

Worldwide newsletter 3

November 2013

Dear reader,

This is already the third issue of the international Newsletter, which we send to all patient associations known to us, doctors specialized in ME and researchers all over the world. Our Newsletter is always accompanied by links to two short webinars about ME, provided with English subtitles, including the transcripts.

If you have information about ME that you want to share, we ask you to mail us your input by 10 December, seeing Newsletter #4 will be sent on 12 December.

The idea behind this newsletter is that only by worldwide solidarity and making one, united fist, recognition of ME as a biomedical disease will advance in more countries. We hope that this newsletter contributes to a domino effect in this regard.

We also would like your comments on the contents of the newsletter. Or maybe you would even like to strengthen our editorial team?

For information you can contact us at contact@me-cvsvereniging.nl, attn. Rob Wijbenga.

As of 28 January 2014, the Newsletter will be sent every four weeks, that is, if there will be enough material. That's (also) up to you.....

On behalf of the project Science for Patients and the ME/cvs Vereniging Nederland, I wish you the very best for the new year,

Rob Wijbenga
Chair to the ME/cvs Vereniging Nederland
Coordinator project Science to Patients

Denmark

Here is some information about Karina Hansen who is a severe ME patient in Denmark. She was committed to Hammel Neurocenter on February 12, 2013 against her will for treatment that could be detrimental to her health. In Denmark ME is considered a functional disorder called bodily distress syndrome and the treatment is cognitive behavioral therapy, graded exercise therapy, and possibly anti-depressants. I am one of the managers for the Facebook page Justice for Karina Hansen [.https://www.facebook.com/JusticeForKarinaHansen](https://www.facebook.com/JusticeForKarinaHansen) We have begun petitions to help Karina.

Petition 1 - <http://tinyurl.com/au3c7t4>

Petition 2 - <http://tinyurl.com/p55nxdp>

Petition 3 - http://www.avaaz.org/en/petition/Justice_for_Karina_Hansen/?copy

We are providing updates on our Facebook page so please like us to stay up-to-date. Please also see the links below for more information on Karina Hansen.

Thank you for taking the time to read this!

For more information :

<http://dxrevisionwatch.com/2013/05/11/something-rotten-in-the-state-of-denmark-karina-hansens-story/>

<http://dxrevisionwatch.com/2013/05/...hing-rotten-in-the-state-of-denmark-update-1/>

Source: Phoenix Rising

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Great-Britain

Still the most beautiful, intriguing and touching documentary to be seen, as actual as ever, Voices from the Shadows, made by Josh Biggs and Natalie Boulton. Following the lives of Linda, Sophia, Lynn and Naomi, all severely stricken by ME, with comments of Leonard Jason, Malcolm Hooper and Nigel Speight.

I think the film was powerful and it should be actually part of medical curricula in medical schools in the US... (it) shows how medical arrogance combined with narrow vision knowledge can be so toxic and can bring more suffering to a group of patients that are already suffering at deep levels.

Dr. Montoya

Available in plain English, as well as with subtitles in German, Italian, French, English, Dutch, Czech, Swedish, Spanish and Japanese.

<http://voicesfromtheshadowsfilm.co.uk/>

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The Netherlands

ICC/ICP

After quite a long trail starting with non-professional translations immediately after the release of the ICC during the summer of 2011, finally in close cooperation with Mrs. Marj van de Sande an official Dutch translation of both the ICC and its ICP has been effectuated by the Dutch ME/cvs Association, the Support group ME and disability and the Groep MEDenHaag.

The three organizations hope this publication will be a great tool in informing GP's and other health care workers about ME/cfs. There's already a considerable demand for the two publications, as they provide a good source of support in conversations with GP's and specialists.

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Dutch patients raise 54.000 signatures for recognition of ME as an neuro-immune disease

On 29 October a group of Dutch ME patients handed over 54.000 signatures to representatives of the parliament of the Netherlands. This was far more than the needed 40.000 signatures for the submission of a citizens' initiative.

In the Netherlands the parliament has to discuss a subject when it is the wish of more than 40.000 citizens, confirmed by their signatures. With this initiative the government is asked to recognize the disease Myalgic Encephalomyelitis (ME) as a debilitating biomedical disease.



Lawyer of the group handing over the citizens' initiative to a representative of parliament.

The petition was initiated by Groep ME-Den Haag (Group ME The Hague, The Hague being the seat of Dutch parliament), a group founded for the occasion and consisting of ten home- and bedbound ME patients. Two years ago they started collecting signatures. A lot of volunteers have contributed to get the required number of signatures of at least 40,000. Many Dutch celebrities and politicians have signed the petition. Foreign ME experts, such as Prof. dr. A. Komaroff (Harvard), Prof. dr. L. Jason (DePaul University) and Prof. dr. M. Lerner (Wayne State University), have supported the initiative by adhesion statements. Also the three main Dutch patient organizations (ME/CVS Foundation Netherlands, ME/cvs Association and the Support group ME and disability) have declared to support this initiative.

