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Making BC Disability
Research a Priority



Michael Smith Foundation for
Health Research

DHRN Video Project con't

WIRELESS TECHNOLOGIES FOR PEOPLE WITH DISABILITIES

Gary Birch

This video highlights some of the research currently being done to make wireless technologies more accessible. A number of assistive technologies have been developed over the past years for persons with significant physical disabilities to help them with their activities of daily living. Stand-alone devices, as well as solutions that make use of commercially available technologies such as personal computers have given people more control over their home environments.

When people are away from their homes, however, there are fewer options. Researchers are now looking at harnessing the capabilities of wireless devices to serve persons with disabilities when they are out and about. The research includes developing methods of making mobile phones more accessible. This includes examining the many wireless features and services available to mobile users and determining which of those can best serve persons with disabilities. In addition, the accessibility of new services as they become available needs to be addressed.

Available on YouTube: <http://tinyurl.com/ydcg12j>

FINE ARTS AND DISABILITY

Sara Lige

This film concerns the documentation and validation of artists with developmental disabilities. As an artist and parent of an adult child with a developmental disability, Sara realized that this population has had limited opportunity to access creative expression. It appears that an association between developmental disabilities and the arts is generally assumed to be therapy. There is little recognition of persons with developmental disabilities being creative people.

Research has shown a correlation between participation in art based activities and overall health for all people, therefore equal access becomes a health issue as well as one concerned with arts and culture. The methodology of this research project is emancipatory. The goals of the research are to educate the larger community concerning the abilities of adults with developmental disabilities and promote awareness; the intent is also to give voice to a marginalized population.

This film was made as part of a Special Topics graduate level course at UBCO with Professor Stephen Foster.

Available on YouTube: <http://tinyurl.com/ybmj3uu>

DHRN now on YouTube™

Disabilities Health Research Network is pleased to announce that our information video is now on YouTube.

This video explains the role of the DHRN in supporting disability health research in BC and the importance of the need to move forward with work that supports the disability community.

To view the video go to www.youtube.com and search for DHRN. You can also access this video directly at <http://tinyurl.com/y18jsbs>.



www.youtube.com

DHRN Link

Disabilities Health Research Network

Mission

To increase knowledge about biological, social, and community related factors in order to minimize further impairment, improve levels of ability, and enhance community participation of persons with disability.



2009 Annual Conference

The 4th Annual DHRN Conference was held at the Westin Bayshore, Vancouver on October 8-9, 2009. It opened after the AGM with a Disability Film Festival featuring films from the DHRN funded video project and a full menu of films presented by "Picture This..." Canada's first international disability film festival. Our conference evaluation indicated that all was exceptional.

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And more

Sexual Device Manual Available

Thanks to Edith MacHattie and Kate Naphtalie, the Sexual Device Manual for Persons with Disabilities is now available and is already making waves.

Find out how you can download your copy today.

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Travel Subsidy Recipients Share

2009 Graduate Student Travel Subsidy Recipients Sesath Hewapathirane and Veronica Schiariti share their individual stories and experiences. Learn how their awards are helping them contribute to disability research.

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Upcoming Event

2010
February 4-5
Vancouver, BC

Conference DHRN Annual Student Conference

A student advisory committee has been formed to determine the focus and content of the DHRN Annual Student Conference to ensure that this conference delivers to the specific needs of students involved in disability health research. Watch for further announcements in upcoming e-newsletters and save the date!



The Value in Evaluation: Enhancing Research and Program Success

The Disabilities Health Research Network presented its fourth annual conference recently at the Westin Bayshore Vancouver on October 8 and 9, 2009. The conference entitled, "The Value in Evaluation: Enhancing Research and Program Success" was attended by 73 DHRN members representing both the research and community perspective of our membership. The focus of the conference was based on the outcomes of a focus group that the DHRN held in June 2009. The conference agenda was developed around the theme of evaluation.

"I appreciate the generosity of the sharing of such valuable information. This will have great impacts as I approach my programming at all levels. Thank you."

Kicking off the conference on October 8th, the DHRN was pleased to premiere the DHRN Video Project which included four videos and the Picture this... disability film festival. Picture this... produces Canada's first international disability film festival which happens in Calgary every February. This year will be their ninth year. The festival highlights films produced by individuals with disabilities or about individuals with disabilities. Between the festivals, this Calgary based organization, conducts "Picture this... on the road" as a traveling show. The DHRN brought them to open our conference as a "traveling" show which featured seven short films from a variety of genres. The festival was very well received.

