Presentation Summaries from Tullamore Conference 2011

The Academy of Nutritional Medicine (AONM)
dinsdag 11 oktober 2011 om 14:25

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Cardiorespiratory challenges in Myalgic Encephalomyelitis and Fibromyalgia

The autonomic nervous system controls all the organs in the body and receives all visceral sensory inputs from the periphery.

The central autonomic driver neurons are situated in the brainstem where they are organised in a pattern described as organotopic. It means the neurons are sited according to the organ they control in the body, for example, all those neurones controlling the gut are sited together and all those controlling the heart are also together and so on.

Both the sympathetic driver neurones in the rostral (or upper part) ventrolateral medullar oblongata and the parasympathetic central relay and integrative neurones in the Nucleus Tractus Solitarius (NTS) have organotopic arrangements, sometimes referred to as viscerotopic pattern of spatial organisation.

It has been **technically impossible to study functions of the central autonomic nervous system in real-time in humans**. A breakthrough came with the publication in 1998 of a workshop demonstrating **real-time monitoring of the autonomic outcomes** of breathing dysrhythmias in a neurodevelopmental disorder known as Rett syndrome using the NeuroScope method.

This method has been extended to study the interactions of visceral afferents (or sensory signals coming from organs in the body), mainly from the gastrointestinal tract (GIT), with the central autonomic nervous system.

We have introduced this novel clinical technique **of monitoring brainstem autonomic activity in real-time** in the study of Myalgic Encephalomyelitis (ME) and Fibromyalgia (FMS).

Our preliminary results show extensive cardiorespiratory heterogeneity in patients carrying both clinical diagnoses of FMS and ME.

We have identified **three pathophysiological entities** in both conditions. There are three types of cardiorespiratory dysregulations;

- **chronic tissue hypoxia, hypocapnoea and hypercapnoea** all with elements of **vascular endothelial dysfunctions**.
- There is also a group of patients with **cardiodynamic dysregulation usually** in the form of **abnormal inotropic function in the heart**.
- The third category is a group of patients with **patchy dysautonomia of various causes**; many are associated with environmental pollutants.

There is strong evidence based on real patients' data to suggest that **the dysfunction of the autonomic nervous system is a major factor** in the symptoms of patients with FMS and ME and a proper controlled research in this field is overdue.

Dr Daniel Goyal MB ChB DTM&H

Where we are clinically with ME and Fibromyalgia.

Many chronic diseases require a whole systems approach. Hypertension, diabetes, and others, require diet, exercise, medications and nutritional support to achieve disease resolution. **ME** too **requires this whole system approach**.

This modern illness joins other neuro-immune disorders with a probable basis in environmental toxicity. Such toxicity has variable effects often detectable through real-time autonomic profiling.

This presentation discusses these issues and presents some **simple methods** for patients to implement in order **to achieve improved bodily systems** associated with their impairments. Whole food, organic, high anti-oxidant and low sugar are the cornerstones of the various diets discussed.

Correction of nutritional deficiencies and supplemental support for inadequate metabolic pathways all lead to the elimination of pro-oxidative xenobiotics, improvement in the redox state and eventually improved immunity. Often the immune system requires direct assistance through anti-microbials and/or immunotherapies.

Physicians should consider screening for **herpes viruses**, and if clinical suspicion remains, commencement of an anti-viral therapeutic trial. **Immunovir**, where normal kidney function remains, is probably first line and requires 1-3 months trial. Maintenance dose should be titrated to patient response. **Valacyclovir** is probably second line. Responders should be referred to infectious disease or immunology for further interventions. It is unlikely the immune system will recover without successful elimination of toxin.

Greg Crowhurst RNLD PG dip

Speak Your Truth

There is a huge amount of misinformation surrounding Myalgic Encephalo-myelitis; I emphasized, in my presentation, how important it is to stand up for the truth of ME, as a devastating, neurological disease .

For the last seventeen years I have cared fill time for my wife, who has Very Severe ME. I have learned a lot about how to cope, how to care for someone that ill and how to fight.

It is very difficult, there are not many doctors or consultants with the expe-rience and knowledge to know how to treat people with ME. The fact is, if you are to achieve anything for the person you will have to fight every step of the way.

We have shown how it is possible to get a biomedical service, that the person with Severe ME does not have to be left, with nothing being done for them, for decades on end, as is so often the case.

It takes enormous courage, as a carer, not to compromise, to keep on strugg-ling despite the odds, to put oneself on the line, time and time again; to never give up, to find a way through the never-ending, grinding pain and suffering, to make the necessary connections, to advocate, to push, to deal with the inevitable inertia and snail's pace rate of change - and your own anger.

For sure you will be pushed to the edge, as I showed through the paintings I shared, but with my wife so completely ill, giving up has never been an option for me.

Hearing the person's truth - which brings its own issues and then standing up for it, is the only way ultimately, **I believe, that you can help the person with Severe ME and yourself.**

In my presentation I tried to share a little of what I have learned: how to be in the moment with the person, how to focus, how to be gentle, how to keep going and growing.

Art, music, writing, these things keep me alive, and give me enormous hope .