Groep ME-Den Haag is hoping to convince politicians and the medical field with this initiative that something has to change urgently. Currently ME-patients often don't receive a proper diagnosis and appropriate care. They also need to fight for financial support, useful medical devices (like wheelchairs) and home care.

In the Netherlands, like in other countries, ME is still seen as a psychosomatic disease and treated likewise, with Cognitive Behavioral Therapy (CBT) and gradual exercise therapy.

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Sweden/USA

This link is an excellent presentation by Dr. Dan Peterson speaking Oct 16th to members of the Swedish Parliament about ME/CFS. The Swedish Women for ME funded this meeting and sent Dr Peterson, Simmaron Research, and Linda Tannenbaum, OMF to meet with other scientists and clinicians for the purpose of sharing scientific knowledge and initiating collaboration.

Worth a watch! <http://goo.gl/7mSh58>

source: fb OMI, <https://www.facebook.com/OpenMedicineFoundation?fref=ts>

> **Breaking news from OMI to appear next Monday. Look for it also on** <http://www.me-cvsvereniging.nl/english-page>

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USA

Advocates letter of support ME/cfs-experts to secretary of health mrs. Sebelius

[Overwhelming, Growing Support of ME Experts by Advocates in Opposition to IOM Contract: Advocates' Open Letter Re-Sent With Additional Signatures](#). As was the case with the experts' open letter to Secretary Sebelius—which was first published on September 23, 2013 and then updated on

October 25, 2013—the October 28, 2013 advocates’ letter now has been updated with additional signatures and re-sent to Secretary Sebelius and other government officials.

An additional 105 active U.S. and international advocates signed on to support our experts, for a total of 171 active advocates. No signatures were withdrawn from the original version of the letter.

This is an overwhelming show of support by advocates for our experts. With virtually no exceptions, the only prominent advocates who declined to sign the letter were several journalists (who could not participate for professional reasons), the current leaders of the CFIDS Association of America (CAA) and of PANDORA, and a few other individuals with particularly close connections to those two organizations.

[Here is a link to the updated advocates’ letter](#), sent to Sebelius and other officials, including the president of the Institute of Medicine (IOM) today. (Note: If you get a black screen when you go to the link, just press “Download” and you will be able to read the letter):

<https://www.dropbox.com/s/3rewnlskfkfhmjz/Updated%20Signatures.pdf>

To maximize the impact of this unprecedented coming together of advocates worldwide, please help spread the word by sharing the letter on Facebook, on your blog, in emails and, most importantly, on your Twitter feed.

An important goal at this point is to draw government officials’ attention to the letters sent by the experts and the advocates, and in general to let these people know that our community is very involved in this issue.

Unfortunately, this disease makes it difficult to arrange a March on Washington to demonstrate our concern. However, since many influential officials (including Secretary Sebelius) maintain an active presence on Twitter, the next step in this effort is to use that forum to make sure that they know that many people care about this issue.

Source: Thoughts about M.E. <http://thoughtsaboutme.com/>

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Canary in a coalmine

Jennifer, a Harvard PhD student, was signing a check at a restaurant when she found she could not write her own name. Months before her wedding, she became progressively more ill, losing the ability even to sit in a wheelchair. Doctors insisted that her condition was psychosomatic rather than real.

As she dug deeper, she found she had become a part of a hidden world of millions suffering from an illness for which there is evidence dating back to at least the 1930s. The disease, myalgic encephalomyelitis, was re-branded in the 1980s by the CDC as 'Chronic Fatigue Syndrome,' a name which became both a punchline and a Rorschach: a wastebasket of undiagnosed conditions hiding a very real disease. Scientists at the country's top institutions have found evidence of profound metabolic, neurological, and immunological dysfunction in patients with M.E.. However, since the disease is not taught in medical schools, doctors don't know how to recognize it, effectively denying healthcare to a million Americans.

In *Canary in a Coal Mine*, Jennifer documents her own story and the stories of Jessica, a young British woman who runs a children's charity from the room that has been her whole world for the last eight years, Howard, an 80s rock publicist-polymath, Mary, an activist, Liisa, a Canadian ex-buddhist monk, and Leeray and Casie, a mother and daughter bedridden in Georgia. Through extreme diets, experimental medication, political activism, or by moving closer, or farther, from God, each struggles to find their own way to fight, accept, and sometimes, even thrive in spite of 'an illness that has no end.'

