

## **FOR IMMEDIATE RELEASE**

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### **ME/CFS Awareness Rally-Sacramento #MillionsMissing and Shoe Exhibit at the California State Capitol**

Sacramento, CA- Patients, family members and supporters rally together at the California State Capitol steps on Friday, June 2, 2017. This rally of action is preceded by the recent unanimous passing of State Senate bill SCR 40, declaring May ME/CFS Awareness Month in California, the 6<sup>th</sup> state to do so. The Assembly, with an anticipated unanimous passing vote, is next.

The local cities of West Sacramento, Elk Grove and Sacramento passed proclamations last year to recognize of May 12<sup>th</sup> as ME/CFS Awareness Day. For the past two years the Sacramento has lit city buildings in blue and the Sacramento Convention Center's marquee has been lit declaring May 12<sup>th</sup> as ME/CFS Awareness Day.

Proposed reductions to scientific programs (such as the elimination of the Prevention and Public Health Fund or the proposed \$6 billion NIH budget cut in FY 2018), threaten critical medical research, especially in regards to ME/CFS. ME/CFS has historically been in the bottom 4% of diseases funded by the NIH, which is alarming as ME/CFS affects more people than HIV/AIDS and Multiple Sclerosis combined. The mission of ME/CFS Awareness Rally is to raise awareness about ME/CFS, garner support to find a cure, and fight to preserve and grow the few federal ME/CFS research programs still in existence.

The symptoms of ME/CFS include unrelenting physical and mental fatigue, post-exertional malaise, debilitating pain, cognitive and sleep dysfunction and severe immune abnormalities. The economic impact of ME/CFS is catastrophic. The costs due to job loss, disability, medications and medical services for as many as 2.5 American million patients and their families is estimated to cost society \$17 to 24 billion annually. Without funding for research diagnosis and effective treatment, these costs have a significant, long-term impact in the U.S.

**Shoe Exhibit:** Lawn of the California Capitol Steps (South Side) 10:30 am-4:00pm

Shoes of patients from across the US and other countries will be on display with patients' moving and heart wrenching stories attached. Stories will include what patients are missing from their lives due to this debilitating disease. This display will represent a small percentage of the millions missing from their lives.

**Rally-**California Capitol Steps (South Side) 11:30am-1:30pm

## Speakers-

- **Dr. Eric Hassid**-neurologist, founder and medical director of the Institute for Restorative Health
- **Courtney Miller**: Board of Directors of Simmaron Research
- **Teresa Gerringer**: District Director for Senator Glazer, will read a statement from Senator Glazer
- **Marilyn Simon-Gersuk**: Director of Communications & Development of Open Medicine Foundation (OMF)
- **Emily Taylor**: Director of Advocacy and Public Relations of Solve ME/CFS Initiative
- **Mark Carmenzind**: advocate and father/caregiver of Tom Carmenzind who is severely ill from ME/CFS
- **Terry Gilmete**: local ME/CFS patient/advocate for over 30 years
- **Marilyn Yu**: ME/CFS patient/advocate and member of local California Capital CFIDS

## Potential Speakers/Apearances/statements-

- **Senator Ted Lieu**
- **Dr. Janet Dafoe**-son, Whitney Dafoe, is severely affected by ME/CFS and husband Dr. Ronald Davis, Director of the Stanford Genome Technology Center at Stanford University, is diligently trying to find a cure

## Performing-

- **Michael and Marissa Jasper**: local jazz musicians performing recently released "Beachwalk" for ME/CFS Awareness

## ABOUT THE ORGANIZATIONS:

The **Open Medicine Foundation (OMF)** is spearheading chronic complex disease research that follows patterns of success and benefits from collaborating with leading scientists and clinicians from around the globe. These experts bring to our foundation their expertise in immunology, virology, genomics, informatics, molecular biology, epidemiology, infectious disease, oncology, pathology, and clinical medicine. The current focus is on ME/CFS (myalgic encephalomyelitis / chronic fatigue syndrome / systemic exertion intolerance disease), with the expectation that discoveries in this disease will bring answers to other diseases that share some of the symptoms (such as [fibromyalgia](#) and [Lyme disease](#)).

**Simmaron Research, Inc.** is a Nevada-based nonprofit organization dedicated to advancing scientific research, potentially leading to the discovery of diagnostic markers

and effective treatments that will ultimately improve the quality of life for people suffering from CFS/ME and related neuroimmune disorders.

The **Solve ME/CFS Initiative** is the leading national organization exclusively dedicated to biomedical research and federal policy work for ME/CFS. SMCI envisions a world free of ME/CFS and works steadfastly to make this disease understood, diagnosable, and treatable. SMCI is the only ME/CFS organization with a 4-star rating from Charity Navigator, America's largest independent charity evaluator.

The **California Capital CFIDS Association (CCCA)** provides emotional support, referrals and advice to those with the illness, their families and friends primarily in the greater Sacramento metropolitan area in Northern California.

The primary purpose of the CCCA is to provide information to the public and medical community concerning all aspects of this illness. Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) is also known as Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME), and Chronic Epstein-Barr Virus (CEBV).

**#MEAction** is an international network of patients empowering each other to fight for health equality for Myalgic Encephalomyelitis aka ME/CFS. #MEAction is a grassroots organization and platform designed to empower patients advocates and organizations, wherever they might

**Institute of Restorative Health** Dr. Eric Hassid, M.D., is one of only a few Functional Neurologists in the United States. Individuals who come to IRH for neurological treatment benefit from an approach that looks at how all the body's systems interact to create health or disease (such as ME/CFS)

## Contacts

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