBUTION

Community and
Grassroots Distribution:
Film Sprout

UK Impact Distribution
(Theatrical & Non-
Theatrical)
Together Films

Regina Clemente, Managing Director, Shella Films

Impact Campaign Strategy:
Jessica Edwards

Campaign Direction:
Laurie Jones, Global Director of Impact, Shella Films
Erica Ales, US Impact Producer
Hannah Bowlus, US Impact Coordinator
Lucy Wilson, UK Impact Producer

BUDGETS

PRODUCTION BUDGET TOTAL: HIGH SIX FIGURES

Canary in a Coal Mine Kickstarter campaign
 Impact Partners
 Artemis Rising Foundation
 The Harnisch Foundation
 Chicken & Egg Pictures
 The Mara and Ricky Sandler Foundation
 Silicon Valley Community Foundation
 The Lagralane Group
 Sundance Institute Documentary Film Program
 Influence Film Foundation (UK)
 Women in Film
 104 Films, British Film Institute Film Fund (UK)
 Theo Westenberger
 The Paley Center for Media
 Good Pitch
 Ian Darling
 Private donations

IMPACT CAMPAIGN BUDGET TOTAL: \$734,154

Sundance Institute Creative Distribution Fellowship Grant
Time for Unrest Kickstarter campaign
 Ford Foundation Grant
 Wellspring Philanthropic Fund
 British Film Institute Audience Fund (UK)
 Shark Island
 Private donations





THE CAMPAIGN

***Unrest* premiered at the 2017 Sundance Film Festival in Park City, Utah. This kicked off a far reaching public campaign to raise awareness of ME, deepen understanding of the disease, especially among medical professionals, promote better and more empathetic policies and care, and attract scientific research and funding.**

To date, the film has been shown at over 500 community screenings, including virtual screenings for home-bound audiences. There were also intensive campaigns in the UK and Australia, where another 73 non-theatrical screenings were held. *Unrest* has inspired demonstrations and lobby days for funding and support all around the world, and it has helped to build up a powerful, organized constituency that actively advocates for what the ME patient community needs.

THIS FILM AND ITS CAMPAIGN SHOW THAT AMPLE FINANCING AND A RELATIVELY LARGE TEAM (WITH MULTIPLE IMPACT PRODUCERS, DISTRIBUTION FIRMS, AND PR TEAMS) PAVED THE WAY FOR THE MASSIVE REACH THAT THIS TEAM WAS ABLE TO EFFECTIVELY BUILD.

“Riveting... equal parts medical mystery, science lesson, political advocacy primer and even a love story.”

—

[The San Francisco Chronicle](#)



HOW THEY TRACKED IMPACT

REACH

- **Tracked number of screenings** with a registration form (date, location, estimated attendance)
- **Tracked reported turnout** and venue size for all the major theatrical screenings and large community screenings

ENGAGEMENT

- **Tracked new newsletter sign-ups**
- **Tracked online growth** through social media accounts
- **Tracked number of continuing medical education (CME) sign-ups** through a registration form
- **Collected qualitative audience surveys** to assess attitude shifts and intent to take action
- **Collected event host surveys** for insights about hosts, their intent, reported results of events
- **Collected testimonials** from key advocates, influencers, campaign partners

INFLUENCE

- **Tracked new sources of funding** for research for the ME community
- **Tracked press hits** and social media mentions and using a service that calculates impressions
- **Tracked new motions, resolutions, and legislation** proposed/passed that followed *Unrest* events
- **Tracked public statements** by elected officials related to ME and the film



These quadrants represent Doc Society’s framework for mapping impact strategies to story environment



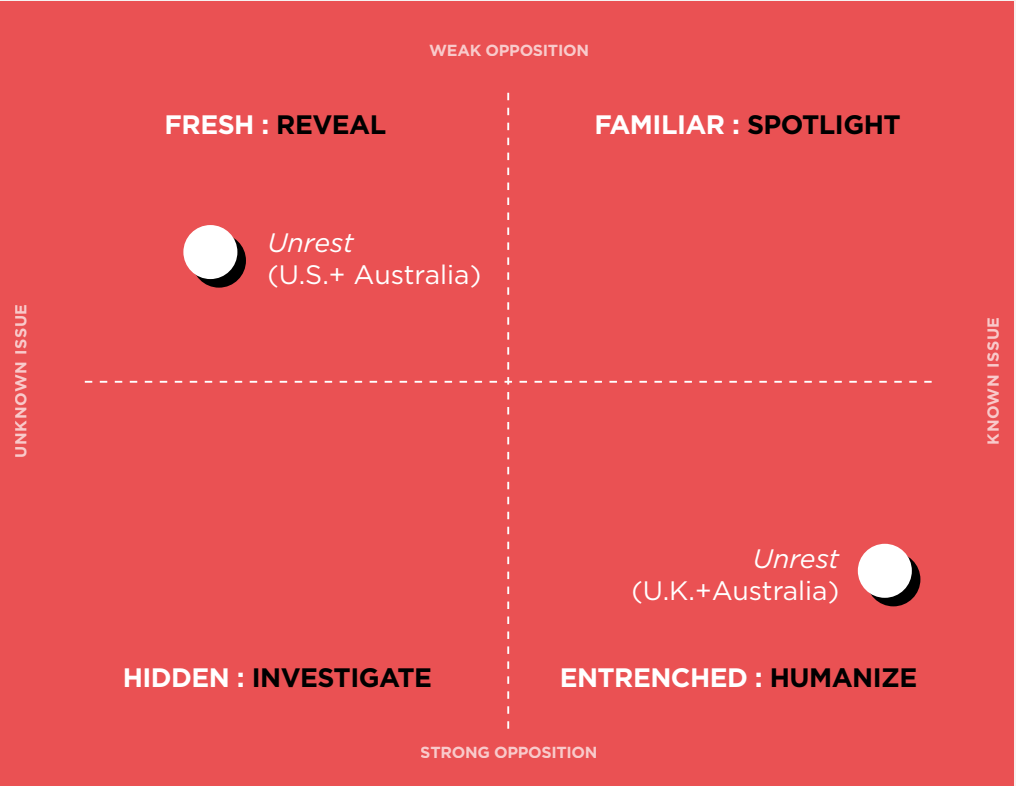
At least a million people in the US have Myalgic Encephalomyelitis (ME), and 15-30 million globally. The vast majority are women, although the disease also impacts millions of men who also don't have access to treatment or care. Yet, despite it being so common, few people know much about this disease. In fact, those who do know often experience negative stereotypes, and the common name “Chronic Fatigue Syndrome” (CFS), has only helped to reinforce that stigma. Because the disease is not taught in most medical schools, many doctors still treat people with ME as if they are hysterical or imagining their symptoms, thereby reinforcing age-old gender stereotypes.

Many patients, 25% of whom are homebound or bedridden and up to 75% of whom are unable to work, are left without any real access to medical care or social support services. At its extreme, these attitudes contribute to poverty, homelessness, and suicide and have led to the forced removal of children from their families, as well as the forced psychiatric institutionalization of both children and adults. Altogether, the result has been a dire lack of attention from the medical community, with little research or funding going towards finding a cure. This leaves patients with few treatment options, or options that actually worsen symptoms, as well as an absence of compassion for patients who are regularly met with suspicion.

So, *Unrest* set out to put the record straight.

Jennifer Brea’s stunning documentary pulls audiences into a world that is often hidden because many patients are too sick to advocate for themselves, and doctors often dismiss patients’ symptoms. However, by capturing stories of people all over the world who struggle with ME, the film provides valuable evidence of a collective experience, and the global scale of the problem.

Unrest
Story Environment:



In the US in the 80s and 90s, the illness came to be known as “yuppie flu” and faced organized opposition in the form of a skeptical medical community and hostile government policies. Today, the core challenge is low awareness among medical providers and scientists, as well as bureaucratic indifference on the part of government agencies. In this context where ME is still a relatively **FRESH** issue, *Unrest* **REVEALS** the largely unseen space of homebound and severely ill patients, and it brings much needed legitimacy to this long-overlooked disease.

In a context like the UK, the issue is far more **ENTRENCHED**. Here, controversial clinical trials, as early as the 1980s and as late as 2011, have produced guidelines for treatment that persist today. The results have come under criticism for privileging a psychosocial lens, ignoring important breakthroughs in biomedical research overseas, and for being harmful to patients. In this context, *Unrest* offers a deeply **HUMAN** portrayal. Told through the eyes of a loving couple who are struggling to find answers in the face of adversity, it inspires audiences to want to help them and people like them find the answers they need.

Australia, on the other hand, was a little more bifurcated. Here, as in the US, ME was a largely unknown illness for the wider public and thus was not up against a major organized opposition. Therefore, it helped to **REVEAL** and make the illness more visible to general audiences. However, it was a different story for patients, and to some extent the medical community, in Australia. For them, as they were up against a medical system entrenched similarly to the UK’s, the film **HUMANIZED** the issue and fostered recognition of the illness.

As a tool for analyzing campaign strategies, Doc Society uses what we call the Four Impact Dynamics; broad categories for the kinds of change you can make in the world with film.

