

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

Worldwide newsletter 4 December 2013

All about connecting
http://youtu.be/_Gcrx2Ab0FM

Den Bosch, The Netherlands, December 12, 2013

Dear reader,

This is the fourth issue of the Worldwide Newsletter, with news from leading research institutes and patient associations all around the world.

This newsletter aims at being a platform for the exchange of news and information between all ME/cfs patient advocates in the world and is sent to all scientists and patient organisations known to us. We kindly request you to consider distributing the information it contains, as much as you can.

Should your institute or association have any news or upcoming initiative to report and wish to share this, please do email us before 26 January 2014 at contact@me-cvsvereniging.nl. The next Newsletter will be sent approximately 30 January 2014, together with the links to an interview with British paediatrician dr. Nigel Speight and two of his webinars.

If you or someone you know wants to contribute to the making of this newsletter, please be so kind as to let us know.

We wish you a very merry, yet restful Christmas and a 'better' New Year.

Rob Wijbenga
Group Science to Patients
ME/cvs Vereniging Nederland
contact@me-cvsvereniging.nl
+31 73 6425864

Australia

Goldcoast

The National Centre for Neuroimmunology and Emerging Diseases (NCNED) at Griffith University did open on December 2, 2013.

The new center is dedicated to research on the interaction between the nervous system and the immune system and is led by one of Australia's foremost authorities on CFS/ME, Professor Sonya Marshall-Gradisnik.

"The NCNED heralds a higher level in Griffith's capacity for state-of-the-art neuroimmunological research in the context of nervous system disorders," she says. "These disorders are a major cause of neurological disability in Australia".

She says she is overwhelmed by the support the community has shown towards the research so far. "Our patients have shown enormous courage in the trajectory of their illness and have contributed greatly to our research through their participation in scientific studies."

Developments at the Centre are expected to be extended in February 2014 with the opening of a specialized CFS Clinic. The integrated facility will provide treatment to anybody living with the condition and will build on the research being conducted with participants which has shown a strong association between the condition and a dysfunctional immune system.

"We now have the capacity, not only for advanced research but also the potential to provide a clinical service to people who have been unable to find appropriate care in the past," says Professor Marshall-Gradisnik. "Our research is leading the way internationally to uncover the causes of this illness and the search for effective treatments based on our unique immunological discoveries."

Gold Coast Health Board Chair Mr. Ian Langdon said he was pleased to enhance the research capacity at NCNED by a contribution to the purchase of new flow cytometry equipment , one of only two currently in Australia to ensure this research center remains at the forefront of this area.

"It is important that the NCNED receives support to purchase such technology from partners like Gold Coast Health as it will benefit local community members in a way previously unavailable to them." (source: Louise Durack • www.ProHealth.com • December 7, 2013)

NCNED Mission:

Its mission is to perform world class biomedical research that will contribute to the understanding of myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) through the identification of physiological mechanisms and biomarkers.

NCNED Aims:

To be recognised for world-class clinical and population based health and medical research.
To collaborate with local, national and international research institutes and researchers.
To translate research into preventative medicine, social and clinical care and public health outcomes.
To create sustained improvements in health and health care for individuals with ME/CFS.

Prahran, Victoria

ME/cfs Australia, Newsletter December 2013:

2014 Link Up Program

The Link Up program enables members across Australia the opportunity to join a group discussion via telephone. The topics relate to people's experience of ME/CFS and is led by an ME/CFS facilitator and/or a guest speaker. [More information & bookings: admin@mecfs-vic.org](mailto:admin@mecfs-vic.org).

Crisis Support and Counselling.

Need a sounding board? Feeling anxious about your health, your future or your child with ME/CFS? Having worrying thoughts and feelings? Struggling with living with ME/CFS? Use this opportunity to talk through concerns and be supported with strategies and tips from a trained telephone ME/CFS Australia (Vic Tas NT) provides professional education services to community organisations, schools and higher education institutions, health services and the GP community. These education sessions are designed to foster a culture that is sympathetic, understanding and proactive in meeting the needs of people diagnosed with ME/CFS. Attending these workshops will help develop your understanding of ME/CFS to recognise symptoms, and offer practical strategies and guidance to people living with ME/CFS and their carers.

