



# *Time For Unrest*

2017 Impact Campaign Highlights

*Time For Unrest* is a global impact campaign that aims to end the stigma and radically transform the way the world views, understands, and invests in Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome.

Its goals are to **reach** mass audiences, **mobilize** patients and allies, **educate** medical professionals, **inspire** scientists, and **advocate** to policymakers in order to build a movement for change.

We are so grateful to you and the countless thousands who through your donations, passion, creativity, elbow grease, and sacrifice have made what just a few years ago seemed unimaginable, attainable. This is just the beginning! In this deck, we celebrate the outcomes of year one and look ahead to year two.

**2013**

**to**

**2016**





Lindsey Dryen, Jennifer Brea, Trish Gillespie, Omar Wasow at Sundance 2014



Good Pitch 2015



The day I decided to make *Unrest*



Ruby & Jessica



Sundance 2014





First interview



Tribeca 2016



Whitney Dafoe



First Millings Missing, May 2015



Behind the scenes at Jessica's, our DP Sam Heesen setting up

**2017**





↑  
TO  
THEATRE

sundance  
film festival





**GOAL #1:**

**REACH**

**Challenge:** The popular conceptions of “Chronic Fatigue Syndrome” have for decades stigmatized, marginalized, and made invisible the millions of patients who have it. This has hampered medical education, patient care, and investment in scientific research.

**Strategy:** Gain mass and strategic recognition of ME as a debilitating illness suffered by millions by **reaching** wide audiences and bringing them into the conversation.

Achieving our goal of reaching wide audiences began at the Sundance Film festival, where *Unrest* had its world premiere January 20, 2017.

*Unrest* was one of 113 feature films selected from 4,068 entries, and one of sixteen documentaries programmed in the US Documentary Competition.



# FESTIVALS





And won a special jury award!







It then went on to screen at over three dozen film festivals around the world, winning numerous prizes and honors. I was fortunate to be able to travel in person for the European/Danish, British, Canadian and Australian premieres, resulting in national press in each of these territories.





UNREST

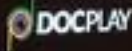
To learn more about ME and how you can provide support, visit:

[meaction.net](http://meaction.net)  
[unrest.film](http://unrest.film)  
[emerge.org.au](http://emerge.org.au)



DOCUMENTARIES

Presented by



Special Thanks



13

Nominations

8

Wins





# T E D T A L K

Days before the Sundance premiere, my TED Talk, “What happens when you have a disease doctors can’t diagnose?” launched on [TED.com](https://www.ted.com). Later that spring, it was featured in NPR’s TED Radio Hour with Guy Raz.



**1.5 million views**

After a successful festival run, *Unrest* opened theatrically in September in several US cities including New York, Los Angeles, Chicago, San Francisco, Berkeley, Seattle, Portland and Atlanta.

In October, it opened in the UK beginning with a week-long run in London and screenings at forty cinemas around the country.

Our theatrical run was crucial for garnering reviews and feature coverage in major outlets like *The New York Times*, *The Los Angeles Times*, *The Guardian*, and *The Telegraph*, as well as radio coverage on NPR and the BBC, and appearances on Megyn Kelly Today and BBC Breakfast.

T H E A T

R I C A L











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Unrest

16 hrs · 🌐



We are so thrilled to share that [Unrest](#) has advanced to the next stage of Oscar voting! There were 170 submissions. Honored to be among these 15 incredible documentaries! Today, our stories are seen and heard! [#TimeForUnrest](#)

Watch [Unrest](#) → <http://unrest.film/watch>

Learn more → <http://unrest.film/trailer>



### Oscars: Documentary Feature Shortlist Cuts Field To 15

The Academy of Motion Picture Arts and Sciences has narrowed the field for the Documentary Feature Oscar to 15 vying for five nomination slots. Among them are a sequel to a previous Oscar winner, a...

