



Dystonia Canada Report

A Newsletter of the Dystonia Medical Research Foundation Canada

Summer 2010



Left: Paralympic Wheelchair Basketball Player Ross MacDonald, who has generalized dystonia, carrying the Paralympic Torch at the 2010 Paralympics Torch Relay in Vancouver (*picture Canadian Press/Darryl Dyck*)

Right: President and Co- Founder of DMRF carries the Olympic Torch at the 2010 Olympic Torch Relay in Vancouver. Story: page 4

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DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

The Dystonia Medical Research Foundation Canada (DMRFC) is a registered non-profit Canadian charity founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. DMRFC funds medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families. DMRF Canada works in partnership with the Dystonia Medical Research Foundation in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and partners with the Canadian Institute of Health Research (CIHR) in funding excellent dystonia research in Canada.

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It is the editorial policy to report on developments regarding all types of dystonia but not to endorse any of the drugs or treatments discussed. We urge you to consult with your own physician about procedures mentioned.

A Message from the Executive Director



There have been many changes at our National Office. We have moved to a new location in downtown Toronto. Our new location at 100 Adelaide Street West offers us more space at the same cost as our previous location.

We have redesigned our logo to include our French Name, Fondation de Recherche Médicale sur la Dystonie Canada. And, at the board of directors meeting in February, the board moved that I become the Executive Director for DMRF Canada. Our special thank you goes to Janet Hieshetter who served as the Executive Director over the past five years.

On the cover of this issue we salute two special individuals in the dystonia family who were bestowed the honour of carrying the Olympic and Paralympic Flames — Samuel Belzberg and Ross MacDonald. Read their stories on page four.

Last Fall I had the privilege of meeting with support groups in Ottawa, Kelowna, Calgary, Saskatoon and Winnipeg. The hospitality and encouragement of the support group leaders, Stu Higdon, Anne Skomedal, Margaret Roy, Diane Haugen, and Brian and Barbara Crowe was just wonderful. Being able to meet and talk with the support group members and their families has given me so much more insight into the complexities of living with dystonia.

Through our partnerships with DMRF in the United States and the Canadian Institutes of Health Research (CIHR) SHOPP program we are funding more Canadian Researchers than ever before. In all a total of six Canadian research projects have been awarded grants this year.

June was bustling with awareness events and fundraising activities with several groups including Hamilton, Sudbury and Toronto raising more funds than ever before. Thank you to all of the Support Groups and Area Contacts for your activities during June Awareness week and throughout the year.

Sincerely,

A handwritten signature in blue ink that reads "Diane Gillespie".

Diane Gillespie
Executive Director

DMRF Canada proudly partners with DMRF in the United States to fund the best dystonia research world-wide. Below are three articles excerpted from DMRF's Spring/Summer 2010 Research Publication Promise and Progress.

Gene May Help Explain Focal Dystonias **Lessons from THAP1/DYT6**

In 2009, DMRF grant recipient Laurie Ozelius, PhD and her collaborators published the highly anticipated discovery of another dystonia gene, THAP1 (a.k.a. DYT6). Numerous mutations in this gene are linked to a mixed-onset primary dystonia that is highly prevalent in Amish-Mennonite families. Following this landmark discovery, a study published in the January 19, 2010 issue of *Neurology* by several collaborating investigators including DMRF MSAC member Mark LeDoux, MD, PhD, screened a group of volunteers with mainly adult onset focal dystonia for mutations in the THAP1 gene. Several unique THAP1 mutations were found in individuals with focal primary dystonias.

This suggests that mutations in different areas of THAP1 are associated with focal dystonias as varied as cervical dystonia, blepharospasm, spasmodic dysphonia/laryngeal dystonia, and others. The finding that multiple mutations in the THAP1 gene are associated with dystonia opens new avenues of investigation. Understanding the role of THAP1 in dystonia may provide important clues about why dystonia manifests in such distinct forms and help explain the disorder in general.



Mark LeDoux, MD, PhD, is one of the many outstanding scientists on the Medical & Scientific Advisory Council.

