

Experts Launch Think Tank for Mystery Disease

Ten leading scientists in Europe have formed a Think Tank for ME and will hold their first meeting on the 13th of June. They want to initiate an effective research effort to find the secret behind the mystery disease that cripples an increasing number of lives.

Myalgic Encephalomyelitis, often referred to as Chronic Fatigue Syndrome (CFS), is a disease which affects at least one million individuals in the US, and an even greater number in Europe. Despite the large number of people affected, there is a lack of serious large-scale research initiatives focused on the disease. The number of patients is rapidly increasing but healthcare personnel lack knowledge about existing research and possible treatments.

Last year's winner of the Nobel Prize in Medicine, Professor Luc Montagnier of France, says, "Scientists have already uncovered a lot about ME, but this information does not reach professional healthcare personnel, and the disease is still not taken seriously. It is about time this changes." Montagnier, one of the discoverers of the HIV-virus, is a supporter of the Think Tank, but is unable to join the first meeting due to his demanding schedule.

Treatable Disease

Ten internationally recognized scientists, many of them prominent leaders in their respective fields of research, have decided to do something about it. They have come together in a Think Tank to promote cooperation among scientists from various disciplines and to stimulate intense focus on innovative and creative research. The first meeting is set in Stavanger, Norway on the 13th of June.

"There are more than 5000 research papers which show that ME has an organic basis with abnormalities in the immune, nervous and gastrointestinal systems and that it is influenced by genetic and environmental factors," states Professor Kenny De Meirleir of Belgium. "Despite these findings, it has been close to impossible to initiate large-scale research to verify these facts and observations. We will never be able to treat ME properly if we do not initiate this type of research."

Using new biotechnological techniques, much of the underlying pathophysiology of the disease has been unmasked. Several treatable clinical entities have been discovered, but this information does not reach healthcare personnel. The result is that patients remain undiagnosed and untreated for years with something that might be fully treatable. This is a huge drain on the economy, as the estimated socio-economic costs for Europe are estimated to be €20 billion annually.

Educate Professionals

An important part of the Think Tank's mission is to spread knowledge about the disease. The incidence of ME and the impact on public health are actually higher than that of other better researched conditions like Multiple Sclerosis and HIV. Research shows that ME can be a very disabling chronic disorder which often diminishes patients' quality of life to levels lower than that of cancer, MS, HIV and lupus.

Professor Ola Didrik Saugstad of Norway states, "There is a total lack of knowledge and understanding about this disease in the healthcare system. We wish to use our knowledge to educate and train doctors, therapists and other healthcare personnel so they can better understand how to manage an ME-patient."

New in ME

The Think Tank meetings are the brainchild of a new organization, European Society for ME (ESME). This society will focus on organizing research and educating professionals in the field of ME.

"Until now ME organizations have been patient-based and only focused on the needs of the patients, so this is something completely new and unique. We are a group of professionals who want to stimulate new research in the field of ME and to help doctors and healthcare personnel to stay informed about the latest developments in diagnosing and treating ME-patients," says ESME board member Mrs. Catherine Miller-Duhen.

Press Conference
The first Think Tank meeting will be held in Stavanger, Norway on the 13th of June. This will be immediately followed by a press conference where the specialists will be available for comments and interviews.
On Friday the 12th of June, a conference will be held to train healthcare personnel in the diagnosis and treatment of ME-patients.

Press conference: Saturday 13th of June, 4 pm, Press room, Clarion Hotel Stavanger, Stavanger, Norway. To register for the press conference and ensure receipt of a press packet, please send an email to Rebecca Hansen at: icerebel62@hotmail.com

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Attachments:

Program "ME Conference for Healthcare Personnel", Stavanger, Norway, Friday 12th of June.
Panel list ESME board
Press release