DEADLINE.COM

[Learn More](#)



Eva Fisher, Beth Mazur and 1.3K others

[Top Comments](#) ▾

# COMMUNITY SCREENINGS

Since our theatrical release, *Unrest* has gone on to screen more than five hundred times in theaters, on campuses, and at schools, churches and hospitals in groups ranging from ten to over 350 people.







New York



London



Norway



Ireland

# 521

Screenings

# 22

Countries

# 34,498

Viewers



# The Telegraph

Could this documentary change the way we perceive chronic fatigue syndrome?



Filmmaker Jennifer Brea in London last week CREDIT: ANDREW CROWLEY/TELEGRAPH



# P R E S S



“ASTONISHING”

- BBC

"BRILLIANT"

- THE DAILY TELEGRAPH

"POWERFUL"

- THE GUARDIAN

“RIVETING”

- THE SAN FRANCISCO CHRONICLE

“REMARKABLY INTIMATE”

- THE LOS ANGELES TIMES

"A REVELATION"

- THE SALT LAKE CITY TRIBUNE

The image shows a newspaper page with a photograph of a man and a woman smiling together. The headline above the photo reads "Frozen by chronic fatigue". To the left of the photo is a column of text with a large letter 'A' at the top. To the right of the photo is another column of text with a large letter 'H' at the top. Below the photo is a circular portrait of a woman and a caption that reads "People's favorite film" and "small talk in France".

The image shows a newspaper page with a photograph of a man and a woman looking at each other. The headline above the photo reads "Er man nødt til at filme sin egen sygdom for at vise, man ikke er tosset?". Below the photo is a column of text.



# 229

## Press hits

### US

[The New York Times](#)

[The New York Post](#)

[The Washington Post](#)

[The Los Angeles](#)

[Times \(Review\)](#)

[The Los Angeles Times](#)

[\(Feature\)](#)

[The San Francisco Chronicle](#)

[Variety](#)

[The Boston Globe](#)

[The Atlanta Journal](#)

[Constitution](#)

[The Hollywood Reporter](#)

[Indiewire](#)

[Film Comment](#)

[White House Chronicle](#)

[Huffington Post](#)

[Chicago Reader](#)

[Chicago Tribune](#)

[Cosmopolitan](#)

[Refinery 29](#)

[Megyn Kelly Today](#)

[Dr. Oz](#)

[Tavis Smiley](#)

[NPR – TED Radio Hour](#)

[PRI – Science Friday](#)

[KCRW – Press Play](#)

[KPCC – The Frame](#)

[Inflection Point](#)

[WNYC – Doc of the Week](#)

### UK

[The Telegraph](#)

[The Times](#)

[The Observer](#)

[The Guardian](#)

# 14,348,498

## Reach

[The Independent](#)

[Daily Express](#)

[BBC World News \(Television\)](#)

[BBC World Service](#)

[\(Radio\): 26:33](#)

[BBC Ouch](#)

[BBC Click](#)

[BBC Breakfast](#)

[The Irish Times](#)

[ITV News](#)

[Channel 5](#)

[Cosmopolitan UK](#)

[The Pool](#)

### CANADA

[CBC – The Current](#)

[The Toronto Star](#)

### AUSTRALIA

[ABC – Triple J](#)

**(Selected clips)**



**GOAL #2:**

**MOBILIZE**

**Challenge:** Patients face several obstacles to greater mobilization. Many are too sick to leave their homes. Many face stigma, shame, and a lack of understanding from friends or loved ones.

**Strategy:** Leverage public screenings of *Unrest*, in physical and virtual events, to **mobilize** a community of ME patients and allies to action.

# CONNECT



*Unrest* is for many patients and their families the first time they have been able to live their private pain in public. The film creates a space to gather together, in a theater, and realize not only that others share our experience, but we can be understood and even embraced by our communities.





I've had ME/CFS for 15 years. It has been a long battle. I saw Unrest last week and for the first time I felt that I could be sick in public. I know that sounds weird but I always tried to either pretend or disappear when I was sick. Thank you for making me feel that I had nothing to be ashamed of and that my illness is just as real as anyone else's.