Counsellor. Young people, their parents and/or carers are welcome to register for this free service. For community organisations, schools, higher education and health professionals: Professional Education Series2014.

Medical Expert Seminar ME/CFS/FM:

DVD's from our recent successful seminar with Professor Dr. Micheal Maes, international ME/CFS expert and Dr. Nicole Phillips, psychiatrist, medical educator and advisor are now available for purchase. If you couldn't get to the seminar, you can watch it on DVD from home

For all information: admin@mecfs-vic.org.au

* * *

Denmark

25 year old severely ill ME-patient Karina Hansen is still kept at the Hammel Neurocenter. It may be a good idea to send her a Christmas card. Take into account that she's sensitive to light, sound and fragrances. Her address:

Kognitiv Klinik, H4
Voldbyvej 15
8450 Hammel
Denmark
Att: Karina and Ketty [Hansen](#)

Ketty being her mother.

* * *

England

Maidstone

The Grace Charity for ME

I have been asked by some lovely people to suggest an ME charity that they could donate to this year instead of sending Christmas cards. I have suggested The Grace Charity for ME

www.gracecharityforme.org

On a recent stay in hospital, a Hospital Booklet provided by The Grace Charity for ME proved invaluable to me and my family, and instigated a discussion with the ward manager about ME which helped me to defend myself.

The result was that he asked to keep the booklet for his own learning and for reference in case I was ever on his ward again, or indeed, if any other ME patients ever came to his ward. For me it was a wonderful change from the usual treatment I receive in hospital, and to think that via The Grace Charity's Hospital Booklet, we may have paved an easier way for any future ME patients on that ward is fantastic.

The Grace Charity also champion 'Stonebird' www.stonebird.co.uk from the lovely [Greg Crowhurst](#) & Linda Crowhurst. and also [Jodi Bassetts](#) phenomenal 'Hummingbirds Foundation for ME' , www.hfme.org

Both of these sites and their owners are very dear to my heart as I am not entirely sure where I would be without either of them now.

HFME provided, and continues to provide me with a wealth of information about ME. A chance visit to this site was the first wake up call that I had regarding the cause of my illness. I shudder to think where I would be now had I not found the HFME, and I know that many others credit Jodi with their survival also.

Stonebird was a revelation to me. It is a fabulous resource for ME patients and carer's alike, created by two genuinely wonderful people who understand life with ME better than anyone, having lived with it for 20 years. It gave me strength and belief during one of my most difficult times of dealing with this life changing illness.

Stonebird helped me to acknowledge that I was still a valuable part of my family's life with this powerful concept:

'The Stonebird represents the idea that you don't have to do anything to be of beauty and value in the world. Even if you cannot move, even if you cannot communicate, even if you cannot think, still you are precious and your presence matters.'

Given that the Grace Charity for ME stand for everything that a true ME advocate should, and are a caring and wonderful charity, and because they promote the invaluable resources of the HFME and Stonebird, both of which are so important to me, (and essential I think, for anyone living with M.E.)

and also because they helped me to defend myself via their Hospital Guide during a most distressing time in hospital, I have chosen to support the Grace Charity for ME this Christmas.

Laura [Brown](#)

If anyone feels they would like to make a donation, cheques can be made out to 'The Grace Charity for M.E.' and sent to:

The Grace Charity for M.E.
20 Dickens Close, Langley
Maidstone, Kent ME17 1TB England

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Norfolk

Breaking news from our great friend Greg Crowhurst and his wife Linda, suffering since decades in the dark from the severest form of ME:

The second edition of their book Severe ME has been published right now. Its subtitle is: Featuring Justice for Karina, paying a tribute to the Danish young ME-patient Karina Hansen (> Denmark) who is confined to psychiatric care against her will since February last, being taken away from her parental home by force, like Sophia Mirza once was....

It is an all encompassing book, an absolute must for everyone who is aware of how severe ME can strike as well as for everyone who doesn't know. It is a monument to the long trail of intense suffering Linda has gone, and the loving, dedicated unconditional care of her husband Greg, with all the experiences they had across all those years, concerning every aspect of Linda's condition and their life: doctors, officials, friends, emotions, you name it. But it also is an extremely practical guide of how to deal with someone who is totally dependent on others to live on, and at the same time

letting her know that she's an invaluable and most precious creature, contributing immeasurably more to the welfare of mankind than all those together who ignore her and others like her.