Investigator Sets Sights on New Therapeutic Target

In 2009 the DMRF began funding a project called "Reduced Striatal RGS9 in an Animal Model of DYT1" led by Jayms Peterson, PhD at Northwestern University in Chicago. The hypothesis of this investigation is that the brains of mice with the DYT1 dystonia mutation express a protein called RGS9 at a reduced level, thereby disrupting the normal communication between certain neurons. The abnormal signaling results in an imbalance of acetylcholine and dopamine neurotransmitters, which is associated with dystonia symptoms. In the course of this work Dr. Peterson is also studying mice bred to be deficient in dopamine, a condition associated with certain subtypes of dystonia. The investigators have been able to diminish the effects of dopamine depletion in these mice by introducing a drug agent that has been explored only in a very limited way to dystonia. Incidentally, the brains of the dopamine-depleted mice have such substantial similarities to those of the DYT1 mutant mice, that this agent may have therapeutic promise for disease associated with reduced dopamine and the DYT1 mutation, of which dystonia is both.

What's the Difference?

Basic Research

Research that expands the body of knowledge about dystonia. Explores the who's, what's, where's, and why's of dystonia and its effects on the nervous system.

Clinical Research

Research about how dystonia affects live human beings: classifying symptoms, treatment trials, diagnostic tools such as rating scales.

Transitional Research

Research aimed at taking laboratory findings from basic research and transforming them into new diagnostic tools and treatments. Includes drug discovery and development efforts led by the Cure Dystonia Initiative.

Designer Dystonia Drugs

DMRF Works with Pharma toward New Meds

Exploring opportunities for drug discovery and development is a critical part of the DMRF's quest for improved therapies. The DMRF has spent years engaging the drug industry and this effort is proving fruitful. The DMRF is now working with several pharmaceutical and biotechnology companies to identify drug targets.

One of these companies is BioFocus DPI, a leading provider of gene-to-drug candidate discovery services. In a landmark development, the DMRF is partnering with BioFocus DPI, a Galapagos NV division, to dramatically accelerate the rational design and discovery of new dystonia drugs. Once completed, this project will identify multiple gene/protein drug targets to complement ongoing DMRF efforts focused on the DYT1 gene and torsin A. More than a year in the making, this partnership is leveraging unprecedented resources toward pursuing therapeutics specifically designed to treat dystonia. The first phase of the project, which entailed developing the assay to screen for potential drug targets, is completed. The next step is to determine if the assay can be used to screen for targets with BioFocus DPI's library of gene specific reagents. The committee of experts advising DMRF on this project includes Cris Bragg, PhD and Xandra Breakefield, PhD of Massachusetts General Hospital, Phyllis Hanson, MD, PhD of Washington University School of Medicine, and Andy Singleton, PhD of the National Institute on Aging.

Canadian Researchers Funded through DMRF Grants and Fellowships

The following Canadian researchers are being funded by DMRF United States and DMRF Canada grants. DMRF Canada fellowships are co-funded in partnership with the Canadian Institutes of Health Research, SHOPP program. DMRF Canada works in partnership with DMRF United States to fund the best world-wide dystonia research.

Robert Chen, MD, PhD, Western Hospital, Grant (DMRF U.S.) Effects of Internal Globus Pallidus Deep Brain Stimulation for Dystonia on Cortical Circuits and Plasticity

William Hutchison, PhD, Toronto Western Hospital, Grant (DMRF U.S.) Activity-dependent Synaptic Plasticity in Globus Pallidus of Dystonia Patients

Amanda Smith, PhD, Ottawa Hospital Research Institute, Fellowship (DMRF U.S. 2010, DMRF Canada 2011-2014) Investigation into the Cause of Myoclonus Dystonia

Bahzad Elahi, PhD, Toronto Western Hospital, Fellowship (DMRF Canada) Regulatory effect of intra cortical inhibition on Paired Associative Stimulation (PAS) induced sensory-dependent, motor cortex plasticity.