This has been developed by studying the films, NGOs, and activists that we have worked with, in order to understand how each conceptualizes their campaigns. More information on the Impact Dynamics can be found at www.impactguide.org. **Here we apply the Impact Dynamics to the goals of *Unrest*.**

CHANGING MINDS:

Raise awareness and deepen understanding about ME

Target audience: physicians, medical students and researchers; caregivers and families of people with ME; public health, gender-equity, and patient advocates

CHANGING BEHAVIORS:

Promote better and more empathetic care and mobilize audiences to action

Target audience: caregivers and families of people with ME, physicians, medical students, and researchers

BUILDING COMMUNITIES:

Foster a constituency with the power to advocate for what they need

Target audience: patients with ME; caregivers and families of people with ME; public health, gender-equity, and patient advocates

CHANGING STRUCTURES:

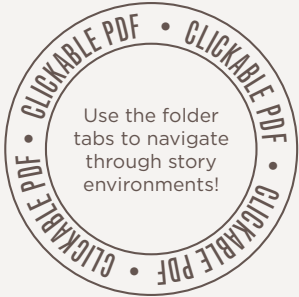
Inspire scientific research and funding, and improve medical education


Target audience: lawmakers, hospital administration, researchers, funders; insurance agency staff, public health, gender-equity and, patient advocates

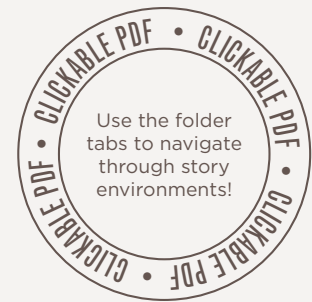




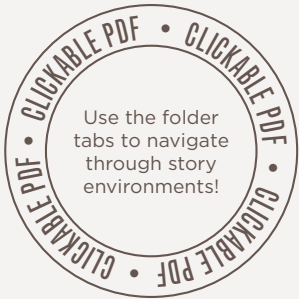
CHANGING MINDS The <i>Unrest</i> campaign raised awareness and deepened understanding about ME	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
STRATEGY			
<p>DEVELOPING THE IMPACT DISTRIBUTION STRATEGY EARLY IN PRODUCTION</p> <p>Director Jennifer Brea began audience development over the 4 years preceding <i>Unrest's</i> release through a 2013 Kickstarter campaign. This not only helped to secure funds so that she could start filming, but it helped her to start building an audience early on. Then, in 2017 when the filmmaking team was ready to launch the campaign, they reached out to that community once more not only for outreach support, but to drive it toward the theatrical, TVOD, and DVD/Blu-ray releases.</p> <p>In addition to this, Jennifer Brea began laying the groundwork for her impact and distribution strategy as early as 2014. Then she began to build her international producing team, consisting of Patricia Gillespie in the US and Lindsey Dryden in the UK, with co-producer Anne Sidsel Trolldtoft Hjorth in Denmark. Embarking on a set of Sundance Documentary Film Program workshops and later Good Pitch in New York in 2015, they began to foster relationships and iteratively plan their path. In fact, it was only from mid-2016 that the team began to expand significantly. At that point, they engaged Impact Strategist Jessica Edwards to map the landscape in detail and create a thorough impact plan for both the US and UK, more than six months before the film’s festival premiere.</p>		<p><i>“I remember addressing the UK ME charities 4 months before Sundance and telling them what a powerful tool this film was going to be, but no one believed it until the film got into and then won a significant award at Sundance. At that point, it also meant the CDC and NIH would take my calls.”</i></p> <p>— Jessica Edwards Impact Strategist</p> <p>That critical preparation, relationship-building, opportunity-mapping, landscape-mapping and deal-setting was critical to the success of the campaign. In other words, the impact strategy was not an afterthought - it was a consideration throughout.</p>	



CHANGING MINDS The <i>Unrest</i> campaign raised awareness and deepened understanding about ME	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
STRATEGY			
<p>SECURING THE IMPACT DISTRIBUTION FOR BROAD REACH AND VISIBILITY</p> <p>The <i>Unrest</i> team opted for a hybrid distribution model and were highly deliberate as they developed and combined their distribution and impact goals. In fact, as noted above, they began writing their distribution and festival strategies throughout production to ensure they could develop a creative approach that enabled them to reach multiple markets and communities rather than handing over all of their rights to one entity with less certain outcomes.</p> <p>So while they did sign with Netflix, it was not an all-rights deal: Netflix acquired the global SVOD rights, and the <i>Unrest</i> team held onto their US broadcast rights and retained control over theatrical, semi-theatrical, and TVOD rights. This aligned with their impact distribution strategy goals of ensuring accessibility, maximizing multiple audiences, and positioning the film as significant in the documentary field. Key components of this strategy included the following:</p> <ul style="list-style-type: none">— Applied to film festivals in key countries where they hoped to have an impact— Secured an Oscar-qualifying limited theatrical release in 13 US markets, and secured 50+ UK cinemas in concert with Together Films, including several Picturehouse sites (exhibiting the Unrest VR project in some venues too: for more on this, see below) and used it all to garner press— Created inclusive theatrical screenings for homebound and disabled people, using the OVEE screening platform (with limited tickets and an online chat room for cinema-like experience) to ensure people with disabilities were welcome in the cinema experience		<ul style="list-style-type: none">— Worked closely with grassroots distribution agency Film Sprout in the US, Together Films in the UK, and community partners globally for a robust college campus and community engagement tour with screenings in medical schools, health/political organizations, and more— In the UK, Together Films raised funding from the British Film Institute (BFI) to support the homebound screenings initiative and VR tour across the UK— Supplied the film through TVOD on iTunes, Google Play, Vudu (through Quiver), Amazon Video Direct, and Vimeo— Timed the DVD release around the holiday season so aficionados could purchase it as a holiday gift for friends, family, or medical providers and thereby share the film more widely— Signed with PBS’ Independent Lens to ensure that audiences in the US who don’t have Netflix could gain access through free public media when it was broadcast in January 2018— Had their SVOD release through Netflix global, one week after PBS in January 2018— Translated the <i>Unrest</i> DVD into 29 languages to make it broadly accessible	
			



CHANGING MINDS The <i>Unrest</i> campaign raised awareness and deepened understanding about ME	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
STRATEGY			
<p>DEVELOPING A STRONG MARKETING AND PR STRATEGY</p> <p>The team deliberately sought out and leveraged film festivals and theatrical openings to build buzz, generate press, and put the need for ME research, medical education, and funding in the foreground. It was also aimed at swaying members of the medical community and engaging with the ME non-governmental organizations community. So, they put together a strategy for all their intended theatrical venues based on audience data by city, as well as the key cinema sites they hoped to hit. They then hired Film Sprout and Together Films, in the US and UK respectively, to turn that strategy into a reality.</p> <p>BUZZ AND AUDIENCE BUILDING</p> <p>The team sought out opportunities to generate strategic buzz around the film. The plans included adding events at all of Britain’s major indie film venues, including BFI Southbank, Curzon Cinemas, and Bertha DocHouse. In the US, special screenings at places like the Aspen Institute and private influencer screenings in the lead up to the theatrical release also helped. In addition, Together Films presented <i>Unrest</i> at the Distributors’ Slate Day (a major British industry event for distributors and exhibitors held annually), which proved critical to bookings.</p> <p>Theatrical screenings in the US and UK were often accompanied by special Q&As with Jennifer Brea and producer Lindsey Dryden (who were both able to add valuable issue context to discussions), and/or other expert speakers from the medical and patient communities. They even developed an <i>Unrest</i> VR component for the campaign, which amplified the experience for audiences in the UK and US.</p>		<p>Jennifer Brea began developing the VR experience while <i>Unrest</i> the film was in production, and secured their first funding for it at Good Pitch New York. On completion, it premiered in the Virtual Arcade at the 2017 Tribeca Film Festival and won the Alternate Realities VR award at Sheffield Doc/Fest. The VR experience was set up in key venues in the US and across the UK alongside film screenings, so that audiences were able to take part in a more intimate experience bringing them even closer to Jennifer’s story, creating heightened empathy for the issue.</p> <p>Jennifer also gave a TED Talk which launched the week of the Sundance Premiere. As noted, this was aimed at starting to build audience early. Then, later that spring, the team participated in the NPR TED Radio Hour. On top of all this, they engaged influencers with a large online following, like Soledad O’Brien, Van Jones, rapper Trip Lee, and actress Geena Davis - all of whom then tweeted about the film. In fact, they organized a Twitter marathon - a revolving conversation between Jennifer and 20+ guests and celebrities - on the day of the PBS broadcast, and did so again to build momentum toward the Netflix release two weeks later.</p>	
		<div><div>TED</div><div><p>TED Talk: Jennifer Brea on what happens when you have a disease doctors can’t diagnose</p><p>https://www.ted.com/talks/jen_brea_what_happens_when_you_have_a_disease_doctors_can_t_diagnose?language=en</p></div></div>	



CHANGING MINDS The <i>Unrest</i> campaign raised awareness and deepened understanding about ME	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
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STRATEGY

PRESS ENGAGEMENT

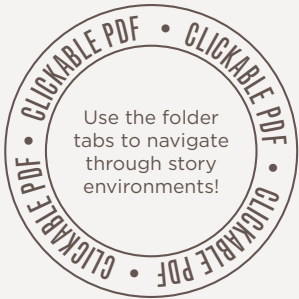
The team **hired publicists in London, New York, Los Angeles, and San Francisco** to target film press, especially health and science reporters. They worked closely with these teams to prepare them to talk about the issues effectively. And they **created new scientific primers for journalists**, to be distributed alongside traditional film press materials to ensure accurate coverage.



