

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

ME/cvs Vereniging
4^e Hambaken 89
5231 TX Den Bosch

073-6425864
contact@me-cvsvereniging.nl
www.me-cvsvereniging.nl

Kvk: 32108065
Rekeningnr: 4286957

Den Bosch, the Netherlands.
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World Wide Newsletter 2- October 2013

This is the second Newsletter accompanying filmed talks of scientists, well-versed in ME/cfs.

As pointed out in the first one of Sept. 2010, the Dutch government subsidized project Science to Patients started with mailing the first two talks in Dutch of prof. K. de Meirleir, less than one year ago. Within this year the published videos have been watched nearly 70.000 times. This includes the talks with English subtitles which we started mailing at the beginning of this year. 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.

Several patients-groups and scientists have reacted in conveying to us that this is an excellent occasion to share news which is of interest to all of us, and are now actively participating. Hopefully more of you will join, so as to make this a wonderful, common, worldwide experience.

So here we proudly present the second issue, with news from more sources than in the first one.

Please do remind that while sharing yours the knife is cutting at both edges: you have an opportunity to share and you help to continue this initiative. Do send us anything which you think worth knowing.

Next issue will be sent November 21st, so kindly send us your contributions a few days before that date. Enjoy this issue and the talks.

In case you didn't receive the first issue of this Newsletter, kindly let us know and we'll send it as soon as possible. Newsletter # 3 will be issued on November 21st.

With the friendliest regards,

Group Science to Patients
ME/cvs Vereniging Nederland
[contact@me-cvsvereniging.n](mailto:contact@me-cvsvereniging.nl)
+31 73 6425864

Overall

To our opinion the hottest news these days has been the letter sent to the USA Secretary of Health Mrs. Kathleen Sebelius, requesting her to recognize the CCC of 2003 as a tool for research, clinic practice and recognition of ME/cfs, instead of the Fukuda criteria of 1994.

Regardless Mrs. Sebelius' reaction, it is the first time top-scientists on ME/cfs are on the same page, about a most vital issue as well. We can't express enough gratitude for the effort they undertook to take such an important and hopeful step.

That's why we recommend to share and sign the links to the petition to support their requests to Mrs. Sebelius and in fact the US government:

<http://www.thepetitionsite.com/255/349/958/fatigue-is-not-a-disease/>
https://secure.avaaz.org/en/petition/Stop_the_HHSIOM_contract_and_accept_the_CCC_definition_of_ME/?fbdm
<http://www.thepetitionsite.com/898/238/310/thank-you-to-mecfs-experts/>

The letter itself is to be read via the link

<https://dl.dropboxusercontent.com/u/89158245/Case%20Definition%20Letter%20Sept%202023%202013.pdf>

Please share this information with as many groups and persons you're able to. Time for lingering recognition of this horrendous disease should be over now.

Belgium

WUCB, the Wake-up Call Movement Belgium, organized an event where about 40 patients suffering from ME/cfs assembled and protested in front of the headquarters of the RIZIV at Brussels, on September 26th. RIZIV is the Belgian public service of social security and is among others responsible for the decision whether allowances are granted or not.

The WUCB is a patient organization of Belgian ME/cfs and fibromyalgia-patients, and is very active, especially in the political field.

During the last year the WUCB received numerous mails from desperate patients who lost their disablement insurance. It is obvious that the RIZIV tries to cut down expenses by suspending patients systematically, thus rejecting their recognition as disabled ones. Consequently a lot of vulnerable persons are being driven into intolerable situations.

The activists presented on the 26th performed a medical inspection as a "performance". Such inspections most often are very humiliating and without any consideration for the patients. In the meantime a delegation of the WUCB was received by leading officials of the RIZIV, to whom they presented their requests.

People at home, not being able to join the event, could join the action by sending an empty box with a letter, wording their rejection of their CFS and/or fibromyalgia diagnosis, the box thus symbolizing its worthlessness.

Yet it is the cause of their misery and problems.

The WUCB also disagrees with the new RIZIV measures with the false promise to compensate psychological and psychiatric consultations (CBT/GET). The measure simply doesn't hold truth,

and shall only be applied to new patients, with a refund for maximum 1100 patients a year. Those who are suffering from ME/cfs or fibromyalgia for a long time and are seriously debilitated, are not being helped by this measures.

The WUCB demands from the government to take measures which do help all patients. Further negotiations will be held in the near future.

Italy

CFS Italian Association www.stanchezzacronica.it was established in Udine in 1991 and later settled in Aviano at the at the Oncological Division of the Cancer Research Hospital. Prof. Umberto Tirelli is the director of the department and the first physician in Italy to study the Chronic Fatigue Syndrome www.umbertotirelli.it. Under his direction many studies have been accomplished and published and several international meetings have been organized. In Northern Italy, the next scheduled meeting will have been held in Mestre – Venice on 4th October. Title: Continuing Medical Education CFS Chronic fatigue syndrome. A pediatric pathology also - Training course for pediatricians.

At the institute there is a weekly out-patients clinic. Hundreds of CFS cases have been diagnosed in our country, however patients have no possibility to have their illness recognized by the health system. In fact, through the National Institute of Health we are trying to have CFS recognized as a formal illness, however we realize that this is a difficult task. In Italy as well CFS patients started to collect signatures in order to hand over a petition to the government.