Kathy Nolan  
Deschennes  
Westford, MA



sherbie  
@sherbsville

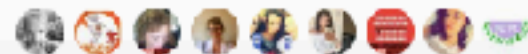
Follow

ive NEVER put a pic on social media. im SOOOOOO scared. but im one of the [#MillionsMissing](#) and its [#TimeforUnrest](#) pls see [@unrestfilm](#) [#MEcfs](#)



8:56 AM - 31 Oct 2017

144 Retweets 370 Likes







# P R I D E

Before we as patients feel empowered to take action - or rally our loved ones to do the same - we have to have the opportunity to recognize the trauma of our experiences, grieve our losses, and find connection and strength in one another.

And in the hollow of that loss, another feeling can start to grow - pride.



Ashanti Daniel at the Los Angeles premiere of *Unrest*



# ORGANIZE

Organizing builds the capacity, networks, and human infrastructure required to achieve massive long-term change. Here are three ways *Time For Unrest* is expanding the organizational resources of our movement:

1) Existing non-profits and community groups around the world have organized screenings or participated in panels, using *Unrest* as a tool to expand their reach and forge new relationships.

2) Dozens of patients, many of whom didn't know each other before the launch of our campaign, banded together to host community screening events, building vital local networks and capacity that can be mobilized in the future.

3) *Time for Unrest* and #MEAction have co-collected thousands of email addresses from hundreds of screenings, which can all be used for future calls to action, whether around fundraising, lobbying, or education.



Members of the Danish ME Association



#MillionsMissing Melbourne activists



Linda Tannenbaum of the Open Medicine Foundation and Carol Head of Solve ME/CFS

# A C C E S S S

We wanted to make sure that people who were homebound - due to ME or any illness or disability - could participate in a social experience of the film, during our theatrical window and beyond. Why miss out because you can't make it to the theater?

We worked with OVEE, created by ITVS, an innovative distribution technology, to enable homebound audiences to watch the film, virtually participate in Q&As and panel discussions, and share their reactions. Audiences could also connect with each other after the screening via video conferencing.





Thank you for making it possible for me to view this from home♥I have POTS SYNDROME with chronic fatigue, it's hard to get to the city for me. -Monica, OVEE NYC

As a homebound ME patient it means a lot to be able to see this today. - Rachel, OVEE NYC

Thank you so much for offering the virtual aspect for those of us...who are too debilitated to make the drive. - Terri and Abby, OVEE LA

This film means such a lot to me as one mainly housebound by this horrendous illness. Bless you all x - Deborah, OVEE UK

Kickstarter Backer 10am Screening



All Liked 32

platform, and then the film will begin.  
Thanks! ❤️ 1

Laurie Jones  
Welcome Everyone! We hope you enjoy this screening of OVEE! ❤️ 2

Laurie Jones  
We will be focusing just on the film today! ❤️ 1

Laurie Jones  
Also, this is a exclusive screening, so we can't share on social media :) ❤️ 2