I am greatly encouraged these days by the pioneering work of the AONM ; they have seemingly burst out of nowhere, with a fresh new energy, a dynamic, ultra-committed approach to working alongside patients and carers and an uncompromising determination to find a way forward, especially for the most severely ill.

In all these years, I have never known anything like it. I feel we are riding a wave of change, at last.

One day soon and it won't be long, now I feel, we will, all of us, surely make that long-awaited and desperately needed biomedical breakthrough.

Ms Catherine Norton

An exploration of the biopsychosocial and neuropsychological aspects of Fibromyalgia Syndrome in the Republic of Ireland

Ms Catherine Norton, a PhD candidate in the School of Psychology, University College Dublin, reported on her large-scale study of Fibromyalgia.

The **study** (with 249 participants) involved an **investigation of self-reported quality of life, cognitive functioning and emotional status** in a cohort of Irish chronic pain patients, primarily exploring Fibromyalgia, Raynaud's and Scleroderma. Patients with Fibromyalgia syndrome report great levels of pain and suffering on a daily and hourly basis.

The results indicate that their **pain is having a very adverse impact on their physical, psychological, social and occupational functionality, with a severe impact on their overall quality of life**.

Her research is continuing, with special emphasis on quality of sleep.

Dr. Raymond N. Perrin DO, PhD

The involvement of cerebrospinal fluid and lymphatic drainage in Fibromyalgia & ME

Dr Perrin who is an osteopath and honorary senior lecturer at the University of Central Lancashire's school of public health and clinical sciences, presented the scientific basis of the **Perrin Technique**, **a manual system of diagnosis and treatment of ME** which he has developed through over twenty years of clinical research.

The lecture explained how the **central nervous system** has a little known process of **drainage into the lymphatic system** and **in Fibromyalgia and ME** this **drainage system is reversed**.

This leads to a **buildup of toxins in the brain and spine** which causes pain, sleep problems, cognitive difficulties and many other severe health problems experienced by patients with Fibromyalgia syndrome and ME.

With clinical examples and drawing on evidence from many other research studies and the latest findings from other recent international conferences, he explained how Fibromyalgia and ME are very similar and often both affect the patient.

He discussed and demonstrated how to physically examine for visible and palpable signs of Fibromyalgia and ME. He offered hope to the many patients at the conference showing how one can restore a healthy 'neuro-lymphatic drainage' and together with other therapies discussed in the conference help to produce a balanced and healthier future.

Dr. Judy Mikovits MD

Virological and immune evidence of human gamma-retrovirus infection in M.E.

On the second anniversary of the publication Dr Judy A Mikovits presented a paper regarding evidence supporting infection of ME patients with Xenotropic MLV-related viruses at the Fibromyalgia ME conference in Tullamore, Ireland.

Dr Mikovits explained the recent finding that DNA samples described in the 2009 Lombardi et al. publication were found to be **contaminated with an XMRV virus clone** named VP62.

The reporting of incorrect viral sequences explains why the experiments designed to replicate the PCR data described in the Lombardi et al. paper have given negative results in many laboratories.

Dr. Mikovits described

- **the detection of gammaretrovirus protein** directly from un-manipulated plasma,
- **direct isolation of gamma-retroviruses** from blood cells of ME/CFS patients shown clearly by electron microscopy,
- **cell-associated and cell-free transmission of virus** to uninfected primary cells and cell lines,
- **antibodies against an envelope protein** derived from a murine leukemia virus in serum of CFS/ME patients.

In the 2009 work, serum from more patients than controls exhibited antibodies against the viral envelope protein. These findings are not affected by the errors in Figure 1 and in the virus genome sequencing and in fact explain discrepancies in Figure 1 and the protein/antibody data shown in the paper.

Individuals whose immune systems have made antibodies to a gamma-retrovirus envelope protein have been exposed at some time to similar polypeptides. The identity of the proteins that elicited in the antibodies is not presently known; all that is known is that they are highly similar to proteins known to be present in gamma-retroviruses.

Dr Mikovits described how XMRV has suffered from an issue of nomenclature. Dr Mikovits and colleagues used “XMRV” to mean viruses with sequences similar to the virus reported by Urisman et al. in 2006 to be present in prostate cancer tissues.

However, **“XMRV” has come to mean only the sequence of the virus molecularly cloned (but not isolated) in 2006 and the nearly identical viruses that have been found in some cell culture lines.** In order to clarify nomenclature for future research on gammaretroviruses, Dr Mikovits proposes referring to gammaretroviruses detected in humans as “HGRVs”, human gammaretroviruses.

Although it is known that a variety of gammaretroviruses can infect human cells in culture, further work is needed to determine whether one or more gammaretroviruses infect humans and whether they are associated with neuro-immune diseases including ME and Fibromyalgia.

Dr Mikovits research is performing serological studies that will be able to determine the proportion of the patient and healthy populations that have been exposed to gamma-retroviral proteins and have mounted an immune response, even if the gamma-retroviral proteins are not identical to those in the “XMRV” sequence, VP62.

Judgments on the value of future research on gammaretroviruses in neuro-immune diseases CFS/ME and Fibromyalgia must await further research utilizing uniformly collected samples from carefully chosen patients and controls.