



MITOLINKS
The Adult Metabolic Diseases Clinic
Mitochondrial Disease
Support Group Newsletter

Thank you to all who attended our latest support group on Wednesday, January 29, 2014.

Kirsten Bartels gave a presentation on her role as a genetic counsellor. Please see her slide presentation attached.

4th Year UBC Kinesiology students (Ashley, Jinelle, Donna and Kezia) joined us to tell us about the upcoming Wii Sport program. Please see the attached bulletin and survey.



Questions shared from Kirsten's presentation:

1. What do members of my family, who have not had genetic testing, have to disclose when applying for insurance?

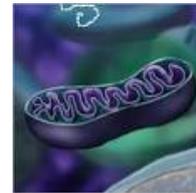
Kirsten's response:

There is no legislation that protects people from genetic discrimination. In general, it is recommended that patients obtain insurance before undergoing genetic investigations since these will become a part of your medical records which you are obligated to disclose to insurance companies. Disclosures are about your health not other members of your family. If you are diagnosed with a genetic disorder, as with any type of medical condition, you will still likely be able to obtain insurance, just pay higher premiums.

2. When should siblings or children be informed they may have a genetic disorder?

Kirsten's response:

This can be a complicated and emotional process. A genetic counsellor can help you decide how to go about discussing this with family members. Even with your consent, a genetic counsellor cannot contact your family member directly to notify them about the genetic disorder. However, she can provide educational material to pass on to your family and assist you in the discussion. If a medical emergency was of concern then a genetic counsellor could notify the family physician of the diagnosis and medical concern.



Talking about genes:

Kirsten gave us a quick and concise look at genetics and inheritance. Please see the attached booklet “**Understanding Genetic Testing**” for a great summary of this complex function of our bodies.

Kirsten's presentation:

DNA is the ‘blueprint or code book’ for our bodies. Most genes are stored in the nucleus. More than 20, 000 genes all with specific functions make us who we are. All our DNA and genes are held together by chromosomes. We have 23 pairs of chromosomes, half from our mother and half from our father.

Mitochondrial cells have their own DNA. 37 genes help maintain mitochondrial function which produces energy for our body. These are inherited directly from the mother. All cells in our body need energy to function.

Mitochondrial disease can be caused by either a genetic mutation (change) in the genes of the mitochondrial DNA or by mutations (changes) in the nuclear DNA affecting the function of the mitochondria.

Gene changes can be described as spelling mistakes, deletions (missing) a word or the duplications (adding) a word or punctuation mistakes.

Nuclear DNA changes can be passed equally from mom and dad. In some cases you need 2 copies of the gene change to see a genetic disorder in the children. In other cases only 1 copy of the gene is need to see a genetic disorder in the children.

In nuclear DNA the cells are all copied the same, however, in mitochondrial DNA each cell can have different numbers of mito-affected genes. This explains why different parts of the body can be affected (more mito-affected genes) and why different members of the family can have varying degrees of mitochondrial disease.



Wii Sports are coming soon to the Adult Metabolic Diseases Clinic!

10 minutes a day of physical activity can produce health benefits – increase flexibility, reduce calories and increase general mental well-being

UBC Kinesiology students Ashley, Jinelle, Donna and Kezia will be assisting patients to get Wii fit! Sign up for a fun filled hour of easy sport and social activity with these delightful and enthusiastic students. Activities will be tailored to your ability. Patients in wheelchairs, friends and family welcome!

To let us know what times are best for you, please either complete the attached survey and send it back to us, or send Margaret an email (margaret.oriley@vch.ca) with the following information AS SOON AS POSSIBLE (the students are hoping to begin the program in February):

- **What time of day would make this program most accessible to you?**
- **What day of the week would work best for you?**
- **What Wii Sports are you most interested in? (tennis, baseball, bowling, boxing, dancing)**

Stay tuned for more information! .

.....
• **Mitochondrial Disease Support Group**
.....
• **Next Meeting: Spring time – date and location to be**
• **determined**
.....