

# PRESS RELEASE

## For Immediate Release

**Press Contact:** Carol Bryant  
**Email:** unrestscreening@hotmail.com  
**Phone:** 01457 764 813

### ***Tameside M.E. patients call for fair health care for all***



Tameside families affected by M.E. are hosting a community screening of *Unrest*, a multi award-winning film by Jennifer Brea, on 18<sup>th</sup> November, 2.30pm at The Magdalene Centre in Broadbottom.

This screening is one of many happening across the UK and the globe, as part of an international social impact campaign, *Time for Unrest*, which aims to increase the public's knowledge of M.E.; challenge the stigma surrounding the condition; and to call for greater research and fair medical treatment. Patients all across the world are organising their own local events like this to widen the reach of the campaign. This event is for anyone who believes in fairness and equality.

At the heart of this local arm of the campaign are Ellissa Bryant and Ursula Humphreys, both Tameside patients whose lives have been struck down by M.E. Ellissa was an elite climbing athlete, having competed across the UK and Europe, often seen on the medals podium, and was in further education with a view to going to university. Ursula was a post-graduate with a promising career in public health policy and planning, working in a management role to protect and promote the local population's health. The goals of both young women now are relegated simply to doing their best to manage their debilitating health condition, day-to-day.

The film *Unrest* tells the global story about an international community of patients with a serious, life-altering illness. The film's director, Jennifer Brea, turned the camera on herself when, at age

28, whilst studying for her PhD at Harvard and just months before her wedding, she contracted a mysterious fever, leaving her bedridden, yet was disbelieved by doctors. Her intimate film offers a first-hand glimpse into the hidden world of millions of people suffering invisibly and left at the margins of medicine and science - people like Ellissa and Ursula.

***“When I got sick, I was shocked to encounter this world I had never heard of and knew nothing about. For decades, people living with M.E. have been missing from their lives. It’s my hope that in telling this story, we will no longer be relegated to the shadows, that our experience will be seen and recognised.” – Jennifer Brea, Director of Unrest***

***“The daily suffering that I go through can not be understood simply by description – it has to be seen to be believed, recognised and acknowledged. That’s why this film is so important.” – Ellissa Bryant, Tameside M.E. patient***

Myalgic Encephalomyelitis (M.E.) is a systemic neuroimmune condition, causing dysregulation of both the immune system and the nervous system. In many parts of the world, it is commonly known as Chronic Fatigue Syndrome. The effects of M.E. are devastating enough to leave 25% of patients housebound or bedbound. 75% of people with M.E. are unable to work.

In spite of the profound individual and social impact of the disease, the NHS has largely ignored the surmounting medical evidence that demonstrates the physiological causes of the symptoms of M.E., instead focusing on therapies that wrongly treat the condition on a psychological basis. This has perpetuated much of the stigma and misunderstanding of M.E., and caused great damage to the 250,000 people in the UK that have the condition. There are currently no approved drug treatments and research investment has been scarce.

*Unrest* shows the profound consequences of this neglect by our public health, medical and research systems on patients and their families, who are left impoverished, often without any support to confront a life-changing illness.

***“My illness has pulled my life from under my feet, literally. It’s stripped away almost all of the things that make me who I am. The lack of awareness about my symptoms meant that I was ill for so long without medical understanding or support from all those around me. My own profession has let me down. Unrest has given me the confidence to say that this is not ok, not for me or anyone else with this condition.” – Ursula Humphreys, Tameside M.E. patient***

*Unrest* also speaks to patients’ incredible resilience and the global social movement they are building to finally end the stigma; and inspires elected officials and policy-makers to think about how they can be stronger allies and support a better future for all.

This Tameside-based event aims to support the campaign by beginning a dialogue locally between patients, the public, clinicians and decision makers. All are invited to work with the event organisers to build the momentum of radical change.

***“Community screenings are a critical part of building the movement to get M.E. the recognition and resources it so badly needs. It will take local communities discussing this disease to change the stigma, spread the word, and create the impetus for concrete change in our lifetime.”- Laurie Jones, Global Director of Impact for Time for Unrest***

It is hoped that this local conversation can spread across the health economy of Greater Manchester – which is the first city-region in the country to receive a £6billion devolution deal

from government for an integrated healthcare system - and begin to reverse NHS cuts that were made to M.E. services. Patients in eight out of the ten Local Authority areas in Greater Manchester have no access to NHS M.E. community nursing and specialist physiotherapy, which is essential for condition management; clinically informed self-care and rehabilitation; and to achieve optimal functioning in the absence of drug treatments. Tameside has fortunately retained this invaluable NHS service.

The debate about equal access to health care and fair medical treatment for M.E. is also to take place in Westminster shortly before Tameside's community event, whereby Jennifer Brea herself will be holding a parliamentary screening of *Unrest* for MP's. Speaking recently on ITV News, Jennifer said:

***“The reality is that we haven't had enough investment in research and in science and patients are often left on their own to try different treatments to see what helps. We're asking Parliament to invest more in research, because that's what we really need to get the best treatments for patients.”*** – Jennifer Brea, Director of *Unrest*

Tameside's community screening therefore is so crucial to give a voice to patients at local level, so that they can also be part of this national - and indeed global - conversation to bring fairness and equality to their lives. Only by having their very serious health condition acknowledged and invested in – in a manner that is at least comparable to other severely disabling diseases – can this be achieved.