For all information about this must-have:

<http://www.stonebird.co.uk/severemebook/severeme.html>

To those who have been able to watch the film Voices from the Shadows Greg and Linda don't need an introduction.

* * *

Newcastle

On December 5, 2013 a one-day conference has been held at the Royal Station Hotel as an update on aetiology, diagnosis and management of ME/cfs.

"A must for any healthcare professional working or interested in the field of Chronic Fatigue Syndrome or Myalgic Encephalomyelitis", as it was announced by the organizers.

Guest Speaker from the USA was Prof. Leonard Jason, Ph.D., well-known to all of us. He is among the most prolific of all CFIDS researchers. For more than a decade, he and his team at DePaul University's Centre for Community Research in Chicago have worked to define the scope and impact of CFS/ME worldwide. He has been talking on 'Diagnostic challenges of CFS/ME'.

"Chronic Fatigue Syndrome is sometimes dismissed as an 'all in your head' illness. A diagnosis is given when a health care practitioner has ruled out other causes for the cluster of symptoms. However Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME) is a complex and serious debilitating medical condition with a diverse range of symptoms. Profound physical and/or mental fatigue is the most well known, while others include pain, disturbed sleep patterns and gastrointestinal problems. CFS/ME affects about 200 000 people in the UK including children", read the invitation to this congress.

The conference's focus was to bring healthcare professionals together to share their knowledge and achievements in diagnosing and managing this serious condition. Leading experts were to discuss latest developments in understanding the aetiology and pathophysiology of CFS/ME;

The conference highlighted the following topics:

- *) General overview of CFS/ME
- *) Aetiology and Epidemiology of CFS/ME
- *) Pathophysiology of CFS/ME
- *) Diagnostic challenges of CFS/ME
- *) NICE and the evidence base - the future
- *) Management of physical activities
- *) Management of psychological symptoms
- *) Diagnosis and management of symptoms in children
- *) Management of sleep disorders
- *) Management of Autonomic dysfunction
- *) New developments in research

Professor Julia Newton, Dean for Clinical Medicine and Clinical Professor of Ageing and Medicine, chaired the conference. On December 4th , short talks on a large variety of aspects of ME, based on questions from patients, were filmed of both prof. Newton and prof. Jason for the Dutch project Science to Patients (> the Netherlands)

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Sweden

Two successful ME/CFS meetings in Stockholm, Sweden

RME, the Swedish National Society for ME Patients, arranged two successful meetings in October 2013.

Round table meeting for researchers/physicians at Danderyd's Hospital, 15th October

Morning meeting – topics of discussion:

- Auto-immunity, triggering infections in ME/CFS, NK cells, HHV6, biobanks.
- Methods of diagnosis: The current situation. How can they be improved? Are the physical tests effective? How many patients can be put through them? How good are the immunological tests? Other markers?

- Treatment: CBT, Rituximab – the situation in Sweden, other treatments.

The discussion was very appreciated by the 18 participants and resulted in an increased interest in attending our meetings twice a year, which RME arranges for “our” network of researchers/physicians at Gotahälsan Clinic in Mjölby.

There was also a consensus for RME to arrange another round table meeting in 2014. The possibility to meet in real life for discussions about different research fields and clinical experiences, and establish deeper contacts for future cooperation, both national and international, is invaluable.

Afternoon meeting at the ME/CFS Clinic:

The team at the ME/CFS Clinic presented their evaluation report on the ME/CFS project which was started in the spring of 2011. They also presented their work at the clinic. Afterwards the group discussed:

- National co-operation.
- Clinics in Sweden work in different ways – how can one approach them?
- Can a joint research project be planned?
- Should a common measuring instrument be adopted?

Seminar in the Swedish Parliament 16th October

RME had together with six different political parties, represented by members of the Parliamentary Standing Committee on Social Questions and the Committee on Social Insurance, invited representatives from the National Board of Health and Welfare, the Swedish Social Insurance Agency, politicians from the 20 Swedish County Councils, researchers, physicians and some members of RME, altogether about 55 persons. A goodiebag with our book *Trötthet är fel ord* (Fatigue is the Wrong Word), the documentary film *Voices from the Shadows, A Primer for Clinical Practitioners* and information for health care professionals compiled by RME was handed over to key persons.