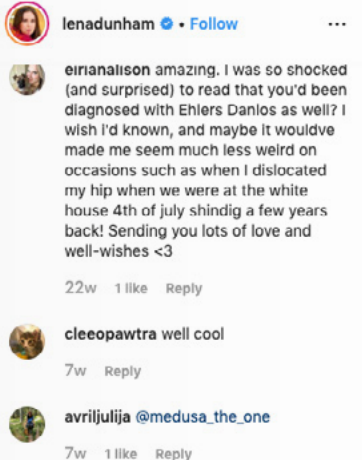
This had been part of Jennifer’s strategy from the start, and its importance was underscored by a moment during production when producer Lindsey was pitching the film in a major industry market and found the film was misrepresented in the press. A press release from the market was rewritten by a film journalist in a way that perpetuated the idea that ME was a psychological illness, which undermined the film’s core intentions and incensed the film’s community of patients.

So, from the film festival launch onwards, the team dedicated a significant amount of time to crafting copy for press and providing fully-referenced and scientifically rigorous FAQ/guides to ME, to ensure coverage of the film and Jen’s story helped to improve public perception of a historically maligned medical condition, rather than undermine it.



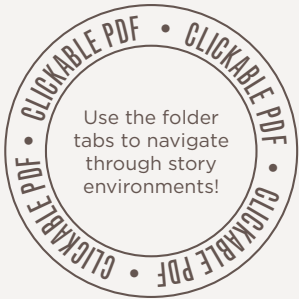
On the steps of BBC Broadcasting House in London



CHANGING MINDS The <i>Unrest</i> campaign raised awareness and deepened understanding about ME	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
IMPACT			
<p>THEY SECURED BROAD AND WIDESPREAD REACH FOR THE FILM AND ISSUES</p> <p><i>Unrest</i> was seen far and wide. The buzz generated by the fall US & UK theatrical release and the community screenings campaign led to 229 press hits that brought the issues to the attention of an estimated 14,348,498 people. And while the film was initially planned for a 2-week UK in the UK, it continued screening afterward and even expanded into additional cities due to high demand.</p> <p>The team also held over 550 community screenings, house parties, and virtual events in 22 countries where they engaged over 34,000 people¹.</p> <p>Then, an estimated 1.3M people saw the film through the US broadcast, according to PBS. The day of <i>Unrest</i>'s January premiere on PBS, a Twitter marathon and influencer engagement strategy resulted in 2,653 tweets on the <i>#UnrestPBS</i> hashtag that received 24.34 million impressions².</p> <p>THEY INCREASED THE VISIBILITY OF PEOPLE LIVING WITH INVISIBLE ILLNESSES</p> <p><i>Unrest</i>'s profile also brought in previously undiagnosed ME patients, mobilized friends and families, and engaged disability allies across many diagnoses, including prominent writers, artists, and celebrity influencers. For example, actress Selma Blair - in the context of her coming out with an MS diagnosis, her activism around it, and her experience being disbelieved - suggested her Instagram followers (1.6M) watch <i>Unrest</i>. And when Lena Dunham tattooed "Sick" on the back of her neck to represent her struggles with endometriosis and Ehlers-Danlos Syndrome, she posted a photo of it on Instagram (3M followers) and tagged director Jennifer Brea.</p>		<p>"I'm so glad this film exists."</p> <p>— Lena Dunham via Twitter (5.59M followers)</p>  <p>"I saw 'Unrest' and cried for the people in the film and for ME people everywhere. They must be believed, they must be helped #timeforunrest."</p> <p>— Stuart Murdoch Musician Belle & Sebastian (22.8K followers)</p>	 

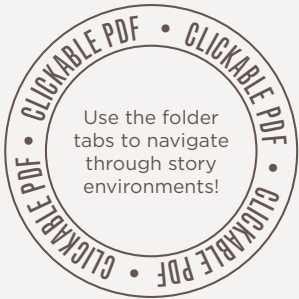
¹This was an estimate based on reported turnout and venue size for all major theatrical screenings and large community screenings.
²The tweets were tabulated using a service that calculates impressions on hashtags.

WHAT HAPPENED

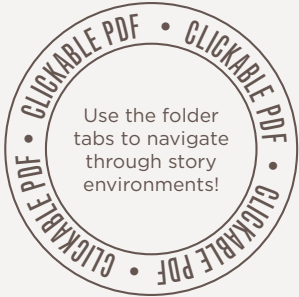


CHANGING MINDS The <i>Unrest</i> campaign raised awareness and deepened understanding about ME	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
IMPACT			
<p>THEY MAINSTREAMED THE ME CONVERSATION</p> <p><i>Unrest</i> helped to finally get mainstream attention for ME. Stories about <i>Unrest</i> appeared on popular platforms. In the US these included: Megyn Kelly Today, The New York Times, The Washington Post, The San Francisco Chronicle, Vogue, The Wall Street Journal, Dr. Oz, and NPR. In the UK these included: The Telegraph, The Times, The Observer, The Guardian, Daily Express, BBC Ouch, Cosmopolitan UK, The Pool, BBC World Service (Radio), and television programs including BBC World News, BBC Click, BBC Breakfast, ITV News, and Channel 5 News. In Australia these included: The Age and The Sydney Morning Herald.</p> <p><i>“An unjust status quo is at its most powerful when the suffering it imposes is blamed on the sufferer. The treatment of immune diseases like ME/CFS - which disproportionately affect women - will one day be remembered in the same light as blood-letting or exorcism. And Unrest will have helped make that happen.”</i></p> <p>— Gloria Steinem</p> <p>Getting shortlisted for the Oscars also raised the profile of the film, leading to Showcase screenings in London, Los Angeles, New York City, and San Francisco, attended by high profile members of the entertainment industry as well as important researchers and advocates in the chronic illness and disability sphere.</p> <p>All of this buzz even led to the creation of new programming. For example, the SBS program <i>Insight</i> in Australia created an episode dedicated to ME/CFS. <i>Emerge Australia</i> took part in radio shows that were broadcast all around Australia. And it may even have led to the greenlighting of a half-hour BBC documentary called “M.E. and Me” on BBC Newsbeat.</p>		<p>In some ways, the team even changed the conversation in the UK. The strategies named above resulted in unprecedented positive coverage from top British press outlets, and many that had historically published pieces that characterised ME in old-fashioned and even negative terms began to publish pieces with depth, insight, and contemporary scientific understandings of the illness.</p> <p><i>“The unprecedented level of outreach ensured that a whole new audience was exposed to the film’s painfully honest depictions of the appalling treatment and injustices experienced by many ME patients. As a result, public awareness of ME as a devastating and life-destroying disease received an enormous boost in the UK. This increased level of ME recognition has opened up an array of challenging new conversations.</i></p> <p><i>From the very beginning, Unrest established itself as an invaluable addition to the ME community’s advocacy toolkit.”</i></p> <p>— Valerie Elliot Smith ME campaigner</p> <p>But not all the attention they received was productive. On March 17, 2019, despite the positive publicity the film had received and the upsurge in biomedical coverage of the illness, Rod Liddle, UK journalist and an associate editor of <i>The Spectator</i>, wrote, “[ME patient] complaints about a virus have no basis in fact” and included misinformed and inaccurate statements. By then, however, 13 months since the film premiered, the campaign had forged strong allies in media who leapt to their defense. Whereas once Liddle’s article would have had authority, the more humanized context created by <i>Unrest</i>, it seemed misplaced.</p>	

WHAT HAPPENED



CHANGING MINDS The <i>Unrest</i> campaign raised awareness and deepened understanding about ME	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
IMPACT			
<p>The cumulative impact of the attention the campaign generated was significant. A Lexis-Nexis search allowed them to compare mentions of “Chronic Fatigue Syndrome” in US newspapers before, during, and after 2017, the year <i>Unrest</i> was released. They found that the film resulted in a nearly 60% increase in coverage during the year of its release:</p> <ul style="list-style-type: none">— 2015: 2,158— 2016: 2,237— 2017: 3,554— 2018: 2,520 <p>These are extremely important developments for a campaign with a primary impact dynamic of raising awareness and deepening understanding of the disease.</p> <p>It’s difficult to calculate the extent to which the film deepened understanding of the disease among audiences worldwide, but the team did survey a small slice. They found that, while 92% of people who were surveyed (n=232) reported they were already familiar with ME before the event, the vast majority of them (76%) nonetheless reported learning new information about the illness. In other words, the film deepened understanding of the disease for most viewers, irrespective of how much information they started with. It’s possible, then - likely, even - that most people who saw the film were also similarly enlightened.</p>		<p>WHAT TRACKING IMPACT TELLS US</p> <p>The team knows they increased awareness and deepened understanding about ME because they:</p> <ul style="list-style-type: none">— Secured broad reach and global viewership, especially among target medical audiences— Noted a rise in social media engagement related to the film— Secured new influencer mentions about ME— Secured a rise in mentions/press coverage about the film and mainstream attention for ME— Observed the creation of new media/programming about ME— Found that a majority of audiences surveyed indicated they had a deeper understanding of ME	



CHANGING MINDS	BUILDING COMMUNITY The <i>Unrest</i> campaign fostered a constituency with the power to advocate for what they need	CHANGING BEHAVIORS	CHANGING STRUCTURES
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STRATEGY

FOCUS ON THE ME COMMUNITY FIRST

Whereas the *Unrest* team initially imagined they would forge relationships with other chronic disease organizations, it soon became clear that they really needed to focus their efforts on building the ME community first and foremost. The film lent special power and legitimacy to their experiences, and that was worth digging into.