Dr. Ryan Scott, PhD, Ottawa Hospital Research Institute, Fellowship (DMRF Canada) Cytoskeletal linker proteins mediate organelle functioning neurons

Manon Le Bel, PhD, Université Laval (Quebec), Fellowship (DMRF Canada), Study of the involvement of relaxing glutamate and expression levels of neurotransmitter transporters in dyskinesia induced by L-DOPA

Sharing a Flame that Unites us All

Samuel Belzberg and Ross MacDonald



What do Sam Belzberg and Ross MacDonald have in common? Both carried historic flames in Vancouver 2010; Belzberg the Olympic flame and MacDonald the Paralympic flame.....and both heroes in their own right.

Sam Belzberg, Vancouver BC resident, co-founded the Dystonia Medical Research Foundation in 1976 with his wife Frances when their daughter Cheri was diagnosed with generalized dystonia. He is the Chairman of the Board of DMRF in the United States, and the President of the Board of DMRF Canada. Mr. and Mrs. Belzberg's philanthropic leadership has supported and inspired over \$25 million in DMRF dystonia research funding to date.

Sam Belzberg: "Carrying the Olympic torch was a special privilege for me. This was an exciting event for Vancouver and Canada – really putting both on the world map. Having the flame run through over 1,000 communities across the nation made these Olympics an event for all of Canadians to be proud of."

Renowned for both his business acumen and his selfless philanthropy, Belzberg's accomplishments and honours include being awarded the Order of Canada in 1989, awarded Officer of the Order of Canada in 2002 and receiving the Governor General of Canada Award in 1992. In 2002, Belzberg co-founded Action Canada, a national organization committed to building leadership for Canada's future through an innovative fellowship program.

Belzberg was bestowed the honour of joining over 12,000 Olympic torch bearers for the 2010 Olympics held in Vancouver BC. The sacred Olympic Flame was lit in an ancient ritual in Olympia, Greece, site of the first Olympic Games. After a short run through Greece, the

Olympic Flame arrived in Athens, where it made a trans-Atlantic flight arriving in Canada and signalling the start of the longest Olympic Torch Relay to take place in a single country with over 45,000 kilometres travelled.

Ross MacDonald, Burnaby BC resident, proudly joined the ranks of over 600 Paralympic torch bearers who carried the torch through eleven communities across Canada leading up to the 2010 Vancouver Paralympics. MacDonald, 32, said he believes the torch experience will inspire him to train harder to get onto the national wheelchair basketball team for the 2012 Summer Paralympics in London.



MacDonald is a member of Wheelchair Basketball Canada's Men's team and previously a member of other basketball and soccer Provincial and Canadian teams. He has been awarded numerous medals and accolades throughout his sporting career.

Diagnosed with generalized dystonia at the age of eight, MacDonald first learned about wheelchair basketball when he was 13 years old. His mother took him to watch the Canadian National Championships in Vancouver. He convinced his mom to enroll him in a wheelchair sports camp and soon after wheelchair basketball became his favourite sport.

Ross works as a Sports Development Coordinator and through this role he has the opportunity to give back. Ross enjoys working with kids especially if they have a disability, so that he can provide guidance and try and be a good role model. He is also a motivational speaker for BC Athlete Voice, in which he visits businesses and schools to tell his story and how sports can benefit people in their life.

When asked what motivates him, MacDonald says, "I always focus on my abilities not my disabilities."

(With thanks to Wheelchair Basketball Canada for picture and excerpts)

Kelby Balch a Strong Young Lady –*Her Story*

Kelby Balch of Simcoe Ontario was diagnosed with dystonia in 2007 at the age of 15 after she had been experiencing months of muscle contractions in her right lower limb. In June of that year her right foot went into a fixed dystonic position.

Kelby has taken the time to raise thousands of dollars for dystonia research. She gives her time to help others and has logged over 300 community volunteer hours during her high school years.

A well-rounded student Kelby recently received the "Lions Shield" award for being the most outstanding grade 12 student. Dystonia has held Kelby back in so many ways, yet her determination to obtain post secondary education is becoming a reality. She will be attending college in Toronto to become an "Intervener" for the deaf and blind.