K.Milde

enter comments here

Audience 29 Welcome Speakers Help & System test



GOAL #3 & 4:  
EDUCATE +  
INSPIRE

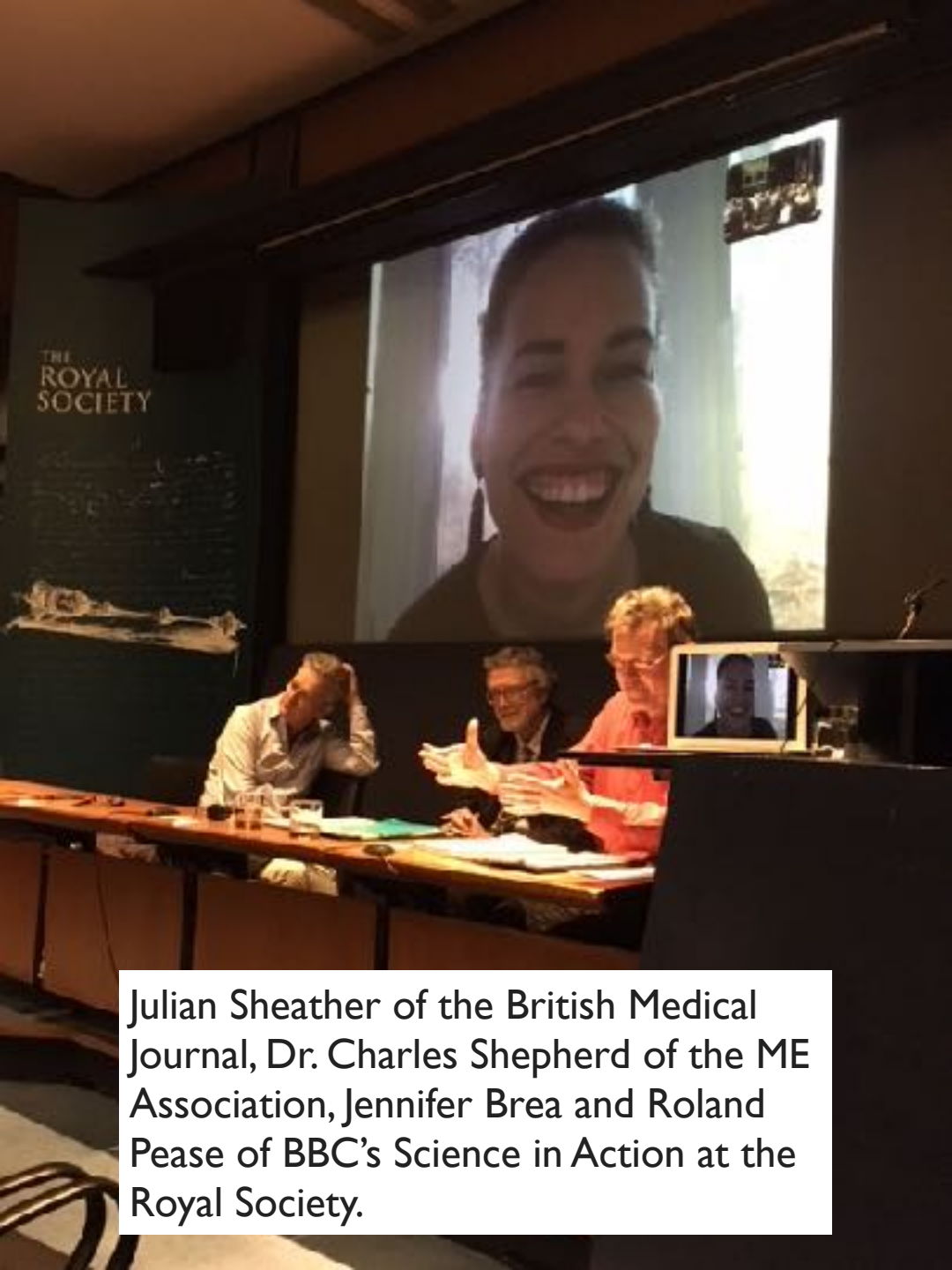
**Challenges:** Most medical schools do not teach ME and the disease has no home in any medical specialty. Owing to this, doctors are ill-equipped to diagnose or treat patients.

Furthermore, because of the lack of funding in the field and low awareness about ME, few scientists study it.

**Strategy:** Leverage targeted screenings of *Unrest* to promote knowledgeable and empathetic care for ME within the medical profession.

Inspire new scientists and funders to join the field.





Julian Sheather of the British Medical Journal, Dr. Charles Shepherd of the ME Association, Jennifer Brea and Roland Pease of BBC's Science in Action at the Royal Society.

During our theatrical release, the Harnisch Foundation and several additional donors generously supported free tickets for anyone working in science & medicine. All told, we offered more than 400 tickets to nurses, doctors, and scientists in Boston, New York, Los Angeles, San Francisco and London.