“This film is saving people’s sanity and I am certain that it is literally saving lives. First, that people with an invisible illness are heard and understood. Second, that awareness will most definitely lead to better funding, research, and a cure”

— Screening participant

So in parallel to the filmmaking process in 2014, filmmaker Jennifer Brea began to build a network that would eventually become #MEAAction. It was inspired in part by conversations with long time AIDS and Gay Rights activist Peter Staley (ACT UP), who participated in Good Pitch New York. They used the film to affirm, encourage, and embolden individuals and #MEAAction, to create a stronger foundation upon which the ME community could expand advocacy, reach, and capacity. Then, during the Sundance premiere in Salt Lake City, they partnered with Sundance and the Bateman Horne Center, a Salt Lake City-based ME/CFS clinic, to host a screening with patients, family, and local medical professionals. And Sundance conducted their own outreach to the University of Utah and local hospitals. So, the community-facing impact screenings began early on.



New York, NY (Stefanie Giglio)

FORGING NEW PARTNERSHIPS

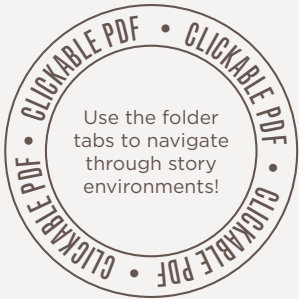
The team engaged a range of partners to host screenings in the six months leading up to the film’s broadcast. Three quarters of them were ME or invisible illness organizations or medical institutions and partners. The US-based Open Medicine Foundation (OMF), for example, took *Unrest* on a speaking tour to raise awareness and cultivate new private support for research, and partnered with patients around the world to host screenings in private homes, theaters, and hospitals. Members of

their Scientific Advisory Board and the CEO also participated in numerous panel discussions throughout the US and abroad.

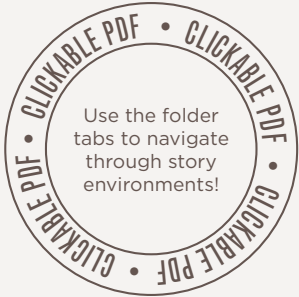
“The film Unrest truly brought ME/CFS out from the hidden shadows.”

— Linda Tannenbaum, Founder CEO and President
Open Medicine Foundation

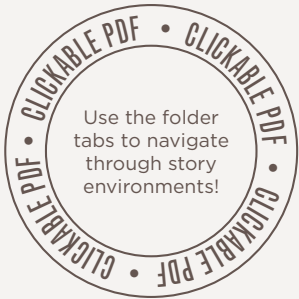
In the UK, the ME Association, Action for ME, ME Research UK, and #MEAAction UK all joined forces to organize a screening in Parliament. **The coalition that formed was sustained for subsequent work together.**



CHANGING MINDS	BUILDING COMMUNITY The <i>Unrest</i> campaign fostered a constituency with the power to advocate for what they need	CHANGING BEHAVIORS	CHANGING STRUCTURES
STRATEGY + IMPACT			
STRATEGY: DEVELOPING A PLAN FOR COMMUNITY SCREENINGS The team developed a phased approach to public viewings of <i>Unrest</i> . Initially they hosted sneak preview community screenings. In this phase they worked with grassroots distribution firm Film Sprout to organize community screenings in the USA. For this model, the screening host pays a screening license fee for the rights to host a single public screening. This allows a contribution toward the outreach costs. Then they created broader public screenings around the PBS broadcast, which included a house party program (more on this below). This was followed by the Netflix launch, which was paired with a Netflix house party initiative. As they proceeded with the plan, they regularly evaluated what was working and what wasn't, and course corrected throughout. For example, in the latter half of 2017 the team realized that a large portion of screening organizers were not large institutions, but rather individuals and smaller organizations such as support groups. So they eventually landed on a plan to ensure cost would not be a barrier for the people who most wanted to see or use the film. Another thing they learned is that because a lot of the work was with individuals, rather than organizations, it took a lot more investment and support to help ensure events were successful. But this investment paid off for the movement in the long-term, because it vested organizers with new skills and experiences, that then helped them organize future screenings and events like #MillionsMissing, the international protests organized by #MEAAction.		IMPACT: PARTNERS WERE ABLE TO RAISE THEIR PROFILE AND FUNDS The film created a valuable platform for many partner organizations. For example, Dr. Charles Shepherd, Medical Advisor to the UK-based ME Association, also made several media appearances, including with Jennifer Brea, BBC Breakfast Time. And Emerge Australia CEO Dr. Heidi Nicholl appeared on TV shows The Feed (on SBS), The 7.30 Report, and Today - a national breakfast TV program. These groups reported a notable increase in media coverage of the condition and their own organizations, including 117% growth for Emerge Australia's Facebook page. This and other visibility served as a valuable fundraising tool for these groups. Open Medicine Foundation (OMF), Solve ME/CFS Initiative (SMCI), the ME Association (UK), and others credit the targeted screenings and the great visibility for ME that <i>Unrest</i> offered with significant increases in donations to support their work. For example: SMCI contributions and grants increased 13% from 2015 (\$1,185,842) to 2017 (\$1,349,866). By contrast, their contributions and grants increased 23% between 2017 and 2018 (\$1,660,871), after the release of <i>Unrest</i> . For OMF, revenue for 2015 and 2016 was \$1,428,007 and \$1,627,743, respectively. Then, in 2017, their revenue jumped 63% to \$2,657,107. <i>"The film has had a major impact here in the UK on public awareness of ME. It has also helped to highlight what it is like to have severe ME to politicians, medical students, and health professionals. On a personal basis, it has been a real pleasure to have been involved with many of the public, parliamentary, and medical events that took place in conjunction with the screenings."</i> — Dr. Charles Shepherd Medical Advisor to the ME Association	

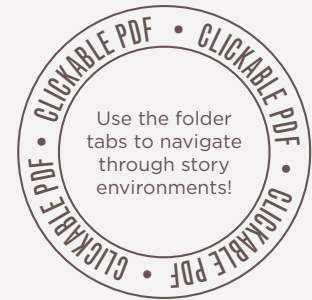


CHANGING MINDS	BUILDING COMMUNITY The <i>Unrest</i> campaign fostered a constituency with the power to advocate for what they need	CHANGING BEHAVIORS	CHANGING STRUCTURES
IMPACT			
<p>For Emerge Australia, this was a game changer. After widespread dissemination of <i>Unrest</i>, Emerge Australia reported their funding increased more than four times over. This allowed the previously (mostly) volunteer run organization to, for the first time, support eight staff members in paid positions, with two of them now working full-time.</p> <p>ALL THIS ACTIVITY HELPED TO BUILD A CONSTITUENCY WITH MORE POWER</p> <p>The team used <i>Unrest</i> to substantially expand #MEAAction. Through the course of the campaign, their email list grew from approximately 10,000 to 48,655 subscribers. The largest group within it, Living with ME (created in Nov 2016) grew to 3,200 members in one year. The community is now more organized than ever for mobilizations, advocacy, and activism both online and offline.</p> <p>Through <i>Unrest</i> engagement activities, the team has been able to build the power of this community to mobilize and advocate for what they need. #MEAAction was able to increase its operating budget six times over. This allowed it to increase from only two employees to eight employees.</p> <p>In addition to this, the organization’s capacity has evolved to include more advocacy and scientific programs, including a new fellowship program, a US advocacy program, a UK Parliament program, and an <i>Unrest</i> Continuing Medical Education (CME) screenings program.</p>		<p>WHAT TRACKING IMPACT TELLS US</p> <p>The team knows they fostered a constituency with the power to advocate for what they need because they:</p> <ul style="list-style-type: none">— Learned anecdotally from partners of the film’s utility in advancing their goals— Heard directly from partners that they were able to increase funds/grow their organizations— Saw substantial growth in #MEAAction’s operating budget and programs— Observed the substantial growth of #MEAAction’s email list and social media presence	



CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS The <i>Unrest</i> campaign promoted better and more empathetic care, and mobilized audiences to action	CHANGING STRUCTURES
STRATEGY			
<p>AN INCLUSIVE AND THUS EFFECTIVE AUDIENCE ENGAGEMENT STRATEGY</p> <p>In addition to raising awareness and building the community, the team wanted to galvanize action. So they made sure screening hosts were prepared to use the film to mobilize and organize audiences based on need and interest.</p> <ul style="list-style-type: none">— They created an advocacy toolkit and added an embedded form to <i>Unrest</i>’s website for the <i>Time for Unrest</i> global petition for ME equality, calling on every government in the world to formally recognize ME and sufficiently fund research at the levels needed to treat it and ultimately find a cure.— They created various subgroups based on interest, with tailored asks for each. In fact, hundreds of Facebook groups allow people to connect locally or based on community. For example: a men’s group, an LGBTQ group, a youth group, a caregivers’ group, numerous ethnic and language groups, and dozens of regional and local groups. <p>As a result, 94% of screening hosts surveyed ended up asking their audiences to take action in some way.</p> <p>EFFECTIVE AUDIENCE ENGAGEMENT IS INCLUSIVE</p> <p>The campaign team also took great care to be inclusive of homebound audiences who wanted to participate but had limited capacity. So they took advantage of PBS Independent Lens’ OVEE virtual screening platform to engage the homebound ME community around the film’s theatrical release through a “virtual premiere”. The virtual screening program (24 virtual “theatrical” screenings that attracted 830 attendees) allowed these audiences to participate in live events, discussions, and panels from home. Then, around the US broadcast and Netflix premiere, they organized home watch parties.</p>		<p>Digital engagement was also important to make advocacy accessible for all. So, the Time for <i>Unrest</i> Facebook group became an important community-accessible hub, allowing members to share best practices for hosting a screening, and the #MEAction Facebook groups connected them around various support, social, and advocacy needs.</p> <p>IMPACT: MOBILIZED AND ACTIVATED COMMUNITIES</p> <p>As a result of screening events, audiences have circulated and signed petitions, lobbied Congress and Parliament, and engaged in other unique community-driven actions. In fact, among those who filled out audience surveys at community screenings, 98% indicated they planned to take some action after viewing <i>Unrest</i>. This was a real boon for a campaign that included extremely health-compromised audiences.</p> <p>Whereas the majority of these pledged to share the film with a friend and on social media, a significant number (over 40%) also pledged to take a bigger action, such as joining a group or organization, speaking with their political representatives about ME, and/or visiting the <i>Time for Unrest</i> website page to learn more about the impact campaign.</p>	

WHAT HAPPENED



CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS The <i>Unrest</i> campaign promoted better and more empathetic care, and mobilized audiences to action	CHANGING STRUCTURES
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IMPACT

ONLINE

The campaign fostered robust online activity and engagement. In March 2017, the *Unrest* Facebook page included approximately 14,000 active followers. Since then, this **online community has more than doubled**, growing to 30,543 engaged Facebook followers. And the film inspired 3,448 Instagram posts with the #TimeforUnrest hashtag.

The *Unrest* **email list more than quadrupled** from 3,000 to 13,656 individuals. *Unrest* trended on Reddit with over 7,000 upvotes and 948 comments. And MEpedia, #MEAction’s wiki encyclopedia about ME, now contains 2,704 articles that have been viewed at least **14,511,783** times (at the time of writing).

In addition, the **Time for *Unrest* global petition for ME equality has thus far collected 9,647 signatures:** www.unrest.film/global-petition.

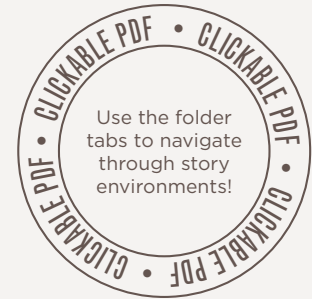
ON-THE-GROUND

***Unrest* also helped to bring in more mobilized advocates.** In the US, Ron Davis and Janet Dafoe spoke in San Francisco in honor of their son, Whitney, who is featured in the film and who has one of the most severe cases of experiencing ME. The Solve ME/CFS Initiative (SMCI)’s Carol Head joined the Washington, DC #MillionsMissing in April 2019 before SMCI’s Advocacy Day on Capitol Hill (the 2017 and 2019 advocacy days were a joint effort by #MEAction and Solve ME/CFS). The 2019 Advocacy Days ended up being the largest in the community’s history, with over 200 patients and family members coming together for in-person meetings with House and Senate offices.

The ground organizers hosted several screenings aligned with #MillionsMissing events with a Nurse’s Day in New Zealand May 2018. There were several events, both big and small, from Christchurch to Auckland to Tauranga to Hamilton. One event, for example, in Wellington, was held at The Embassy Theatre, an internationally renowned art deco cinema. There, they encouraged the display of shoes to signify those who were unable to protest due to their illness, and of notes that greeted patrons to *Unrest*. And a small group made a powerful statement by lying down in a public space.

The film also gave a boost to the #MillionsMissing demonstrations and actions, spearheaded by #MEAction, that had been coordinated all around the world. Specifically, all the local organizing in 2017/2018, especially theatrical and community screenings, led to a massive growth in participation. These #MillionsMissing demonstrations and actions grew from a few dozen participating cities in 2017 (pre-*Unrest*) to over **300 visibility actions in 22 countries** in 2018 (post-*Unrest*). In Helsinki, for example, a conference with three Scandinavian experts included a screening and inspired a #MillionsMissing demonstration. This was the largest day of awareness in Finland to date.





CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
		The <i>Unrest</i> campaign promoted better and more empathetic care, and mobilized audiences to action	

STRATEGY

And *Unrest* helped inspire audiences to get involved. Rivka Solomon, an event coordinator with MassME and advocate with #MEAAction, reported that at one event they held in Massachusetts: *“The audience gave us their full attention. If the big stack of ‘Q&A’ questions was any indication, the attendees were highly engaged. We did not get to answer all of them, but soon after, MassME was given the impressive full list of questions. These are the inquiries compassionate healthcare students and providers have about ME. During the event, we asked the audience to sign up if they wanted our organization’s newsletter. Over 100 did.”*

As a result of the community screenings and other engagement activities, this community became even more organized; they successfully forged new connections, and they developed valuable new skills.



Los Angeles, CA

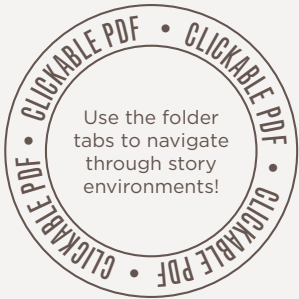


Pastors in Douglasville, Georgia call for NIH funding

TARGETED ENGAGEMENT WITH THE MEDICAL COMMUNITY

Gaining the attention of busy physicians has never been an easy task for documentary impact campaigns. But that did not deter the *Unrest* team. They deployed a few key tactics to ensure success:

- 1. Gave physicians priority during the US theatrical run.** Several donors came forward to fund 400 free tickets to medical professionals who presented their credentials at box offices across the country. This helped to make their attendance a more attractive prospect.
- 2. Secured a Continuing Medical Education (CME) accreditation.** for physicians, nurses, and social workers in the US, through a partnership with the American Medical Women’s Association (AMWA), Indiana University School of Medicine, and the nonprofit #MEAAction. Practitioners had to: a) view the full film, b) view a supplemental educational video with Dr. David Kaufman, an internist with expertise in ME, and then c) take an online test.
- 3. Hosted medical influencer events.** For example, in Atlanta the team hosted a 200 seat accredited continuing education event in collaboration with the Centers for Disease Control (CDC) that was attended by physicians and CDC staff. They screened at Harvard Medical School with students, residents, and faculty, as well as patients and clinicians from the community. Jennifer also brought clips and spoke at multiple conferences, such as the National Health Council, National Organization of Women, Exponential Medicine, and the Drug Information Association. And she joined a panel discussion at a screening at the Royal Society in the UK, one of the oldest national scientific institutions in the world, that was attended by more than 70 academics, clinicians, parliamentarians, and medical opinion formers.
- 4. Went deep in one state.** Organizers for the ME & FM Association in Massachusetts spent 18 months doing outreach throughout the state, but primarily in Cambridge and Boston. It was a strategic area of focus because of the cluster of medical and educational institutions there, and because they had a strong and motivated paid organizer there with significant experience and organizational support. The team emailed every student and medical organization and plastered the cities with notices about the film. These efforts led to 15 screenings across the state, enabling them to profoundly influence conversations within the medical community there.



CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
		The <i>Unrest</i> campaign promoted better and more empathetic care, and mobilized audiences to action	

STRATEGY

One screening with the Massachusetts Department of Public Health in Boston in March 2018, for example, was a landmark event; it was the first event about ME ever held by a State Department of Public Health in the US. At least 140 public health employees, researchers, scientists, epidemiologists, analysts, healthcare professionals, and school and public health nurses attended.

After another screening held at Massachusetts General on January 9, 2019, the event coordinator said:

“We believe this is the largest event ever held for ME/CFS. It is not a rare disease, yet it has lived in the shadows. Now it is finally getting real attention. We hope at this event medical misinformation will be replaced with the facts: ME/CFS is a serious disease that significantly limits a patient’s ability to live a normal life. Yet it is severely underfunded by the National Institutes of Health (NIH), resulting in tragically little research and patients’ lives ruined. Without more NIH funding the status quo will continue: no known cause, treatment or cure. We expect this ground-breaking event, held in the medical mecca that is Boston, will start to change all that.”