The seminar was very successful with excellent and very informative presentations by Dr. Daniel Peterson, Simmaron Research, USA, who talked about history and current research, Dr. Olof Zachrisson, Gottfries Clinic, Sweden, who talked about diagnosis and treatment and Pernilla Zethraeus, member of RME and former member of the Swedish Parliament, who gave her view from a patient’s perspective. Our member Dr. Lars Lagerstrand did an excellent job as moderator for the panel of politicians from the above mentioned committees.

The main Swedish television news program did broadcast a report the same evening, interviewing Pernilla Zethraeus at home, showing her serious situation, and Dr. Olof Zachrisson about the situation for patients in Sweden. Ewa Milerad, chief physician at the ME/CFS Clinic at Danderyd’s Hospital was also interviewed about their work. The headline of the report was 40 000 patients in Sweden but few get health care.

We are very pleased with the two above events, and with the report on the television news, and hope that they will lead to a change for ME/CFS-sufferers in Sweden.

Our work continues!

Lisa Forstenius, Chairman

The Swedish National Society for ME Patients (RME)

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The Netherlands

The government subsidized project Science to Patients is entering a new phase. Since November 2012 short English subtitled talks have been broadcast of the Belgian prof. Kenny De Meirleir (20 talks), the Dutch cardiologist prof. Frans Visser (6 talks) and one talk of dr. Meinte Vollema, neuropsychologist and completely new in the field.

An interview and six talks of dr. Nigel Speight, former paediatrician at Durham, GB and eight talks of dr. Charles Shepherd were filmed last autumn and will be broadcast with Dutch subtitles from January 7 onward, whilst last week eight talks of prof. Julia Newton and eight talks of prof. Leonard Jason were filmed in Newcastle, which will be subtitled next spring and broadcast from June 2014 onwards.

See: <http://www.me-cvsvereniging.nl/broadcasting-science-to-patients-2014>

* * *

USA

General

About unconditional resistance

Twilight Zone: IOM Committee Nominations Not Even in the Realm of Reasonableness

Today, the IOM published the [provisional IOM committee appointments](#) for the institution's ME/CFS "study." I have only taken a brief look at the list of nominees. Others are in the process of "vetting" the nominees and researching their background. I thought about this long and hard and have come to the conclusion that providing input on the committee members will accomplish little and likely legitimize this rigged game. The fact that the number of nominees who are not experts in the disease (8) exceeds the number of experts (7) quite clearly exposes HHS's intent in burying our patient population for good with an unscientific definition that will set us back for decades and in producing a result like the IOM delivered in the case of Gulf War Illness. The government quite obviously does not want this disease defined correctly. Remember when Dr. Unger said at the last CFSAC meeting that the CCC are too complex for physicians? I am sure brain surgery e.g., is very complex and only a few physicians are qualified to perform it. Does that mean that we shouldn't do it at all? Or does that mean that the brain-surgery experts should perform the surgeries and educate the non-experts on what they need to know? The difference in approach here is that people who are required to have brain surgery are considered to be sick. We are just considered to be lazies and crazies.

I mean no offense to some of our more esteemed experts who were nominated, but the concept of convening a committee with any non-experts, let alone with a majority of non-experts, is nothing short of ludicrous. It's insanity that is not even in the realm of reasonableness. The rationale reportedly given by the IOM, i.e., that the definition "will be used by physicians/clinicians with and without experience in ME/CFS, so the participation of committee members from both perspectives is very important" is mind-boggling. In no other area of any significance or in any complicated field

would the definition of a crucial issue, such as a disease definition, be turned over to non-experts. It's unthinkable.

This is like saying that we should have law students on the U.S. Supreme Court because they will one day be required to interpret Supreme Court decisions. Hey, why not let dermatologists decide what the best way to perform open-heart surgery is? After all, they may have to deal with the cosmetic aspect of the scar left by the surgery at some point.