Balch family at the DMRF Children & Family Symposium in Chicago: from left, sister Morgan, father and mother Lance and Karen, Kelby

Kelby and her family attended the John H. Menkes Children and Family Dystonia Symposium last summer. Says Kelby of her experience there: "The Dystonia Symposium gave me the opportunity to see all the different types of dystonia, some very similar to my mine. It showed me that I am not alone in this fight and many others are walking the same road as I am. I also saw how dystonia can wreck your body to the point where you need to have 24 hour care or guide dogs. I have been able to stay in contact with many of the kids I met." Kelby is currently awaiting a decision from the medical team at London University Hospital regarding her candidacy for deep brain stimulation.

Kelby submitted the following essay to her school as part of her studies:

A Name is Just a Name

February 6th, 1992 at 9:34 AM I was brought into this world. My parents had hoped that one day I would fulfill their ambitions of which they had had for me. They knew that I would grow up to be a unique individual, thus was their reasoning for giving me a unique name; Kelby. I always believed that having a unique name would someday have its advantages. Over the last 18 years of life, my name has truly made me unique amongst my peers and those that I have met. However, it wasn't until I was diagnosed with a rare neurological disorder, Dystonia, that I soon realized I would be known for more than my unique name. My life was about to take a drastic change.

Dystonia is a rare neurological disorder, which is a result from an abnormality in the part of the brain

known as the Basal Ganglia. The basal ganglia does not send the correct messages to my muscles, and as a result they contract and spasm, which then twists my limbs into noticeably awkward positions. Positions that make onlookers cringe and feel the need to stare, allowing their eyes to follow me as I pass by. No longer am I just another student walking down the hallway that no one notices or pays attention to, or just another tourist taking in a new city, *I am different.*

Those three words were the hardest words that I had to learn to accept. No longer was I able to continue doing the activities that once occupied all of my free time, or was I able to do things that I once took for granted. As my condition progressed, I required the need to rely on my

parents for almost everything. Driving me when I had some where to be, providing thousands of dollars for my medical needs, and standing up to doctors who repeatedly told me it was all in my head. If it wasn't for the constant support from family, friends and peers around me, I would not be as accepting of this twisted monster, which they call Dystonia.

Living with Dystonia has changed my life drastically. I have become a much stronger individual and have learned to speak up for myself. It has given me a new perspective on life and I have learned to deal with my Dystonia in such a way that leads doctors to question if I'm even upset that I'm living like this. Of course I am not happy living my life twisted and in excruciating pain on a day-to-day basis, but being depressed and upset will not make the situation any better.

If it weren't for my Dystonia I would not have met some exceptional individuals who I now call members of my Dystonia "family". These individuals are the strongest people I know. They give me support and are the reason that I keep fighting. We keep each other sane, and we can all relate to one another on various levels. If it wasn't for my dystonia I would not have become such an advocate for individuals living with special needs. I would not have learned to speak up for myself, and ask for help when needed. It is my hope to go onto post secondary education to become a special needs teacher. I hope to be able to offer a different perspective, empathize and educate students with various disabilities. I will succeed and turn this hope into a reality, in spite of my Dystonia.

After all, a name is just a name. It is the individual who is truly unique

One Through One Meditation

Tim Williston, Area Contact in New Brunswick sent this article on meditation. Tim says that following meditation has helped him in so many ways and this information made a difficult exercise much easier to perform.

The following is called the One through Ten Meditation and is used to prepare for Qigong practice. It allows one to relax, sink and root the mind. This meditation allows extension of the energetic field before connecting with the Divine or a higher power. This meditation is used to create a sacred healing space and is taught in a rhyming one through ten counting format described as follows.

1. One is Fun, therefore take pleasure in your practice. Imagine a smile melting down the front of your body like warm oil, melting all stress and tension into the Earth. A second smile melts down the back of your body, dissolving all stress and tension down into the Earth. A Third and final smile melts down the centre of your head, relaxing all thoughts, judgments and feelings and flows down your shoulders, arms and out of your hands. The melting continues to flow down the centre of your torso, like warm oil, melting all emotional blocks and tension, and then flows down your legs and into the ground. At this point your mind and body should feel content, relaxed and peaceful.