We also held key influencer events – one an accredited, continuing education event in Atlanta in collaboration with the **Centers for Disease Control**, attended by physicians and CDC staff. Another at the **Royal Society** in London attended by scientists and clinicians from leading institutions.

While the focus of 2017 was our festival and theatrical launches, the early enthusiasm from doctors & scientists has been incredible. This is just the beginning of our medical outreach, which we hope to ramp up in 2018.



# EXPONENTIA Medicine

By Singularity Univers

At the 2017  
Exponential Medicine  
conference with Dr.  
Andy Kogelnik



# 2017 Research & Medical Outreach

## United States

Centers for Disease Control  
Exponential Medicine Conference  
American Public Health Association Annual  
Conference  
City College of San Francisco Registered  
Nursing  
Denver Biolabs  
Forward  
Fred Hutchinson Cancer Research Center  
HealthSavvy, Inc.  
Naviaux Lab, University of California San  
Diego School of Medicine  
Nevada Center for Biomedical Research  
Nova Southeastern University, Institute for  
Neuro Immune Medicine  
Open Medicine Foundation  
Pennsylvania College of Health Sciences  
University of Tennessee Health Science  
Center, Department of Occupational  
Therapy

University of Utah School of Medicine  
Alumni Association  
Wright State University Boonshoft School of  
Medicine Physician Leadership Development  
Program

## United Kingdom

Royal Society  
London School of Hygiene & Tropical  
Medicine  
MediCinema  
Chelsea and Westminster Hospital  
Guys and St Thomas' Hospital  
RBI Newcastle Hospital

With much more to come in 2018!

# Early Impact

## Research

While it is still early days, we have had several scientists at both academic institutions and in the private sector - from Stanford and Silicon Valley, to Costa Rica and Oxford - begin to explore how their labs could get involved in research, attending conferences and requesting samples.

## Clinical care

A clinical professor of rheumatology at a leading US institution was so inspired, she decided to investigate what rheumatology residents were being taught about ME at her institution. When she found out the answer was “nothing at all” she decided to organize an hour-long lecture, the first of its kind at her institution.

**GOAL #5:**

**ADVOCATE**



**Challenges:** From the lack of medical education, to gross inequities in research funding, massive barriers to accessing clinical care or basic services, and the specter of forced institutionalization in some countries, the policy environment to support and treat ME patients is broken.

**Strategy:** Mobilize patients & allies, and leverage targeted screenings of *Unrest* to engage elected officials and policymakers for change.



Jessica Taylor (subject of *Unrest*), Charles Shepherd of the ME Association, Jennifer Brea and the Countess of Mar at the Speaker's House







# United Kingdom

We partnered with the ME Association and the Countess of Mar to screen an excerpt of *Unrest* to 40 Members of Parliament. It was eye-opening. After the screening, we mobilized in partnership with #MEAAction thousands of patients and allies to reach out to their Members of Parliament asking them to watch the film by requesting a screener. To date, over 70 additional members have requested to watch *Unrest*.

Our asks? The reform of medical guidelines, the establishment of centers of excellence (specialty clinics for both care and applied research), and investment in research funding.



**Vince Cable** @vincecable

[Follow](#)

Recognition needed for [#MyalgicE](#) or ME. Damaging, debilitating but hidden illness not recognised by [@NICEcomms](#) or many agencies.

10:40 AM - 24 Oct 2017 from [Richmond, London](#)

230 Retweets 471 Likes



53 230 471



**Paula Sherriff MP** @paulasheriff

[Follow](#)

Watched powerful [@unrestfilm](#) last night with local family whose lives are profoundly affected by M.E/CFS. Very insightful, go see if you can

1:50 PM - 25 Nov 2017

25 Retweets 106 Likes



5 25 106



**Mark Tami** @MarkTamiMP · Oct 25

Very clear from watching the [#Unrest](#) film on [#ME](#) that more needs to be done, in terms of funding and research, to tackle this disease