To learn more about the film and campaign visit [timeforunrest.org](http://timeforunrest.org) or, on social media, post using **#timeforunrest**

Tameside's community screening will be held at **The Magdalene Centre, Mottram Road, Broadbottom, SK14 6BB**, on **Saturday 18<sup>th</sup> November 2017** at **2.30pm**, followed by Q&A session.

This is a free event but please contact the organisers to reserve your seat.  
Email [unrestscreening@hotmail.com](mailto:unrestscreening@hotmail.com) or Tel. 01457 764 813

**Ends**

## Notes to Editors:

### General Information

1. M.E. is characterised by post-exertional malaise (a severe worsening of symptoms after even minimal exertion).
2. The terms M.E. and Chronic Fatigue Syndrome (CFS) are often used interchangeably. There is a fierce debate about the inappropriateness of the term CFS and the damage it has caused to promoting an accurate understanding of the disease. This issue is covered in the film.
3. The absence of diagnostic testing, unclear treatment guidelines and a lack of medical education means that most doctors find ME difficult to diagnose and patients spend on average five years seeking a diagnosis.
4. ME can be more disabling and is roughly twice as prevalent as multiple sclerosis but has no medical specialty home (patients are often managed within primary care non-specialism).
5. ME patients score more poorly on quality of life surveys than those with multiple sclerosis, stroke, diabetes, renal failure, lung disease, heart failure and various cancers.
6. 75% of patients are left unable to work, costing the British economy £3.3b in lost productivity each year. (See <http://2020health.org/2020health/Press/Latest-News/28-09-19.html> ).
7. An estimated 15-30 million people around the world are suffering from ME.

### Clinical guidance and NHS treatment

1. There are only two treatments recommended by the National Institute of Clinical Excellence's (NICE) standards that inform NHS provision. Both are predicated on the condition being psychological in nature and able to improve through exercise, although have since been clinically discredited and shown to make the condition worse.
2. NICE recommended treatments Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) are based upon the "deconditioning hypothesis", whereby ME patients are thought to have become afraid of movement and so require psychological interventions to help them re-evaluate their belief systems in relation to their M.E; and physical exercise to recondition their muscles. This supposes a psycho-somatic cause of symptoms rather than the presence of a disease state. Physical exercise is shown to worsen the condition.  
See <http://www.meaction.net/wp-content/uploads/2015/05/ME2FCFS-RESEARCH-SUMMARY-Jamie-Seltzer.pdf>
3. Existing NICE guidance is premised upon the findings of the PACE Trial (funded by the Department for Work and Pensions), which has since been discredited, with major methodological flaws uncovered from analysis of the original research data.  
See <http://www.meaction.net/wp-content/uploads/2015/05/ME2FCFS-RESEARCH-SUMMARY-Jamie-Seltzer.pdf>
4. Each clinical guideline should be reviewed every 2-4 years to account for emerging clinical evidence, although CG53 has not been reviewed since it was first published in 2007.
5. More than a decade's worth of medical evidence has emerged since the NICE guideline was written. It very clearly demonstrates the physiological causes of the symptoms of M.E., rendering the existing clinical guidance very much out of date and causing great damage to thousands of patients.

6. NICE announced on 20<sup>th</sup> September 2017 that it would be conducting a review of its Clinical Guideline CG53 “Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (or Encephalopathy): Diagnosis and Management”, published 2007.  
See <https://www.nice.org.uk/news/article/nice-to-begin-review-of-its-guidance-on-the-diagnosis-and-treatment-of-cfs-me>
7. The NICE announcement follows widespread direct campaigning by the ME Association and Time for Unrest.
8. Stakeholder consultation called for the guideline to be broadened in scope to include the aetiology of the disease and in particular identified that the themes of diagnostic criteria; information and support; and recommended treatments should be scrutinised, in conjunction with available medical evidence.  
See <http://www.meassociation.org.uk/2017/09/breaking-news-nice-decides-to-fully-update-its-guideline-on-mecfs-20-september-2017/>

## Medical Evidence

1. Numerous studies demonstrate the presence of a distinct disease state (with interaction with the endocrine system, impaired mitochondrial functioning, the metabolism, microbiome, central nervous system – e.g. see <http://www.meaction.net/wp-content/uploads/2015/05/ME2FCFS-RESEARCH-SUMMARY-Jamie-Seltzer.pdf>) and reduced white matter volumes in the midbrain and right temporal lobe in people with ME (see <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5633338/>)
2. Studies show that at present [without effective treatments], recovery rates are limited and with poor prognosis. See:  
Bombardier & Buchwald. (1995). Outcome and Prognosis of Patients with Chronic Fatigue vs Chronic Fatigue Syndrome.” *JAMA Internal Medicine*. Vol 155(19), pp. 2105-2110.  
<http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/621153>  
Joyce et al. (1997). “The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review.” *QJM: AN International Journal of Medicine*. Vol 90(3). pp.223-233.  
<https://academic.oup.com/qjmed/article/90/3/223/1633580/The-prognosis-of-chronic-fatigue-and-chronic>  
Vercoulen et al. (1996). “Prognosis in chronic fatigue syndrome: a prospective study on the natural course”. *Journal of Neurology, Neurosurgery and Psychiatry*. Vol 60. pp.489-494.  
<http://jnnp.bmj.com/content/60/5/489.short>