—
Rivka Solomon
Massachusetts ME/CFS & FM Association

Through trial and error, the team learned that sometimes all it takes is partnering with the right organization to gain the traction you need with the audience you’re looking to reach. For example, getting a local government institution to co-sponsor the event helped with their PR efforts and legitimized their events.

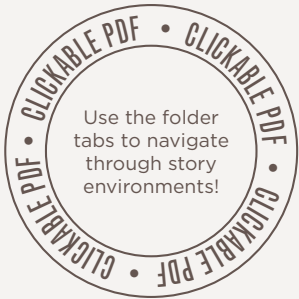


LED TO BETTER EQUIPPED MEDICAL PROFESSIONALS

“We now have a way to help all our friends and family and doctors understand the disease, that it is real, and what we are going through. It has changed the understanding of all these people. I send it to doctors often, who gain insight and respect for the reality of this disease after having been people who didn’t believe in it before. It’s enabled us to get help from people who were not willing to help us before they saw Unrest. It has helped my therapist understand what I’m going through so he can help me better - invaluable to me.”

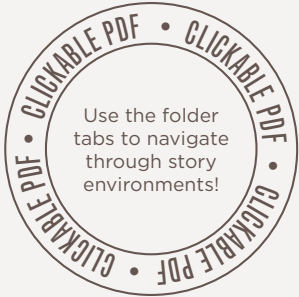
—
Janet Dafoe, PhD
Unrest film participant and caregiver for her son Whitney

WHAT HAPPENED



CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS The <i>Unrest</i> campaign promoted better and more empathetic care, and mobilized audiences to action	CHANGING STRUCTURES
IMPACT			
<p>The campaign helped educate the medical community about ME. For example, it had a powerful impact on a key medical influencer. Jennifer’s appearance on Megyn Kelly Today resulted in a long-running relationship with Dr. Natalie Azar, an NBC News medical contributor. A few years prior, using information from UpToDate (a medical resource software system), Dr. Azar reported on national television about ME/CFS as a disease that could be treated via cognitive behavioral therapy (CBT) and graded exercise therapy (GET) – both treatments that have since been removed from recommended therapies by the CDC. Dr. Azar was so inspired by <i>Unrest</i> she gave NYU’s first lecture on ME to her rheumatology fellows, and lectures the first year medical students as part of the Practice of Medicine curriculum every fall. She explained: “I feel equal parts grateful that my work in media led me from a misguided news segment to literally changing the lives of countless patients I diagnose now on a regular basis; to frustrated and dismayed that the medical community’s awareness of this illness still tragically lags.” Dr. Azar has since consulted with the CDC and UpToDate to modernize their guidelines, and participated in the CDC’s first continuing medical education module for ME/CFS. She has also appeared with Jen on Dr. Oz.</p> <p><i>“I am only one health care provider who has been appropriately re educated; countless others need to be so that patients’ complaints are no longer psychologized, dismissed, or ignored.”</i></p> <p>— Natalie E. Azar MD, Asst. Professor of Medicine and Rheumatology NYU Langone Medical Center</p> <p><i>Unrest</i> also influenced medical professionals more broadly speaking. The film’s most successful medical events were those that brought together physicians who practice and who also teach, along with students, residents, and patients in university settings. This is because, according to Jennifer Brea,</p>		<p>there can be a hard hierarchy between patient and provider: the provider feels the need to show up as an expert, and patients are afraid to be honest for fear they won’t get what they need. But these screening events illustrate how the film and these events helped to break down that patient/provider hierarchy, allowing them to talk to one another in a more intimate and honest way.</p> <p><i>“I felt embarrassed to be a doctor, hearing some of the stories in that movie, and I think we, as doctors, have to get much better at saying, as Jennifer Brea said in her TED talk, “I don’t know, I can tell you’re sick, I don’t know what’s wrong with you and I’m not even sure how I’m going to help you.” Admitting we don’t know is not the answer, but it’s a damn good start.”</i></p> <p>— Doctor attending an <i>Unrest</i> Screening</p> <p><i>“If you say too little, they can’t help you, and if you say too much, they think you’re a kind of mental patient.”</i></p> <p>— Omar Wasow in <i>Unrest</i></p> <p><i>“Very good film, exactly the same life of Jennifer Brea and his [sic] husband. My doctor saw the film and he understood better my illness, my family and my friends too, I am not alone with this illness.”</i></p> <p>— Audience Survey Respondent</p> <p><i>“The movie was fantastic, brilliant really. It was a great springboard for what turned into a mini health seminar about MECFS [sic]. Thank you. Inviting a medical researcher and then (sympathetic) medical professionals helped boost interest in the medical community about the screening... They also learnt from each other’s content, and now refer to each other. I imagine that in areas near leading MECFS research institutions there is a similar cluster of medical professionals that know about the disease, and whose expertise can add value to each screening... Thanks so much to the UNREST team for all your hard work. What an incredible advocacy tool you’ve given us!!”</i></p> <p>— Young person with ME attending an <i>Unrest</i> screening</p>	

WHAT HAPPENED



CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES
		The <i>Unrest</i> campaign promoted better and more empathetic care, and mobilized audiences to action	

IMPACT

Medical professionals at these events were impressed by what they learned. One doctor said, “Amazing. What I saw was eye opening to someone who usually has his eyes open.” A physical therapy student said he wanted to learn more. An occupational therapy student said the event sparked conversation among her peers from across multiple disciplines, and that, “the voices of the panel were definitely heard.” Two staffers from a Boston disability organization discussed holding an event focused on chronic illness. (To learn more about this event: www.meaction.net/2019/01/31/huge-event-for-me-in-massachusetts/)

The team has **enrolled 200 physicians, nurses, and social workers for *Unrest* CME credit**. As of this writing, they have not yet widely disseminated *Unrest*’s CME option as an advocacy and educational tool, so these sign-ups were primarily through word-of-mouth - a strong indicator of need and interest... and of what’s to come. For example, they are also pursuing accreditation in the UK and Australia.

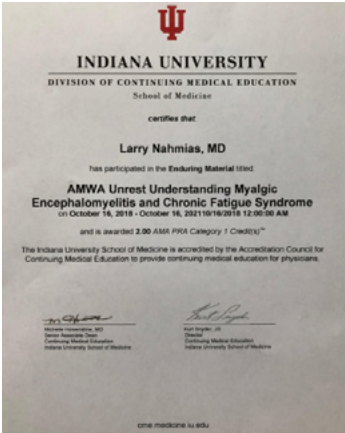
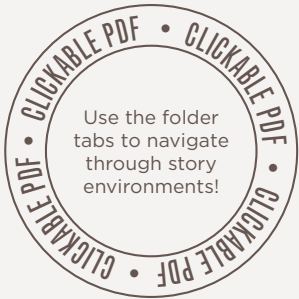


Photo of one participant's CME credit.

WHAT TRACKING IMPACT TELLS US

The team knows they promoted better and more empathetic care and mobilized audiences to action because they:

- Increased #MillionsMissing demonstrations and actions around the world
- Secured new signatures on a global petition for ME equality
- Learned that the vast majority of audiences surveyed *intended* to take some action
- Learned anecdotally from partners that screenings led to new volunteers and membership
- Secured new stories of transformation from individuals
- Increased online community engagement
- Trained medical professionals in ME care through the CME program



CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES The <i>Unrest</i> campaign inspired scientific research and funding, and improved hospital policy
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STRATEGY + IMPACT

TARGETED ENGAGEMENT WITH POLICYMAKERS

Before the film even premiered at Sundance, the team **showed clips in private settings to strategic stakeholders** like the NIH and CDC. The aim was to identify routes to collaboration, build buy-in among them, and prepare them for what was coming. This allowed them time to develop a plan and come out ahead with a proposal when the film was released.

They went on to screen the film **in the UK, Scottish, and Finnish parliaments**. They also invited MPs to public screenings in the UK, Scotland, Finland, and Australia. The team **delivered photos and petition signatures**, collected digitally and at in-person screening events, to key influencers worldwide.

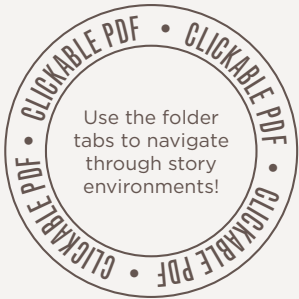
In the US, the team also **emailed digital screeners to every US House and Senate staffer** and fostered relationships with New Jersey Senator Cory Booker and Massachusetts Senator Ed Markey. Then, the ME community **mobilized pressure to get their reps to watch *Unrest* during its broadcast**, and several Chiefs of Staff and legislative assistants did so. The team also offered *Unrest* VR and an excerpt of the film to staffers and members of the Appropriations Committee on Capitol Hill in September 2017.


