

ME/cvs Vereniging - de organisatie van de patiënten zelf -

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World Wide Newsletter 1 - September 2013

This is a first and feeble attempt to come to an international platform where activities of ME/cfs-support groups can be shared all over the world.

Without the cooperation of all of you, it will not become a success. So please share anything worthwhile sharing by mailing it to contact@me-cvsvereniging.nl, and we will incorporate it in the next WWN, which is bound to appear about October 10th.

It is our firm conviction that chances of recognition of ME/cfs as a severe, neuro-immune disease are much higher when we support each other all over the world, as national governments tend to isolate national patients and support-groups in order to postpone recognition of ME/cfs as such, to prevent large expenses on care and social insurances.

Our government subsidized project Science to Patients started with mailing the first two talks of prof. K. de Meirleir, subtitled by ourselves, to as many groups as possible all over the world less than one year ago. Within this year the published videos have been watched over 64.000 times. It gives us an excellent opportunity to come in contact with all of you, and we already received a lot of enthusiastic reactions, for which we thank you profoundly.

Now let's build on, and move to the next step... share, share and share. Let's make one big fist, all over the planet....

With the friendliest regards,

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Australia

Medical Expert Seminar: M.E/CFS/Fibromyalgia - Sat 21st September

EXPERT Medical Seminar - Sat 21st September - Melbourne: 10.30am - 1.00pm. The Alfred Hospital, Prahran.

ME/CFS Australia (VicTasNT) is thrilled to have International ME/CFS expert - Professor Michael Maes; prolific writer, researcher and practicing psychiatrist and National ME/CFS expert Dr Nicole Phillips; medical writer, advisor, and practicing psychiatrist present to the Melbourne community including members, medical practitioners, allied health practitioners and the general public on Myalgic Encephalomyelitis/chronic fatigue syndrome/fibromyalgia.

This seminar challenges the commonly held view of ME/CFS as a psychosomatic disorder. We encourage health practitioners to take this opportunity and attend this cutting edge seminar.

Dr. Maes holds over 12 appointments worldwide across Schools of Medicine, Psychiatry, Hospitals and Research Clinics for his work with the phenomenological and epidemiological aspects of mood disorders (e.g. depression, panic disorder, post-traumatic stress disorder, ME/CFS) and the supra-multi-disciplinary field of “pathway and drug discovery processes” in depression, mania, anxiety disorders, stress and schizophrenia, ME/CFS and more particularly the immune-inflammatory pathways and its connections and sequels. He has published more than 550 scientific papers worldwide.

Dr Nicole Phillips is a private psychiatrist in Armadale, Melbourne. Nicole’s interest in womens mental health led to her to establish an innovative psychiatry referral service at the Mercy Hospital for Women, and work for some years in the hospital’s mother-baby unit for post-natal depression. She has had a 25-year interest in Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and from 2001 to 2013 was medical advisor to ME/CFS Australia (Victoria) and medical editor of its quarterly journal, Emerge. She is a passionate educator and regularly speaks to medical professionals, ME/CFS sufferers and the general community. She has many publications to her name. In 2008 and again in 2013, Nicole was honored with an award presented by the Governor of Victoria for her work with ME/CFS Australia (Victoria).

Information: <http://www.mecfs-vic.org.au/medical-expert-seminar-mecfsfibromyalgia-sat-21st-september>

Belgium

WUCB, the Wake-up Call Movement Belgium, organizes an event where as many people as possible will assemble in front of the building of the RIZIV, the governmental institute of health- & invalidity insurance in Brussels.

A troupe will playfully perform a medical inspection. Two large banners and a huge transfer will be attached on, in front of or above the main entrance of the RIZIV, with the text ‘crime scene- do not cross’. Moreover a delegation of the WUCB will hand over their complaints about the RIZIV, receiving a large amount of mails of desperate ME/cfs & fibromyalgia-patients, who have lost their allowances because their recognition as disabled has been withdrawn.

Participants have the opportunity to be transferred to Brussels by two hired buses. The action takes place on September 26th, from 13.00-16.30 pm.

Moreover people who can't participate are invited to send an empty box to the RIZIV on September 23rd or 24th, containing a letter in which patients return their diagnosis to sender, as it proved to be an empty box.

Information: <http://www.wakeupcallbeweging.be/>

The Netherlands

Group ME Den Haag

In the fall of 2011 an independent group of 10 Dutch ME/cfs patients started to collect signatures in order to hand over a petition to the government. If 40.000+ are collected, and they do meet the demands the law imposes on them, the government is obliged to discuss the subject. With this initiative the government is asked to recognize the disease Myalgic Encephalomyelitis (ME) as a debilitating biomedical disease.

On September 10th 2013 the initiative has been presented to the press with a round table conference. Several experts, journalists, politicians and a number of stakeholders did participate. During the conversation the citizens' initiative, the current, unwanted, situation for ME patients and how the 'Groep ME Den Haag' envisions the future for ME patients has been discussed.

Many foreign ME experts, such as Prof. dr. A. Komaroff (Harvard), Prof. dr. L. Jason (DePaul University) and Prof. dr. M. Lerner (Wayne State University) as well as tv-host Llewellyn King, have supported the initiative by adhesion statements. Also the three largest Dutch patient organisations (ME/ CVS Stichting Netherlands, ME/cvs Vereniging and the Support group ME and disability) have declared to support this initiative.

The actual handing over of 53.000 collected signatures will take place during the first or second week of October. The Group hopes this event will be covered by a lot of press and tv-stations.

Information: <http://www.deziekteme.nl/>

Three main organizations join forces

A large insurance company didn't prolong its contract with the Dutch cardiologist prof. Frans Visser, who will also give six short talks in the project Science to Patients. Prof. Visser is one of the extremely rare medical practitioners who has expertise in ME, especially in POTS and orthostatic intolerance.

In the Netherlands there are three large patient's associations. This was caused by the fact cfs having been coined to ME in the late 80s. There has been a considerable schism during the last 10 years, at the advantage of institutions and the government who coerce ME/cfs patients into CBT and GET.

On this occasion all three associations did agree to cooperate in a protest against the insurance company concerned. This may prove to be a historic event. When forces will be joined in the future as well, it may have a considerable impact on the fight for the rights of ME/cfs patients in Holland.