It might make sense—after completing a first draft of a definition for ME/CFS—to have a session with non-experts, such as internists, family doctors and pediatricians to let them ask questions and give input and based on that to refine the definition. That seems sensible. But the question of educating non-experts on the definition is a separate one and letting know-nothings—those who have no prior experience with this extremely complex disease, maybe the most complex disease of our times—determine how it will be defined is indefensible.

The idea that the IOM committee for ME/CFS will include a majority of non-experts reminds me of comments made by Republican Senator Roman Hruska of Nebraska about Nixon's nomination of G. Harold Carswell to the U.S. Supreme Court. In response to criticisms of Carswell as being a mediocre judge (58% of his decisions as a federal district court judge having been reversed on appeal), Hruska said: "Even if he was mediocre, there are a lot of mediocre judges, people and lawyers. They are entitled to a little representation aren't they, and a little chance? We can't have all Brandeises, Frankfurters and Cardozos." Carswell was rejected by the Senate. Harry Blackmun was ultimately appointed and later wrote the majority opinion in *Roe v. Wade*.

As if the appointment of non-experts was not bad enough, one of the nominees is a mental-health expert. I thought even the government had moved past calling this disease psychological. At least it pays lip service to that effect. The FDA classified ME/CFS in the group of serious or life-threatening diseases. This IOM panel is not a committee on coping mechanisms for the disease. Talk therapy can be helpful for ME patients, as it could be beneficial to any patient with a serious chronic disease. But why in the world would a professor of psychology who researches mental-health services be involved in defining the disease? And what makes her think that she is up to the huge responsibility she is handed for very suspicious reasons? Why is she not wondering what she could possibly contribute?

Most of the appointments are completely outrageous and yet some patients are almost relieved because it "could have been worse," because we all expected the government to stack the deck against us with non-experts. Are we so used to being treated as sub-humans that we rejoice over any crumbs that are being thrown to us, no matter how rotten they are? This reminds me of the ludicrousness of the East German government's propaganda. Everybody was expecting it and we all figured that there was nothing we could do about it anyway.

Well, we can do something about this and that is unconditional resistance. Let's not lend credibility to this kangaroo court by deluding ourselves into thinking that we have influence over the outcome of the IOM "study" by giving input on the appointees. The only way we will survive this rigged game is by continuing to demand the cancellation of the IOM contract altogether. Compromising means surrendering.

[Jeannette Burmeister-Thoughts on M.E.](#)

Miami, FL

NSU

Check out the many new things going on at NSU COM Institute for Neuro-Immune Medicine!
Some highlights:

- Mary Ann Fletcher, PhD is bringing her Diagnostic Immunology to the Institute, joining the faculty as the Schemel Professor of Medicine, and bringing her outstanding team.
- Mariana Morris, PhD joined the Institute faculty and launched the NSU Gulf War Illness Consortium, a DoD funded effort to find effective treatment for veterans suffering from Gulf War Illness.
- Gordon Broderick, PhD, and Travis Craddock, PhD, joined our faculty to create the institute's Computational Biology program.
- Paula Waziry, PhD joined the faculty to develop a better understanding of just what latent viruses do to the cells they infect
- Lubov Nathanson, PhD (a founding faculty member of the institute) is putting the final touches on the nanostring we will use to complete our dynamic modeling work.
- Irma Rey, MD, Medical Education Director, has developed an on site training program for the Allergy Immunology Fellowship at Larkin.
- Maria Vera, MD will join our clinical team in the coming weeks to expand our services in Kendall and also work with the informatics team as we develop web based platforms to help with both our clinical and research missions.
- Nancy Klimas, MD, Director of the Institute is working to develop a philanthropically funded translational medicine program to move research to clinical trials faster.

It's been a busy few months (did I mention we submitted 11 grant applications since June?)
My best to one and all, Nancy Klimas

* * *

Mountain View, CA

OMI/OMF

Symptom Relief Possible Today for many with ME/CFS, Fibromyalgia or Lyme
(\$12 Crowdfund for B12 study)

The Open Medicine Foundation & Institute collaborates with the best scientists and clinicians around the world to find treatments and ultimately a cure for ME/CFS/FM/Lyme (Borrelia).