Tim and Nancy Williston



2. Two is Shoe, Thus imagine your shoes or feet melting into the ground like ice on a hot pavement. The energy of the feet fuses with the Earth, melting in five directions--forward, backward, left, right and down. This connects your mind and body with Earth energy.

3. Three is Tree, therefore feel yourself extending tree roots from your feet to twice your bodies height deep into the ground. The roots expand in five directions--forward, backward, left, right and down, securing you're rooting and connection with the Earth energy.

4. Four is Core, thus imagine your roots extending deep in to the core of the planet. The Earth energy flows into these roots, ascending up the legs, spine, over your head, down the chest and enters your lower Dantien. This action allows you to draw Earth energy deep into your body and circulate it through

the Microcosmic Orbit (up the spine and head and down the face and front centreline into the lower energy chamber). A solid connection to the Earth roots your physical, mental, emotional and spiritual energies and fills up your Lower Dantien with energy.

5. Five is Alive, therefore feel the Earth energy building up within your Lower Dantien. The energy increases to the point that your Dantien can no longer contain its power. It rushes up the centre of your chest like a might river, dividing into two streams which flow through your arms and out each palm into the Earth. This action releases and emits the energy stored in your Lower Dantien.

6. Six is Thick, thus imagine the room or environment where you are standing being filled with energy. This energy becomes so thick; it is as if you are submerged under water. This fuses the environmental energy with your energy and the Earth's energy into one dynamic field of energy.

7. Seven is Heaven, therefore allow your Baihui point (Top, centre of the scalp) to open up and draw in the divine healing white light into your Upper Dantien (physically inside your head). Let the divine light fill your head and the entire Upper Dantien area till it floods and shines down from the Upper Dantien into your chest, filling up the entire Middle Dantien within the rib cage. Finally, the light shines down from the Middle Dantien filling up the lower abdominal area and the entire Lower Dantien. This light connects you with the Heavenly healing white light energy from the divine, filling up all three Dantiens and your Taiji Pole (the column of energy running from the top of your scalp, down and along your spine). Thus Heavenly and Earthly energies fuse within your body.

8. Eight is Open the Gates, therefore imagine opening every pore on your surface tissues, and begin to draw the environmental energy into your Taiji Pole upon inhalation. Upon exhalation imagine your centre core vibrating and glowing like a neon light. This visualization energizes your centre core, harmonizes your energy and breath and prepares you for Qi and Shen (energy and light) projection.

9. Nine is Shine, therefore imagine that your centre core becomes completely full of energy and overflows by shining (from the Taiji Pole outward) through your pores until it fills up the entire room, like a bright phosphorus flare. This visualization fuses Heaven Qi, Earth Qi and Man's Qi with the external environment.

10. Ten is Begin, With all things now in order, you are physically, mentally, emotionally, energetically and spiritually in harmony with your body, the Heavenly energy and Earthly energy. You can now begin your practice. *From: Vero Beach Qi-gong Society*

In Memoriam - Shari Farber Tritt



It is with profound sadness that we announce the death of a member of the DMRF family, **Shari Farber Tritt**. Shari and her husband Ira touched the hearts of millions through the dystonia documentary film, TWISTED. Shari was an inspiration every day. Although dystonia took much from her, she never let it defeat her. Shari had a love of life, an infectious laughter, a devotion to her family and the courage she demonstrated was a source of strength for so many in our community. Shari died on Saturday June 5, after a tragic accident in their swimming pool. She will be missed by many. Our sympathies go out to Ira, her parents, Harriett and Joel, and her sister Beth.

Stu Higdon Retires as Ottawa Gatineau Support Group Leader

Stu Higdon who has led the Ottawa Gatineau Support Group for 15 years has retired as Support Group Leader. On behalf of the Dystonia Medical Research Foundation Canada we would like to pay tribute and honour Stu and his wife Mary for their absolute dedication to help people with dystonia. Stu has brought so much passion and energy to this cause, and has accomplished so much over the years. As well, he has provided much insight and guidance to the small team at the National Office. Stu is leaving an amazing legacy. Thank you so much Stu for everything you have done and for being who you are.