Agenas (L'Agencia nazionale per i servizi sanitari regionali) coordinated by the Institute of Health will publish in the near future the Italian guidelines for diagnosis and treatment of CFS. For our Nation this is a big step forward.

The main goals of our association are:

- create awareness of the severity and widespread nature of the illness
- create awareness that CFS is a debilitating disease
- offer support, understanding and friendship to those who are affected by CFS and their family member, as they are often isolated and have to fight against the unbelief they meet
- stimulate discussion and subsequent knowledge of CFS
- increase knowledge among medical personnel, educationalists, employers, politicians, society in general
- promote national and international research meetings.

C.F.S. Associazione Italiana Sindrome da Stanchezza Cronica ONLUS

Centro di Riferimento Oncologico Istituto di Ricovero e Cura a Carattere Scientifico

V. F. Gallini, 233081 Aviano – Pordenone (Italy) tel. +39-0434-659394

cfs@cro.it - www.stanchezzacronica.it



The Netherlands

Maartje

Meet Maartje Slot, a captivating young lady with a rather severe form of ME/cfs, and her life-companions Nelson the Dog and Iep the Cat. They're just three of a kind, inseparable friends through thick and thin as we call it in Holland. You might call it for better and for worse.

Maartje is most of the time bedridden, although she has a few days off and on when her body allows her to take a short outing in her Maartmobile, a 45 km/hour vehicle in which she's visiting pastures and animals of the beautiful Frisian countryside.

She's gifted with an extreme sense for language, words and imagery, and on her fb-wall and in her blogs captures and enchants scores of fellow-sufferers, touching their hearts and stirring their souls.

To honor the friendship between Iep and Nelson, she posted a beautiful short film on October 8th, with the introduction:

**"For as long as I can remember
In my most sacred conversations
Not a word was spoken"**

Here's the link to the short film she made, accompanied by the most beautiful piano performance:

<http://youtu.be/rtO4ew15rel>

Enjoy and let go.

USA

The Clinical Systems Biology Lab (previously with the University of Alberta, now also with Nova Southeastern University) of prof. Gordon Broderick is in very close collaboration with Dr. Klimas, the Executive Director and Founder of the Institute for Neuro-Immune Medicine (INIM) at Nova Southeastern University as well as Dr. Mary Ann Fletcher, Director of the Clinical Immunology Lab at INIM (she was with the University of Miami but has now joined all of us at Nova INIM).

Right now they are especially interested in differences iME/CFS between sexes. They recently published a first comparison of men and women diagnosed with CFS and Gulf War Illness.

<http://www.biomedcentral.com/1471-2172/14/29>

They have also recently submitted a paper to PLoS One with another member of the INIM team, Dr. Travis Craddock. This work is currently under review - this paper examines the basic physiological reasons why immune disorders of this type may present differently in men vs women. The paper is not yet available online but they discuss the approach briefly during a recent talk (see minute 23:30 up to 30:15):

<http://www.nova.edu/promo.html?id=cfsmegwi?video=oit/nim/cfsme/gwi-consortium.mp4?title=CFS/ME%20and%20Gulf%20War%20Illness%20Patient%20Conference%202013&subtitle=Introducing%20the%20new%20GWI%20Consortium>

Please do not be distracted by the math. The basic theme is the interaction between immune function and the regulation of stress and sex hormones. This interplay they feel is a key component of the illness. Perhaps of greater interest to the readership is that this work is beginning to point to therapeutic targets and they now have under review several grants submitted to government and private foundations to support some initial clinical trials.

Prof. Gordon Broderick as well prof. Nancy Klimas have agreed to cooperate with our project Science to Patients. Most likely somewhere during 2014 short talks of both of them will be filmed on location.

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The Blue Ribbon: ME/CFS and the Future of Medicine is a documentary film currently in production in the United States. It will feature interviews with world ME/cfs experts such as Dan Peterson, Andy Kogelnik, Chris Snell, Staci Stevens, Nancy Klimas and others.

Its thesis comes from a recent talk by Andy Kogelnik suggesting that “medicine is at a crossroads”; indeed revolutions in genomics, proteomics, and epigenetics will change the way we understand not just ME/cfs but the nature of medicine and disease itself.

The filmmakers plan to show a range of ME/cfs patients from across the spectrum of severity. ***The Blue Ribbon*** will rally researchers, journalists, advocates, and policymakers around a simple and clear moral purpose: “*We vanquished polio. We tamed AIDS. Meet the last great disease to conquer.*”

The goal is to equip groups to stage 300 screenings of the film each year across the world, changing the global conversation one community at a time. The filmmakers will furnish an Event Planning Guide and Press Kit to help local groups stage screenings of the film that are well advertised, publicized, and attended.

The filmmakers have raised about \$24,000 so far but are still raising capital to fuel the ongoing production. Donors who give \$1,000 will receive “Producer” credit; donors who give \$2,500 will be listed as “Senior Producer”; finally, donors who give \$5,000 are “Major Funders.”

For more information, please visit www.mecfsdocumentary.com or follow the production on Facebook at www.facebook.com/cfsdocumentary.

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OMI-The Open Medicine Institute

The HLA DNA study is almost done and we hope to have initial results by early next year!!

We have a lot going on and hope to report more very soon.

We are working hard on increasing our database for ME/CFS, Borrelia (Lyme) and Fibromyalgia in order to unite the neuro-immune groups together as one for research purposes.

More to come...

www.openmedicineinstitute.org