In the UK they **partnered with the ME Association and the Countess of Mar**, who sits in the House of Lords and is a long term campaigner for ME in the UK, to get an excerpt of the film and a discussion about the condition in front of members of the UK Parliament. The event was impressively attended by over 53 MPs. The team then **galvanized thousands of patients and allies to reach out to their Members of Parliament**, requesting they watch the film by soliciting a screener. As a result, 70+ additional members requested to view it. In Scotland they screened the film for **members of the Scottish Parliament** on

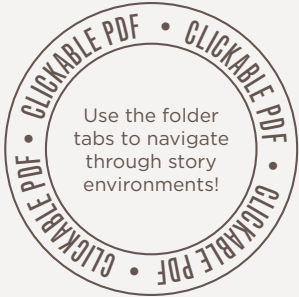
January 30, 2018. The event was attended by over 70 people, attracting an unprecedented number of Members of Scottish Parliament and described as “one of the most popular events I have seen” by the event manager.



A lie-in in Edinburgh, Scotland



CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES The <i>Unrest</i> campaign inspired scientific research and funding, and improved hospital policy
IMPACT			
<p>ADVANCED CRITICAL NEW POLICY WORLDWIDE</p> <p>The <i>Time for Unrest</i> campaign inspired new political allies and advanced significant new policies.</p> <p>In the UK: Between 2018 and 2019 there were three British parliamentary debates on ME. During one of these debates (on June 21st, 2018) <i>Unrest</i> was mentioned four times. 40 MPs participated in the third, during which 27 of them made pleas on behalf of constituents.</p> <p><i>“Some constituents came to see me to tell me about the film. It had screenings in Winchester and Chandler’s Ford in my constituency, which were oversubscribed - packed to the gunwales - and there was not a dry eye in the house. I pay great tribute to Jennifer and her partner Omar who made that film... I was struck by watching her at the Princeton University reunion day, during the rather surreal procession through the streets by old boys and girls from Princeton. She so enjoyed seeing old friends that day and looked full of life, but within an hour of it finishing she was absolutely poleaxed on the floor, saying that she felt her eyes were being pushed out of her head from the inside. It was horrible to watch.”</i></p> <p><u>The Parliamentary Under-Secretary of State for Health and Social Care (Steve Brine)</u></p> <p>The result was the unanimous passage of a motion to increase government funding, research, and ME treatments, to support proper training for medical providers, and to suspend potentially harmful treatments. However, the ultimate test of the film’s impact will be when the National Institute of Care Excellence (NICE) in the UK publishes an update to its existing clinical guidance (available here: https://www.nice.org.uk/guidance/cg53) on the diagnosis and management of ME and Chronic Fatigue Syndrome.</p>		<p>This update is expected to take place in 2020. Whether the current and highly controversial guidance, which proposes Cognitive Behavioral Therapy and graded exercise - treatments that misattribute physiological symptoms as psychological ones and can actively harm patients - will be amended is yet to be seen.</p> <div><h3>NICE to begin review of its guidance on the diagnosis and treatment of CFS/ME</h3><p>NICE is to begin a review of its 2010 guideline on the diagnosis and management of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) following a recent public consultation with patient and professional groups.</p><p>20 September 2017 Share</p><div><p>Sir Andrew Dillon, NICE chief executive, said: “The strong message from stakeholders was that the continuing debate about the causes of this condition and the best approach to treatment argued for a review of the current guideline.</p><p>“We will now recruit a guideline committee which will include people with the condition and their carers, the healthcare professionals who treat them and the organisations which commission that treatment. As with all the guidance we produce, we will also ensure that stakeholders have the opportunity to provide evidence and insights throughout the development of the guideline.”</p></div><div><p>“ The strong message from stakeholders was that the continuing debate about the causes of this condition and the best approach to treatment argued for a review of the</p></div></div>	
<p>In Australia: MP Adam Bandt participated in a 2018 #MEAction screening of <i>Unrest</i> at the University of Melbourne. Soon after, he formally asked the National Disability Insurance Agency (NDIA) to collaborate with the ME/CFS community to develop appropriate guidelines for National Disability Insurance Scheme (NDIS) assessors and for ME/CFS to be added to the National Disability Insurance Scheme’s List B of permanent conditions. Then, in March 2019, Australia’s Health Minister Greg Hunt announced \$3 million for research into ME/CFS.</p>			



CHANGING MINDS	BUILDING COMMUNITY	CHANGING BEHAVIORS	CHANGING STRUCTURES The <i>Unrest</i> campaign inspired scientific research and funding, and improved hospital policy
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ADVANCED CRITICAL NEW POLICY WORLDWIDE

In the US: In 2018 the **Senate introduced its first resolution for ME/CFS since 1993, which passed in 2019**, officially recognizing the illness and committing to discovering the medical cause and improving care for those experiencing its symptoms. Then, in 2019, #MEAAction and Solve ME/CFS went to Washington, DC to lobby Congress to appropriate \$15 million for medical education and an epidemiological study. This legislation is jointly proposed by Democrat and Republican Senate allies that were cultivated by the team during the *Unrest* campaign.

“We’ve just been able to mobilize so many more constituents to have meetings with their Senators and congresspeople since releasing Unrest. The film also transformed our conversations and relationships with many congressional staffers who viewed it, deepening their commitment to fighting on behalf of their constituents with ME.”

—
Laurie Jones
Managing Director, #MEAAction

IMPACT

Also in the US, a regional director for **Kaiser Permanente** (a major US Health Maintenance Organization HMO with 4.5 million members) **committed to overhauling the ME/CFS diagnosis and treatment process** to bring it in line with the CDC’s recent changes, wherein it no longer recommends Cognitive Behavioral Therapy or graded exercise therapies as treatment. This is a vital development as members struggle just to get an ME/CFS diagnosis.



WHAT TRACKING IMPACT TELLS US

- The team knows they inspired scientific research and funding, and improved health care policy, because:**
- They prompted new policy debates in the UK parliament
 - Legislators made public pleas on behalf of ME constituents
 - A new motion passed in the UK to increase government funding, research, and ME treatment
 - A US Senate resolution S. Res. 225, sponsored by senators they had recruited using *Unrest*, passed and the US House introduced an identical, bipartisan Resolution 399
 - Australian MP Adam Bandt formally requested appropriate guidelines for disability insurance
 - Australian Health Minister Greg Hunt announced \$3M in research for ME

ETHICAL & EMANCIPATORY PRACTICES

FOLLOWING THE LEADERSHIP OF FILMMAKERS WITH DISABILITIES

The work that the *Unrest* team did offers a great example of ethical and accountable documentary impact practices for the field. Not only was **the team made up of people with ME** or other disabilities (in addition to the director herself) in paid positions, such as executive producer and creative advisor Debbie Hoffmann, re-recording mixer and sound designer Jim LeBrecht, and producer Lindsey Dryden, it also included, invited, and empowered their network to actively participate throughout the filmmaking and campaign implementation as well.

They used the Kickstarter platform to **prototype messaging and campaign ideas with patients, caregivers, and advocates** early on and made sure their **distribution and engagement plans were inclusive**. Key among these plans was the previously mentioned virtual screening program and premiere, which allowed home-bound community members to participate in or engage with post-screening panel discussions. They also developed a robust social media engagement program so that anyone could get involved at whatever level was possible for them.

HAVING A TEAM THAT INCLUDED PEOPLE LIVING WITH ME AND OTHER DISABILITIES WAS CRITICAL IN ENSURING THEY COULD DEVELOP A FILM AND CAMPAIGN PLAN THAT WAS SENSITIVE TO THE ISSUES AND NEEDS OF THIS COMMUNITY.

This meant that they knew to build in plenty of time for impact producers and partners on the ground to take the time they needed to get the outreach done in a healthy and sustainable way. It also meant they were sensitive to protagonists' physical and health requirements, and the emotional impact of taking part in a film that any documentary subject experiences, both during filmmaking (e.g. understanding how much light contributors could withstand, how long they could engage for, etc.) and after (e.g. creating a support system amongst the protagonists so that they could lean on each other in the lead up to the film's release and after, should they need to).

However, not every accessibility strategy went as planned - accessibility in theaters proved more challenging than anticipated. For example: the UK theatrical premiere took place in a cinema venue that advertised itself as fully accessible. But what that actually meant was that people with disabilities could access the cinema screen as viewers, but not as talent on-stage. In assessing the building's accessibility, it seemed no one at the cinema company had ever considered that a wheelchair user would be onstage presenting a film. The team also wasn't able to get captioning or audiovisual done in time for the festival run. They nonetheless learned on the go what it would take to make their events accessible - and they have a powerful, dedicated, and growing community to show for it.



“In this way,” writes Jennifer Brea, “the project has not only defied stereotypical storytelling tropes about disability and disease, but also helped redefine who gets to tell such stories and how.”

The end result is not only a powerful impact campaign that changed minds, changed behaviors, changed structures, and built community, but also a film and campaign that improved participants' lives.

- The film and campaign has helped Jessica Taylor-Bearman reach a much larger number of people internationally with her advocacy, through her Facebook page, The World of One Room, and with her book, *A Girl Behind Dark Glasses*. She was featured in a few different news articles and regional news programs, which she leveraged to promote ME awareness further. The platform the film created even helped her reach Parliament, where she went with Jen to challenge the current state of ME treatment and make people more aware of the abominable care people with ME receive. She also received treatment from an ME charity, which supported her even more when they found out about her story. She explains: “There has been an overwhelming response to the film and I am so grateful for the opportunities that have come from it.”