Devoted support group member, Kathryn Sullivan organized a surprise farewell party for Stu that was a resounding success complete with dinner, DMRF Canada commemorative crystal, great gift certificates, flowers and a hand-made 7 X 8 quilt from Stu's home province of Newfoundland.

In his note to the membership Stu said: "I wish to sincerely thank everyone for supporting me for the past 15 years, either as telephone callers, treasurer, newsletter editor, social gatherings, the annual Walk and Wheel on Parliament Hill, Awareness programs on

radio, TV, as well as the many other activities you have pitched in to help with during my time as leader.

I would like to express my appreciation to my wife Mary who has constantly stood behind me and encouraged me, my brother Gordon, who passed away last year of cancer after having dealt with generalized dystonia all his life and who was always a strong inspiration to me, my own family who always supported me throughout my 15 years with the Group, and finally to my God who overlooked my shortcomings and provided me with the health to help others. Thank you so much for your friendships. May God bless each and every one of you."

Moving forward, John Heney has stepped up to assist with the group as Area Contact. Jennifer Greer and Dorothy Hearty will be active in organizing information sessions and events, Branka Jovic continues as the editor of the Ottawa/Gatineau newsletter. Coffee meeting callers are still very much involved. Thanks to all of the group members for your support!

University of Calgary Researching Dystonia Related Sensor Device

In 2009 a team of researchers at the University of Calgary, Department of Geomatics Engineering recruited volunteers with dystonia to spend one hour working with a computer for the purpose of following patterns on a computer screen using a computer mouse and performing a similar task for a three dimensional motion analysis.

The research focused on understanding the motion associated with dystonia and the development of devices to increase the quality of life of those afflicted with Dystonia. These devices will likely assist in daily tasks such as eating soup, drinking coffee and writing.

Wesley Teskey, M.Sc., Ph.D. Candidate, NSERC CGS-D and AIF Scholar has been the lead contact with DMRF Canada in providing updates on the research. Following is our interview with Teskey about the unique device.

Tell us about the device?

We use inertial sensors (accelerometers and gyroscopes) that monitor patient motion. Both of these sensor types can be found inside the Personal Navigation System (PNS). The new iPhone also has these sensors embedded, so we may shift to that platform for logging motion in the near future.

How does the device operate, what are the functions, what are the goals?

The inertial sensors are motion sensors. They log motion data which we later interpret to determine movement disorder components of motion. There are two main goals:

1. Assessment of movement disorder motion: this can include evaluation of patient frequency of motion as

well as direction of motion (lateral, vertical). The main usefulness of this is that it can be used to help doctors with evaluation (and diagnosis) of movement disorders.



Wesley Teskey

2. Attenuation (active mitigation) of movement disorder motion can also be carried out. This can include electronic as well as mechanical attenuation. One example of electronic attenuation is the use of a computer program to interpret the writing of a patient with a movement disorder (using specialized optical character recognition algorithms). Also, one example of mechanical attenuation is an orthosis that dampens movement disorder motion while a patient is completing a task (we are not specifically involved in research in these areas of attenuation yet, although we may be in the near future).

How will this device assist people with dystonia/movement disorders?

We may create any of the following in the near future:

1. A device to help doctors characterize movement disorders by detailing the motion that a patient is undergoing. This can be very beneficial for someone in a remote community that does not have easy access to a doctor (or movement disorder specialist) because they can send the details of their motion over the internet and have it analyzed remotely. It can also help to bring standardization across medical professionals studying movement disorders by introducing objective means of quantifying disorders.

2. A daily monitoring system that can track patient motion during the day to assess the usefulness of different medications. This system can either be attached to a patient's hand (not our preference) or can consist of specified motion a patient can carry out once or twice a day (such as lifting a device with inertial sensors and holding it in front of them in a static mode for a predetermined number of seconds).