The Gottfries Clinic in Gothenburg, Sweden, along with several U.S. ME/CFS/FM/Lyme experts have observed significant reduction in fatigue and cognitive symptoms in 20%-50% of their patients that have a MTHFR mutation in response to alternative formulations of Vitamin B12 and Folate supplementation. Preliminary data has shown that these mutations are commonly found in ME/CFS/FM/Lyme patients.

Imagine if this treatment improved your quality of life or your loved-one's significantly. We want to give the international patient community access to this low-cost treatment by rigorously validating it.

Most patients or doctors do not know about this relatively inexpensive therapy. We want to confirm these findings and tell the patients themselves so that they could tell their own doctor!

The Open Medicine Institute is launching a multisite, multicountry, double-blinded, placebo-controlled clinical trial lead by Dr. David Kaufman and Dr. Andreas Kogelnik, Open Medicine Institute, Mountain View, CA in collaboration with the Gottfries Clinic, Gothenburg, Sweden and Dr. Dan Peterson, Simmaron Research, Incline Village, NV to confirm these findings, and bring symptom relief to thousands, possibly millions of ME/CFS/FM/Lyme patients around the world.

It takes a community to fund research that truly matters. We can do this together to validate the effectiveness of this safe, low-cost treatment so that it could help patients everywhere.

Take the \$12 for B12 Challenge TODAY!
Give \$12, \$24, \$120, \$1200

<http://youtu.be/L72TfSufnww>

Our goal is to fund this by Feb 14, 2014, start it in March, and have results by end of the year.

The 100-patient, multi-center trial will cost \$275,000. To kick this off, \$30,000 has already been donated. 100% of the donations will go towards this study. We are asking for \$12 (or multiples of twelve) to reach the necessary target.

Target: \$275,000, 100 patients
Getting there: \$30,000, 12 patients

Whatever you can do to help make this happen will make a tremendous difference! Thank you for your help so that we could help so many.

Together for a cure,
Linda Tannenbaum, Executive Director
linda@openmedicinefoundation.org
Open Medicine Foundation, www.openmedicineinstitute.org

* * *

Reno, NV

WPI Investigators Invited to Russian Conferences on ME/CFS

On November 14th and 15th, Drs. De Meirleir, Lombardi and Khaiboullina were invited speakers at the prestigious 4th All Russian Federation Meeting for physicians and general practitioners held at the Korston Hotel in Kazan, Russia.

The goal of this meeting was to provide doctors with new and updated guidelines on treatment, prevention, and post therapeutic management of patients with various diseases. The WPI team presented the latest advances in understanding the pathogenesis of ME/CFS (referred to as neuro-asthenia in Russia). Dr. Lombardi presented his latest findings on the role of plasmacytoid dendritic cells in the gut of ME/CFS patients. Dr. De Meirleir spoke to physicians about the merits of using the Canadian Consensus Criteria for diagnosis of ME/CFS.

In addition In addition to discussing the latest advances in diagnosis and treatment of ME/CFS, the WPI team had a chance to meet with a number of neurologists and infectious disease doctors who typically see patients with ME/CFS and who were eager to discuss potential research collaborations with the WPI. During a round table discussion, the WPI team and their Russian collaborators outlined a joint research project aimed at understanding the pathogenesis of ME/CFS and evaluating efficacy and mechanism of action of therapeutics employed by each group. This potential project will represent the largest ME/CFS study conducted in Russia to date. The WPI team has agreed to provide technical expertise regarding diagnosis, study design, and data analysis.

"I was encouraged by the opened-minded environment regarding ME/CFS and also by the commitment of the Russian government to address this serious health concern," stated Dr. Lombardi.

Although ME/CFS likely impacts the Russian Federation to the same extent as it does elsewhere in the world, a serious research program has never been implemented in Russia. Therefore, it is the goal of the WPI to assist its Russian collaborators in addressing this issue and advancing ME/CFS research and treatment.

On November 20th, Drs. Lombardi and Khaiboullina also attended the International Symposium titled The Development of the Institute of Fundamental Medicine and Biology: Modern Trends in Research and Education held at Kazan Federal University. Drs. Lombardi and Khaiboullina presented research results, conducted in collaboration between WPI and the Institute of Fundamental Medicine and Biology, Kazan Federal University. Drs. Lombardi and Khaiboullina were praised by the Director of the Russian Institute for their willingness to share knowledge and expertise with colleagues in Russia and around the world. In addition to informing symposium attendees about ongoing projects, they established new collaborations with multiple departments at the Kazan Federal University.

