**FOR IMMEDIATE RELEASE**

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**A PRESENTATION OF BOOKS RELATED TO MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME (ME/CFS) WILL BE MADE TO THE DANIEL ISLAND LIBRARY TO RAISE AWARENESS ABOUT THE DISEASE**

DANIEL ISLAND, SC — May has been declared Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Awareness Month and May 12, 2021 as ME/CFS Awareness Day pursuant to the State Concurrent Resolution S.0673 and a City of Charleston Proclamation. To celebrate these legislative achievements and honor the many South Carolinians who suffer with ME/CFS, a collection of books related to the disease will be presented to the Daniel Island Branch of the Berkeley County Library System. The presentation will be made by Robert Jacobs, MD and joined by family, friends, and others with ME/CFS. Dr. Jacobs is a retired Physician, caregiver for his wife who has had ME/CFS for more than 10 years and advocate for ME/CFS serving on the Community Advisory Council for Sole ME, one of the premier ME/CFS advocacy organizations. According to Dr. Jacobs, despite the historical, tourism and quality of life allure of this beautiful state, there is a paucity of medical care available to patients with ME/CFS, minimal medical awareness and essentially no research activity. Around the globe and here in South Carolina, ME/CFS patients are fighting for their lives with a surprising lack of awareness by the medical community.

**WHO:** Robert Jacobs, MD, Sandra Jacobs, friends, and others with ME/CFS.

**WHAT:** Presentation of books to raise awareness about ME/CFS and the many thousands of individuals suffering with the disease.

**WHEN:** Tuesday, May 11, 2021 at 10:30 AM

**WHERE:** The Daniel Island Library, 2301 Daniel Island Drive, Daniel Island, SC 29492

**Additional information**

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a severe, chronic neuro-immune disease manifest by dysfunction of the neurological, immune, endocrine and energy metabolism systems. There are no available diagnostic tests, no FDA-approved treatments and no cure. ME affects 16 to 39 thousand SC residents, up to 2.5 million Americans and 17-20 million worldwide. Despite its prevalence, ME/CFS has long lived in the shadows and has been stigmatized as a psychogenic illness, with those afflicted viewed as lazy or malingering rather than having a serious medical disease.

All of this changed in 2015 when the Institute of Medicine, now the National Academy of Medicine, declared that “ME/CFS is a serious, chronic, complex, systemic disease that can profoundly affect the lives of patients.” And according to Dr. Francis S. Collins, Director of the National Institutes of Health, “Of the many mysterious illnesses that science has yet to unravel, ME/CFS has proven to be one of the most challenging.”

We are currently facing a unique opportunity to better understand ME/CFS and that is related to COVID. An estimated 25–35% of COVID-19 patients develop an array of chronic symptoms after their acute illness and evidence of infection have cleared. This is now commonly called Long COVID. Many Long COVID patients develop an illness that is strikingly similar to ME/CFS, an observation made by Dr. Anthony Fauci as far back as June of 2020. In addition, about 80% of ME/CFS patients, numbering as many as 2.5 million Americans, develop their illness following a viral infection. Therefore, a better understanding of Long-COVID through ongoing research will likely enhance the understanding of and development of treatments and cures for ME/CFS and other post-viral diseases.

Securing both a State Resolution and City Proclamation to raise awareness about the lack of health equity for ME/CFS patients was a grassroots effort by family and friends of people with ME/CFS.

Important facts:

* ME/CFS affects an estimated 1 to 2.5 million American children and adults of all races.
* The number of Long COVID patients with chronic ME/CFS symptoms is projected to be at least 3.2 million, more than doubling the ME/CFS disease burden.
* 75 percent of ME/CFS patients are women.
* There is no diagnostic test, no FDA-approved treatment and no cure.
* At least 25% of ME/CFS patients are home- or bed-bound at some point in their lives. Many are unemployed or have reduced productivity.
* People with ME/CFS have a lower quality of life and more functional impairment than those with other disabling illnesses such as multiple sclerosis, heart disease, and end-stage renal disease.
* Symptoms typically persist for years and recovery is the exception.
* An estimated 84-91% of ME/CFS patients are not yet diagnosed or have been misdiagnosed.
* ME/CFS costs our economy $17- $24 billion annually in lost productivity and direct medical costs.
* Clinical care and medical education are in a crisis with fewer than 12 clinics in the US that treat ME/CFS patients. Few physicians have received training about how to treat ME and, consequently, often recommend treatments that exacerbate symptoms.
* ME/CFS has been in the bottom 5% of NIH funding for decades, typically less than $6 million a year.
* The 2015 Institute of Medicine (now the National Academy of Sciences) report noted the essential need for more research, observing that “remarkably little research funding has been made available ...especially given the number of people afflicted.”

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