3. A device that we may be able to produce (in the near term) to help patients overcome their disorder is a computer program that analyzes and interprets patient's writing (i.e. converting it into letters a computer can understand). For example, a program written for an iPad can possibly achieve this. Patients' often complain that their writing is not legible so this could be very helpful to them.

Can you tell us about the research team?

We are a team consisting mainly of engineering and kinesiology researchers. With decades of research experience and a broad background, our team is well suited to advance the understanding of dystonia and help improve the quality of life of those afflicted. Team members are:

Dr. Naser El-Sheimy – Department of Geomatics Engineering at the University of Calgary

Dr. Brian MacIntosh – Faculty of Kinesiology at the University of Calgary

Ken Grandia – President of Trimet Environmental Consultants Ltd.

Dr. Derek Lichti – Department of Geomatics Engineering at the University of Calgary

Dr. Phillip Gardiner – Faculty of Kinesiology and Recreation Management at the University of Manitoba

Dr. Mohamed Elhabiby – post doctorate fellow

Wesley Teskey – PhD student in the Department of Geomatics Engineering at The University of Calgary

Most of people on the team are advisors and contribute through their feedback and critique of the work. My supervisor, Dr. Naser El-Sheimy, and Dr. Brian MacIntosh take care of most of the financing for the research. Dr. Mohamed Elhabiby who joined the group about a year ago helps with data processing and writing papers. I am chiefly the person that is collecting data, processing data and writing papers. Ken Grandia has helped a lot with finding patients for examination and ideas about how to proceed.

When do you anticipate that the public will be able to use this technology?

Probably in the next year or so; but this depends very much on circumstances. If we enter into an agreement with a company to do a more thorough product design it may take a few years. If we engage a group of medical researchers and offer them our services, we may be able to directly impact patients within a year if these professionals use our technology to help them make key decisions.

You have had patient trials, what has been the result of those trials?

So far we have one published paper and two more submitted. I have also presented a separate paper at an academic conference earlier this year. All papers were written with the assistance of Dr. Mohamed Elhabiby and Dr. Naser El-Sheimy (they are also co-authors). There are four more papers we hope to have submitted for publication by the end of this year.

Is there anything else you would like to add?

Just a thank you to all the patients and others who helped us carry out this research by volunteering their time. Also thank to Bruce Wright who designed the PNS system and all member of the MMSS (Mobile Multi-Sensor Systems) Research Group (this is the group run by my supervisor, Dr. Naser El-Sheimy).

Thanks as well to the following funding agencies: AIF (Alberta Ingenuity Fund) which has

changed its name recently to Alberta Innovates Technology Futures, NSERC (the Natural Sciences and Engineering Research Council of Canada) and GEOIDE (Geomatics for Informed Decisions).

I would also like to personally thank all the collaborators I have named in this article.



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	Tracy	Henry	Chatham-Kent, Sarnia-Lambton Support Group Leader	519.354.6833	tracyhenry@sympatico.ca	
	QC	Steve	Tremblay	Quebec Provincial Representative		steve.tremblay@dystonie-qc.org
		Ginette	St-Hilaire	Quebec On-Line Support Group	http://dystonie-qc.org	webmaster@dystonie-qc.org
Chloe		Belisle	Montreal Support Group Leader	514.696.0949	honeylocas@sympatico.ca	
Queenie		Grosz	Montreal Area Contact	514.223.2394		
NB	Edna	Jordan	Fredericton Area Contact	506.453.0708		
	Tim	Williston	Fredericton Area Contact	506.457.2388	tim.williston@hotmail.com	
	Shirley	Sharkey	Moncton Support Group	506.204.2722	j.s.sharkey@rogers.com	
NS	Marcellin	Chiasson	Port Hawkesbury Area Contact	902.625.1811	marcellin.chiasson@ns.sympatico.ca	
	Marion	Nauss	Queen's County Area Contact	902.677.2506		
NU	Sharon	Gee	Nunavit Area Contact	867.979.3791	candsgee@northwestel.net	

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