"Our main focus was to implement a research collaboration to study the inflammatory component of patients with ME/CFS as well as gut immunity," explained Dr. Lombardi. "Our discussion was productive and generated new opportunities for future collaboration."

Participants of the symposium included, among others, President of the Kazan State University; President of the Institute for Fundamental Medicine and Biology, Kazan Federal University; Assistant

Professor, Okinawa University, Japan; Professor, Okiyama University, Japan; Associate Professor, Karolinska University, Sweden; Associate Professor, Center for Neurology and Cell Biology, Kuibry University, Portugal; Professor, Cancer Center, Philadelphia, USA; and Chairperson of the Department of Genetics, Kazan Federal University.

* * *

Washington DC

David and Goliath, or, the Sick and the Bureaucracy

(note: although the date of Susan Kreutzer's action has past while incorporating and reading this, she's an icon and hers is a most remarkable and inspiring action, mr. King's article being most actual)

Malcolm Gladwell, the New Yorker writer, has grown rich with a series of books exploring the sociological dimensions of success and failure. In his latest, "David and Goliath: Underdogs, Misfits and the Art of Battling Giants," Gladwell celebrates the many Davids who triumphed over the odds because they were nimble and resourceful.

If he wants to observe a classic David-versus-Goliath rumble, Gladwell might want to go to Washington on Tuesday (Dec. 10). He will see a frail woman go up against the federal government with a humble petition and a small following of mostly very sick people.

Her name is Susan Kreutzer and she suffers from the debilitating and mysterious disease Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis, which is the name patients favor.

Kreutzer and others will begin their demonstration at 9 a.m. outside of the headquarters of the Department of Health and Human Services on Independence Avenue, where she will hand over a petition. Then she will move up the street to Capitol Hill to demonstrate and hand-deliver petitions to members of Congress. She will end her day of petitioning her government outside the White House.

Kreutzer has no idea how many, if any, demonstrators will join her, but she assures me she has the required permits to demonstrate. Another time, only six demonstrators turned out, but they unfurled a huge banner and stood on the street, telling the oft-ignored story of their suffering to anyone who would listen.

Telling your story in Washington without a big-bucks lobbying firm or celebrity friends is not an easy assignment. Not only is there the high chance of being ignored but there is also the chance of being discounted as one of the apocalyptic "end of days" proselytizers, or those who believe the CIA has it in for them and who habitually assemble at the White House and elsewhere. In other words, it is easy to be dismissed as a "crazy."

But Kreutzer, who will have a warm-up demonstration on Dec. 9 in San Francisco at the HHS offices there, believes in the strength of small voices, of a murmur in the cacophony of Washington petitioning. "I feel I have to do this," she said.

This year, the victims of CFS are particularly upset with HHS and its dependent agency the National Institutes of Health (NIH). They are fuming at the decision of NIH to seek a new clinical definition of their disease, supplanting the Canadian Consensus Criteria, which has been the diagnostic gold

standard for researchers who are deeply committed to finding a cure for a disease that affects as many as 1 million Americans and another 17 million people worldwide.

It is a disease that simply confiscates normal life and substitutes an existence in purgatory, where victims can be confined for decades until death. Sometimes they will be so sick they must lie in darkened rooms for months or years; sometimes they can function for a few hours a day, usually followed by collapse. Dysphasia -- word confusion -- increases. Lovers leave, spouses despair and the well of family compassion runs dry.

The first and major complaint of all those in researching the disease and those suffering from it is that NIH spends a trifling \$6 million on this circle of hell that could have been invented by Dante.

The second and immediate source of anger laced with despair is that NIH has, apparently arbitrarily, decided to have the clinical definition of the disease reclassified by the Institute of Medicine and has diverted a precious \$1 million to this purpose. Thirty-six leading researchers and physicians from the United States, risking retribution in funding, protested the move but were ignored. They were joined by colleagues from abroad, bringing the blue-ribbon protesters to 50.