ETHICAL & EMANCIPATORY PRACTICES

- The film and campaign raised Ron Davis's profile and increased support for his research to find appropriate treatments to save his son, Whitney. Janet Dafoe, his wife, explained: "*Unrest* has helped a lot in giving Ron credibility in working on this disease with other scientists who know very little about it. It got the word out to people who would never have known about this disease, people who then became donors to Ron's research, and people who then interviewed him for articles, people who only did this because of seeing *Unrest*. Interviews and donations from all over the world. Newspaper and magazine articles all over the world. This never would have happened without *Unrest*. It has made me much more credible as an advocate. It has raised awareness of Whitney's plight and has increased his platform for helping and encouraging patients to have hope and not give up. We believe that has prevented suicides and given people hope and courage to keep fighting."
- While it's difficult to know for certain, the film may have increased visibility and pressure on Danish authorities to end state guardianship of Karina, a participant in the film whose family was shown attempting to secure her return home. Since the film's release, Karina and her family have been part of a TV documentary on the Danish Broadcasting Corporation: www.dr.dk/tv/se/psykiatriens-dilemma/psykiatriens-dilemma-2/psykiatriens-dilemma-diagnosens-pris-2-3

"I have thought, since the first time I saw the film, that it was the greatest thing that ever happened to anyone with ME. It brought to life the struggle and insanity that people live with every day. I believe the illness sucks the will to fight out of people, and the fact that you [Jennifer Brea] came around and refused to accept your fate has changed the life of millions. I personally believe that the structural/CSF issues are the key to solving this illness, and as far as I can tell, the reason we know about that is 100% attributable to Unrest."

Darwin Jackson
Unrest film participant





THE TIMELINE

2013-16

2017

REAL WORLD EVENTS

OCTOBER 2013:
Launch of Kickstarter for production/filming

MAY 2014:
Distribution strategy developed by producers Brea and Dryden concurrent with production

OCTOBER 2015: *Unrest* participates in Good Pitch New York

JANUARY 2017:
Unrest premieres at Sundance Film Festival, Utah. Numerous other film festivals and screenings follow around the globe

Wins Sundance Film Festival Special Jury Prize, Documentary Editing

FEBRUARY 2017:
Unrest producing team is awarded the inaugural Sundance Institute Creative Distribution Fellowship

MARCH 2017:
CPH:Dox Danish and European premiere

APRIL 2017:
Nashville Film Festival Grand Jury Prize, Best Documentary Feature

RiverRun International Film Festival Audience Choice Award, Best Documentary Feature

*Unrest*VR premieres at Tribeca Film Festival

JUNE 2017:
Sheffield Doc/Fest Film Festival UK premiere

Sheffield Doc/Fest Illuminate Award and Alternate Realities VR Award

JUNE 2016:
Jennifer Brea gives a TED talk

THE CAMPAIGN

IMPACT & ACHIEVEMENTS

MAY 2017:
#MillionsMissing demonstrations held in a few dozen participating cities

#MEAction New York works with the State Health Commissioner to send out a letter to over 85,000 physicians to educate them about ME

JULY, 2017:
CDC removes outdated and harmful recommendations for graded exercise therapy and Cognitive Behavioral Therapy for ME from its website

JUNE TO DECEMBER 2017:
550+ community screenings throughout US and UK run by Film Sprout and Together Films, respectively

2017

SEPTEMBER 2017:

NIH announces \$7 million in grants to establish 3 Collaborative Research Centers and a data management center for ME/CFS research

REAL WORLD EVENTS

AUGUST 2017:

Melbourne International Film Festival Australia premiere

OCTOBER 2017:

Limited theatrical release in the US and UK

DECEMBER 2017:

DVD and iTunes digital release worldwide

Unrest is shortlisted for an Academy Award for Best Documentary Feature

THE FILM

SEPTEMBER 2017:

Launch of Kickstarter for impact campaign

Unrest VR and an excerpt of the film are presented to staffers/appropriations committee members on Capitol Hill

OCTOBER 2017:

Excerpt of *Unrest* shared at a special event in UK Parliament with over 53 MPs

NOVEMBER 2017:

Stakeholder discussion event held at the Royal Society with 70+ academics, clinicians, parliamentarians, and medical opinion formers

NOVEMBER 2017:

Continuing education event held in Atlanta in collaboration with the Centers for Disease Control (CDC) attended by physicians and CDC staff

THE CAMPAIGN

IMPACT & ACHIEVEMENTS

2018

MAY 2018:

300+ visibility actions held in 22 countries for #MillionsMissing

#MEAAction meets with US NIH director, Francis Collins, to demand urgent action to accelerate progress for ME

JULY 2018:

CDC launches new web pages about ME, geared to practitioners. A step in the right direction, but not all recommendations from stakeholders are implemented

OCTOBER 2018:

ME patient, Mary Gelpi, sends a petition with 50K signatures to US NIH director calling on him to increase annual funding for ME/CFS to \$100 million

JANUARY 2018:

PBS Independent Lens broadcast of *Unrest* in US

Netflix global broadcast of *Unrest* (one week after PBS Independent Lens)

JANUARY 2018:

Screening held for members of Scottish Parliament

MARCH 2018:

Screening at the Massachusetts Department of Public Health in Boston

APRIL 2018:

Living with ME group created to support new community members
Now, 4,100 large

AUGUST 2018:

Emerge Australia and #MEAAction co-host an *Unrest* screening at the Bio21 Institute, University of Melbourne, with remarks by MP Adam Bandt

JUNE 2018:

First UK Parliamentary debate on ME

SEPTEMBER 2018:

MP Adam Bandt cites #MillionsMissing and advocates for the ME community in Australian Parliament

OCTOBER 2018:

Second UK Parliamentary debate on ME

2018

DECEMBER 2018:

#MEAction’s MEPedia — its wiki encyclopedia about ME — surpasses 10 million views

REAL WORLD EVENTS

THE FILM

THE CAMPAIGN

DECEMBER 2018:

MP Adam Bandt formally tables an ME/CFS petition, asking the National Disability Insurance Agency (NDIA) to collaborate with the ME/CFS community to develop appropriate guidelines for National Disability Insurance Scheme (NDIS) assessors, and for ME/CFS to be added to List B of permanent conditions for NDIS

IMPACT & ACHIEVEMENTS

2019

MARCH 2019:

Australia’s Health Minister Greg Hunt announces \$3 million for research into ME/CFS

A Kaiser regional director commits to overhauling the ME/CFS diagnosis and treatment process, to bring it in line with the CDC’s recent changes

ME resolution to improve conditions for ME patients proposed in Danish Parliament

MARCH 14, 2019: ME resolution passed unanimously in Danish Parliament

JANUARY 2019:

Third UK Parliamentary debate on ME and passage of a motion for an increase in government funding, research, and ME treatments, for medical provider training, and for suspension of potentially harmful treatments

APRIL 2019:

NIH holds first ever ME research conference and young investigators workshops

Stanford researchers announce they have created a nanoneedle device that can accurately identify people with ME/CFS – a potential biomarker for the disease

AUGUST 2019:

The federal government’s Canadian Institutes of Health Research will spend \$1.4 million to create and develop a national research network to study ME/CFS

APRIL 2019:

Largest US Congress “lobby day” in ME community’s history with 200+ patients and family members holding in-person meetings in Congress

MAY 2019:

In a historic moment, US Senate passes its first resolution in support of ME/CFS, S. Res. 225

A woman with short brown hair, wearing a dark green dress with a white floral pattern and a long necklace, is leaning over a person lying down. She is holding the person's hand with both hands. The person lying down has their eyes closed and is wearing a dark shirt. The background is dimly lit, showing a window with pink curtains and some household items.

CONCLUSION

CONCLUSION

While we may be far off from a cure for ME, more funding is nonetheless beginning to move towards researching the illness. Over the course of a two-year campaign, *Unrest* has undeniably increased broad public awareness and understanding of the need for this research. In fact, the campaign led some networks to increase their funding at least six times over, secured \$3M in new funding in Australia, and may have contributed to new funding in the US, Canada, and the UK as well.

Campaign activities also fostered a sense of identity and power among the ME community of patients, caregivers, and allies. It consolidated #MEAAction and helped it to grow substantially, leading to the growth of #MillionsMissing demonstrations and actions all over the world. As a result, the film has helped to strengthen and build a powerful constituency that has the resources, capacity, and partnerships necessary to advocate for what they need.

This film and campaign is a testament to what's possible with ample funding, a robust team, and ethical, compassionate, and strategic planning. We are inspired by the *Unrest* team's ongoing work and leadership.

Keep an eye out for renewed medical community engagement in late 2019 with the formal release of the continuing medical education (CME) program, which will bring *Unrest* to ten more medical schools across the US, and will mobilize the ME community to do outreach via a "Postcards to Doctors" program. Also look out for the 2020 release of the *Unrest* VR project.



CREDITS

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WWW.UNREST.FILM

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INSTAGRAM.COM/UNRESTFILM

CONTACT:
INFO@UNREST.FILM

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2019

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Case study written by:
Sahar Driver

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Jessica Edwards
& Maxyne Franklin

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