THOUSANDS UNITE IN THE UK FOR THE #MILLIONSMISSING

Tuesday 7 May, 2019

Global week to raise awareness for myalgic encephalomyelitis (ME) health equality

For Immediate Release

From 5 to 12 May 2019 hundreds of thousands of people worldwide and in the UK will demonstrate for #MillionsMissing, a global week spearheaded by #MEAction **to highlight the plight of ME sufferers and to call on health officials and governments to end the inequality of funding and research into this debilitating illness.**

The demonstrations will see the lining up of 'empty' shoes of ME sufferers from across the UK, footwear that has been unused and made redundant by this debilitating illness. The powerful and symbolic display of how ME is ruining lives for millions of people in the UK and worldwide will be taking place in over 75 cities across the world. **In the UK, major demonstrations will be taking place in over 30 cities, including London, Glasgow and Sheffield.**

"This is about more than a disease. This is a social justice issue. We are fighting for the research funding and medical education we need to stop this epidemic. We are fighting for our lives." – Jennifer Brea, co-founder of #MEAction, and director of the award-winning *documentary, Unrest.*

In the UK, **the #MillionsMissing campaign will focus on demanding increased funding for biomedical research into the diagnosis and treatment of ME**. From 2006-2015 ME had £4 per patient per year spent on research funding, a small percentage of which had a biomedical focus. In comparison, MS patients had £80 per patient per year. Funding for ME must reflect the impact and severity of this disease.

In a recent House of Commons debate, over 40 MPs unanimously passed a motion that called for increased funding for biomedical research, the suspension of Graded Exercise Therapy and Cognitive Behavioural Therapy as treatments for the disease, updated training for medical professionals and to protect ME families from unjustified child protection procedures.

Carol Monaghan MP, who led the ME debates in Parliament, says:

"During my first election campaign in 2015, I visited a constituent at home who had been living with ME for over 30 years. I knew very little about ME and I considered it to be a condition that simply made a person tired. I suppose this is typical; unless an individual has personal experience of ME, it remains very much an unknown condition. As a result, at the moment there is a woeful lack of awareness and of quality medical research into ME. If things are to improve, it is important that the causes, diagnosis and treatment are fully investigated."

Belle and Sebastian singer, Stuart Murdoch, who has had ME for 28 years, talks about ME:

"Explain it to me? Why so little funding, for so many people, in so much pain? Just tell me the reason, and I'll retract my question. Tell me why we aren't as deserving as other citizens who have equally debilitating conditions? We just want to know."

Rachel Elliott describes the impact that Graded Exercise Therapy (GET) had on her young daughter:

"As a teenager, my daughter, Cherry, dutifully followed her doctor's recommendations for Graded Exercise Therapy for her diagnosis of ME. Unfortunately this, and later the Lightning Process, encouraged her to push her system beyond safe limits with the catastrophic negative effects only emerging over a period of months. Now 21, Cherry is 100% bedbound in a darkened, silent room and fed by a tube."

About Myalgic Encephalomyelitis (ME):

Myalgic Encephalomyelitis (ME) is a chronic, debilitating, multi-system disease that affects approximately 250,000 men, women and children of all ethnicities, ages, and genders in the UK.

Media:





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Scan Me:

Learn more here: www.meaction.net

About ME Factsheet: http://bit.ly/MEFactsheet

About #MillionsMissing:

#MillionsMissing is being spearheaded by #MEAction, an international network of patients and allies empowering each other to fight for health equality for ME.

Learn more here: http://millionsmissing.org

CASE STUDIES AND PRESS CONTACT #MILLIONSMISSING UK

Please contact #MEAction's UK coordinator Espe Moreno for case studies and interview opportunities:

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#MEAction press kit: https://www.meaction.net/tools/press-kit/

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