For further details: <http://www.kickstarter.com/projects/959776320/canary-in-a-coal-mine>

Trailer:

http://www.youtube.com/watch?v=4J5CRGPvgl4&feature=share&list=PLSX_kPpxAZX7uKr0d_gkQgs93Rg93xD3s

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Reno/Brussels/Kazan

Prof. dr. Kenny De Meirleir from Brussels, who has been so kind to give 20 talks on ME which have been broadcast by the Dutch ME/cfs association (for transcripts <http://www.me-cvsvereniging.nl/sites/default/files/Web%20seminar%201-20%20KDM.pdf>), has become a medical director at the WPI in Reno. He has also started a practice and has seen his first patients last month.

He will be in Reno again during the last week of January 2014. All his necessary equipment will be ready to use by then. Appointments can be made via IraDS@ehmb.be.

Prof.dr. De Meirleir will be in Reno for ten days every two months, besides continuing his practice in Brussels. This has become possible due to his retirement from the VUB, the university of Brussels.

On November 14th he attended a congress in Kazan, Russia where he expounded the purport of the ICC to an audience of 1000 GP's. The ICC will be translated, printed and distributed among GP's, and a blood- and tissue-bank has been set up.

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Reno, Nevada

Nevada Genomics Center and WPI Acquire Advanced Research Technology

Kris Kruse, Ph.D., Director of the Nevada Genomics Center (NGC), and Vincent Lombardi, Ph.D., Research Director of the Whittemore Peterson Institute (WPI), are pleased to announce that the University of Nevada, Reno, in collaboration with the WPI, completed the acquisition of Life Technologies' next generation sequencing platforms: the Ion Torrent Personal Genome Machine and Ion Torrent Proton. The purchase order for these two highly advanced research platforms was placed through a federal HRSA grant, and the equipment is now available for use through the NGC. Next generation sequencing allows for the identification of novel pathogens and other genetic risk factors associated with particular diseases. These types of investigations can lead to personalized therapies

based on an individual's own DNA profile. "We're very excited to have these advanced platforms placed in the Nevada Genomics Center so that we can offer next generation sequencing services to research labs within the entire University research community and beyond," noted Kruse. The NGC is also home to faculty with expertise in bioinformatics and advanced digital data analysis in support of the University's research goals. Karen Schlaugh, Director of Bioinformatics for the NGC, will be integral to the process of discovery by facilitating all data analysis using computational biology tools.

The collaboration between the WPI and NGC will provide new and exciting opportunities for the entire Nevada research community. "We are happy to be able to support our community by combining the institute's efforts and resources with the University's," explained Dr. Lombardi. "Sophisticated technology such as this allows WPI and University researchers to stay in the forefront of biological research in our search for answers to many serious diseases.

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Incline Village, Nevada

Simmaron has two exciting funding priorities to help scientifically redefine ME/CFS:

- Arthropod-Borne Disease in Post-Infectious Fatigue: Simmaron has been awarded access to samples from the NIH directed XMRV investigation to study the presence of antibodies to vector-borne pathogens in 293 highly characterized CFS/ME patients and controls. This study will assess the similarities and differences in exposure to multiple tick and mosquito-borne pathogens among this geographically diverse patient cohort, with the potential to aid in subsetting and identifying a role of infection in precipitating CFS/ME.
- Assessment of the prevalence of clonal T-cell receptor gamma gene rearrangements in CFS patients with herpes virus infections: Simmaron will assess the diagnostic and prognostic potential value of analyzing CFS/ME patients for T-cell receptor gamma clonality. As CFS/ME is associated with increased incidence of lymphoma and certain other cancers, this study will investigate the value of T-cell gene rearrangements in identifying a subset of patients who are at risk of developing cancer, for diagnostic and treatment purposes.

- source: <http://simmaronresearch.com/research/#sthash.oatLNxf8.dpuf>

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Washington DC – Mecfs Alert

On 22 October 2013 Episode 51 of the series of talks with ME-experts and ME-advocates has been released.

In it Llewellyn King, executive producer and host of MEcfs-Alert, is interviewing dr. Alan Pocinki, internal medicine specialist, who focusses the treatment of ME/cfs on sleepdisorders, pain and disturbances of the autonomic nervous system.

Access to the interview with

http://www.youtube.com/watch?v=2h3PE36EtQ&feature=share&list=UUxrPmgVwJ7-gLqZJK_qLeFg

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Life's Essence

By: Michelle from Mount Horeb

There's so much life around me,
and so very little of it left inside me.
But that doesn't matter.
As long as I have enough to still see You by,
to bear witness to beauty and love.

Those who believe that life, at its essence,
is meant for more than this,
are all lost in not knowing.

[Jamison Hill](#)

Source: The Blue Ribbon, www.mecfsdocumentary.com

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