Still nobody knows why the move to reclassify the disease. One school of thought is that NIH would like to abandon the current and well-accepted diagnostic criteria, known as the Canadian Consensus, in order to treat the disease as more of a mental one rather than a physical one.

I approached HHS for a comment and for a word with Dr. Howard Koh, the assistant secretary in charge, but have received no response.

Will this David, Susan Kreutzer, fell this Goliath, HHS?

Llewellyn King

Llewellyn King is executive producer and host of "White House Chronicle" on PBS. He is co-producer of ME/cfs Alert, the series of interviews with ME-scientists and patients-advocates. His e-mail is lking@kingpublishing.com

Also see: <http://forums.phoenixrising.me/index.php?threads/me-demonstrations-scheduled-for-s-f-on-12-9-2013-and-washington-d-c-on-12-10-2013.26686/>

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Georgia

Ryan Prior Launches Fundraising Platform for Blue Ribbon

On December 3 the [Blue Ribbon Foundation](#) announced the launch of Step Up for M.E., an online platform that facilitates international fundraising for the ME/CFS community. The platform is modeled after those by non-profits such as the Muscular Dystrophy Association, the American Cancer Society and the Alzheimer's Association, all of which use online fundraisers to raise millions of dollars for research, education, advocacy, and legal aid, and to bolster support for the families of those afflicted with these illnesses.

"We wanted a dynamic, easy-to-use platform for our patient community to emulate successful models of grassroots advocacy in other diseases," said Nicole Castillo, the director of the Blue Ribbon Foundation.

Established by Ryan Prior and Nicole Castillo, co-directors of an upcoming documentary film on ME/CFS, the Blue Ribbon Foundation intends to serve as a 501(c)3 charity that will foster interdisciplinary collaboration between ME/CFS patients, physicians, and researchers. It entails a comprehensive vision to revolutionize ME/CFS physician education, and consequently, transform the health care of our patients.

The Step Up for M.E. platform will help support the proposed educational initiatives of the Blue Ribbon Foundation, including \$50,000 annually for a medical fellowship to inspire medical students about neuro-immune diseases, as highlighted by Llewellyn King.

“We were impressed by a quote by Dan Peterson from the pre-released documentary footage: ‘It’s scary to think who is going to take care of these patients when the first generation of the pioneers is retired,’” said Joey Tuan, a member of the Blue Ribbon Foundation’s Board of Directors. “We want to rally the community around a positive cause in response to Peterson’s concern about the trajectory of ME/CFS care.”

Learn more about the new platform and to become involved in grassroots awareness activities in your community below. View the Foundation’s fellowship (video) that outlines its proposal to inspire the next generation of ME/CFS physicians.

From the website of [The Blue Ribbon Foundation](#):

"In the spirit of a true grassroots organization, The Blue Ribbon Foundation started as an idea, which manifested into a documentary (The Blue Ribbon: ME/CFS and the Future of Medicine), and eventually shaped a movement.

The Blue Ribbon Foundation’s mission is to foster an international public dialogue that can lead to finding the cause, cure, and prevention of neuro-immune diseases.

The Foundation’s Board of Directors consists of:

Linda Tannenbaum (Executive Director, Open Medicine Foundation)

Joey Tuan (Co-Founder, HealClick.com)

Giridhar Subramanian (Analyst, CSX Transportation)

Hannah Tsui (Entrepreneur)

Nicole Castillo (Cinematographer, Editor, The Blue Ribbon documentary film)

Ryan Prior (Producer, Writer, The Blue Ribbon documentary film)

We also have a team of volunteers who help run day-to-day operations.

The Foundation’s programs consist of:

(Next six months)—Producing the documentary feature film The Blue Ribbon: ME/CFS and the Future of Medicine.

(Next 6-12 months)—Screenings of the documentary and administering the Blue Ribbon Fellowship for medical students to study ME/CFS at some of the premier neuro-immune institutes in the world.

(12 months+)—Raising funds for medical research (most likely for the Open Medicine Institute’s initiatives) via the Step Up for ME program.

The Blue Ribbon Foundation is a non-profit corporation established in the State of Georgia and currently applying for 501(c)3 status. Donations made after the filing date are tax-deductible to the fullest extent of the law. See us for more details."

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