M I T O L I N K S
The Adult Metabolic Diseases Clinic
Mitochondrial Disease
Support Group Newsletter

Thank you to all who attended our latest support group on Tuesday March 19, 2013 and a very special thank you to Dr. Gabriella Horvath who joined our support group to answer your questions about mitochondrial disease. Dr. Horvath is a biochemical geneticist with a special interest in neurotransmitter disease. We are fortunate to have Dr. Horvath and her expertise. She joined the Adult Metabolic Diseases Clinic team approximately 2 years ago and continues to work with our medical team providing expert advice and clinical care to patients on a part-time basis at VGH and at BC Children's Hospital.

We apologize to all our Telehealth connected out-of-towners for the delay in hooking you up to our main group in Vancouver. We have reviewed the process and challenges to providing this service and the technical difficulties encountered and will be suspending this service until further notice.

Meeting Highlights

Medication Precautions:

Dr. Andre Mattman, who is a member of our physician team and a medical biochemist, has reviewed the current medical literature on mitochondrial disease and medications to avoid. The medication precautions list is included at the end of this newsletter. The list includes medications to avoid because they may damage the mitochondria or impair the production of ATP (energy). The list is drafted as a letter to your family doctor as there are medications that may also have an impact on the mitochondria, but are important medications for other medical conditions. The Adult Metabolic Diseases physicians recommend and encourage family doctors consult the clinic when prescribing medications they are not sure may affect your mitochondrial disease.

Safe and Effective Supplements:

Dr. Horvath mentioned that BC Children's Hospital (BCCH) recommend specific supplement brands for their pediatric patients. BCCH have a contract with two companies that provide their supplements. These are provided in bulk to hospitals. The pharmacist recommends products that are well know brands and easily available. If you need assistance in choosing which product to buy your local pharmacist can help you decide which brand and the quality control guidelines for these products. All certified products must display a CAS number (CAS Registry Numbers are unique numerical identifiers assigned by the Chemical Abstracts Service to every chemical described in the open scientific literature). Look for these numbers on the supplement package or ask your pharmacist to assist you.

Complex Chronic Diseases Program:

Dr. Horvath announced the opening of the new Complex Chronic Diseases Program at BC Women's Hospital. The program is open to both men and women. Your AMDC physician will discuss if a referral to this clinic would be good for you. Please see the announcement below:

BC Women's Hospital & Health Centre is pleased to be hosting this important new program.

This program is for people who suffer from a group of complex chronic diseases which include but are not limited to:

- **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome**
- **Fibromyalgia Syndrome**
- **Lyme disease**

Our goal for the program is to provide patient and symptom-centered care with the support of our multidisciplinary team of health care providers. This approach emphasizes that treatment choice takes patient preferences into account, and that self-care is supported as well as treatment. Central to this is the development of partnership in care, and facilitation of patient involvement during assessment and in the decision making about treatment decisions.

The Complex Chronic Diseases Program is now accepting patient referrals

Medication Precautions

Dear Physician,

This patient has a mitochondrial disease disorder. The mitochondria are organelles within all cells of the body aside from red blood cells and serve to generate ATP to meet cellular needs. As many medications have an inhibitory effect (direct or indirect) on normal mitochondrial function (ie damage the mitochondrion itself, or impair ATP production), certain medications may cause a patient's mitochondrial disease manifestations to deteriorate. We have listed the most commonly used medications that are most likely to have an adverse effect on baseline function when used in a mitochondrial disease setting. Other non-listed medications, may also have an adverse effect but are not listed because of one of two reasons: the medication is used rarely in regular practice (eg AZT), or the potential adverse effect has not been verified and may be small in comparison to the potential benefits. When starting a new medication, unlisted in the table, in a mitochondrial disease patient, contact our clinic if you have any doubt about the relative safety.

Medications Contraindicated for Patients with Mitochondrial Disease

Pharmacologic Category	Medication	Mechanism of Mitochondrial Toxicity
Anticonvulsants	Valproate	Uncoupler, inhibition of fatty acid oxidation, acyl CoA, carnitine depletion, toxic metabolite 2, 4 diene valproate.
Anesthetic Agents	Propofol	Inhitibition of electron transport chain
Analgesics	ASA (for high doses and at any dose for children)	Uncoupler leading to decreased ATP generation efficiency.
Antibiotics	Gentamicin	Most toxic other aminoglycosides less so
Antibiotics	Linezolid	Inhibits ribosomal 50s subunit inhibiting mitochondrial protein synthesis

MitoAction Web News:

Membership is Free!

Receive support and news via email. Join to receive updates and information from MitoAction: http://www.mitoaction.org/

Mitochondrial Disease Conferences:

In an ongoing effort to improve mitochondrial disease patient care, MitoAction, in collaboration with the organization's Medical Advisory Committee, will host the 2013 Mitochondrial Disease Clinical Conference on May 4, 2013 at Hotel Marlowe in Cambridge, MA.

Next Support Group Meeting

Topic: To be announced
When: June 19, 2013
Time: 11:00-12:30
Where: To be announced
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