**Chris Ruane MP** @ChrisRuane2017 · Oct 25

Attended the [#unrest](#) event at [#parliament](#) to hear of the daily struggle of people living with ME [#timeforunrest](#)



**Chris Evans MP** @ChrisEvansMP · Oct 24

Attended today's viewing of the film [Unrest](#) - a must watch. The condition ME urgently needs more research funding [#TimeForUNREST](#)



# United States

Our US advocacy outreach is just gearing up, supporting long-standing efforts on the part of #MEAAction and Solve ME/CFS. Senator Cory Booker's office hosted a VR cocktail event, Congressman Raul Grijalva attended a theatrical screening with constituents in Tucson, and the entire Massachusetts delegation – Senator Markey, Senator Warren, and all representatives – signed a declaration calling for meaningful and immediate investments in research in advance of a screening organized in Arlington, MA.





Without **meaningful and immediate investments** in biomedical research, the 28,000 people living with ME/CFS in Massachusetts will struggle to find answers to critical questions about the disease's cause, diagnosis, and treatment. Events like today's, bolstered by the advocacy and outreach performed by many in this room, have helped bring this devastating condition out of the shadows and into the spotlight. **We will keep our constituents with ME/CFS in mind as we push for expanded biomedical research opportunities in funding in the U.S. House and Senate.**



Joint statement from the **entire Congressional Delegation**: Sen. Elizabeth Warren, Sen. Ed Markey, Rep. Richard Neal, Rep. ... Nikki Tsongas, Rep. Joe Kennedy, Rep. Katherine Clark, Rep. Seth Moulton, Rep. Michael ... Stephen Lynch and Rep. Bill Keating

**Shared at the UNREST film v... Theatre, Boston area on November 12, 201**

ME advocate Rivka Solomon at the Arlington, MA screening

**2018**

We are just three months  
into the *Time For Unrest*  
campaign.

This is just the beginning.



In **2017**, the focus was our festival run, theatrical launch, and publicity. In **2018** we will deepen and scale our outreach in medicine, science and policy, and build bridges to other disease communities to achieve our campaign goals.

# REACH

# 1.4 million



In 2017 we will broaden our reach, chiefly with the broadcast of *Unrest* in the United States on PBS's *Independent Lens*.

JAN 8, 10 PM

# UNREST



# MOBILIZE

## 233

233 households have already signed up to host *Unrest* watch parties during the week of the PBS broadcast, Jan 5 to 14. These will be opportunities to engage new partners, invite friends and neighbors who may not already be a part of the movement to join in, raise money for research and a variety of ME-related causes, and take action.

## 100

May 12th, the international day of awareness for ME (and fibromyalgia), we aim to organize 100+ screenings around the world as part of a day of action that will also include *#MillionsMissing* protests, rallies and other mobilizations - on and offline.



# EDUCATE & INSPIRE

Building on the CDC and Royal Society screenings, we aim to accredit *Unrest* for continuing medical education credits in the US, UK and Australia; screen the film or segments of it at medical conferences as well as private companies; and screen at at least 50 new universities with an emphasis on medical school and science department engagement.

## **CONFIRMED**

NHS Scotland  
Harvard  
Stanford

## **PROPOSED**

Columbia  
Oxford  
Cambridge  
Pfizer

# ADVOCATE

In the US, we aim to leverage the PBS broadcast for congressional outreach, and expand our state-level outreach to departments of public health as well as state houses & assemblies. In the UK, we will screen at *Unrest* at the Scottish Parliament and continue to engage new parliamentary allies. In Australia, we will ramp up federal political engagement. Around the world, we aim to support the efforts of organizations and activists to screen *Unrest* at their national representative bodies.

## **CONFIRMED**

Scottish Parliament  
MA Dept of Health

## **PROPOSED**

Australian Parliament  
Irish Dáil  
The National  
Assembly for Wales

NJ Dept of Public  
Health  
NY Dept of Public  
Health & State House

Thank you for all you have  
done to make this possible.

We can't wait to see the  
impact 2018 will bring!



With gratitude, from our team!