The third annual general meeting was also held at the conference where we discussed future direction of the DHRN. The decision was made to send out an online survey to get the feedback of our membership keeping in mind that funding will cease as of March 31, 2010. This follows the decision of the Michael Smith Foundation for Health Research to cease funding of all Health of Population networks as of March 31, 2009.



Our conference evaluation gave us important feedback on the success of the conference. The most highly rated presentations were delivered by Faye Wightman, President and CEO of the Vancouver Foundation and Marla Steinburg, Director of Evaluation for The CAPTURE Project. Faye spoke about the Government Non Profit Initiative which is described on their website (www.nonprofitinitiative.gov.bc.ca) as being created to bring the two sectors of government and non-profit together to become partners in improving the collective well-being of British Columbians. She spoke of the importance of

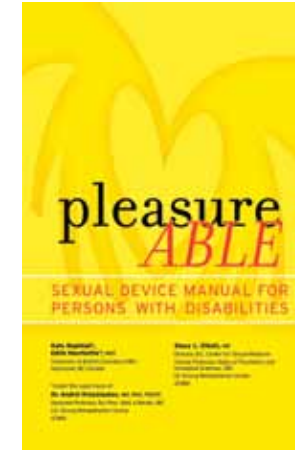
working together and creating more strength within the non-profit sector. There is a need, Faye articulated, to open a dialogue between government and non-profit to address the current reality of complex issues. Marla's down to earth presentation mixed humour with great tips for creating evaluation success. People felt ready to tackle their evaluation issues with her tips on

planning, data collection, analysis and interpretation, reporting and dissemination and utilizing results.

The networking opportunities were much appreciated as people were given the opportunity to connect with others about their work. Sylvie Zebroff, former Director of Programs for the DHRN, was presented with a beautiful print by Stan Greene for her significant contribution to the DHRN. Sylvie has accepted a new role with Community Living BC as their Family Partnership Advisor. Everyone enjoyed the Westin Bayshore Vancouver and took away tools to assist them with their evaluation challenges.

"The Keynote was an excellent speaker. The session was very informative as to what is being done to bring people and funds together."

Sexual Device Manual Available



DHRN members Edith MacHattie and Kate Naphtalie are pleased to announce the completion of their manual entitled, "Sexual Device Manual for Persons with Disabilities". Under the direction of Dr. Andrei Krassioukov, MD, PhD, FRCPC and Stacy Elliott, MD, this project was funded through the DHRN. This manual is already making waves after being recently released in September of 2009. Dr. Krassioukov and Dr. Elliott in fact just presented the manual as part of a presentation made to the International Spinal Cord Society 48th Annual Scientific Meeting held in Florence, Italy

did a podium presentation of their manual at the 2009 Congress on Spinal Cord Medicine and Rehabilitation Conference held in Dallas, Texas. This conference is put on by five major organizing bodies including the American Association of Spinal Cord Injury Nurses, American Association of Spinal Cord Injury Psychologists and Social Workers, American Paraplegia Society, Therapy Leadership Council in Spinal Cord Injury, and the American Spinal Injury Association. MacHattie and Naphtalie have also presented the manual at the Fraser Health Authority Bridges conference to 200 Occupational Therapists from across the region. The manual has been well received as a resource that can generate more dialogue between clinicians and their clients.



on October 21-24, 2009. Almost one hundred downloads have been made to date including several from rehab specialists and doctors attending this meeting. Dr. Claus Hultling from Sweden has complimented this new manual which seems to have hit a nerve in terms of filling a void for resources in this area.

The Sexual Device Manual for Persons with Disabilities includes research, clinical expertise and product information. It is intended for health care professionals and their clients with various disabilities. The American Occupational Therapy Association (AOTA, 1986) has defined sexual expression as "engaging in desired sexual and intimate activities" and has categorized it as an activity of daily living (ADL) placing it in the same realm as dressing, eating, and toileting in terms of rehabilitation activities to focus on. (Friedman, 1997) The hope is that this manual will encourage dialogue between clinicians and their clients surrounding sexual and reproductive issues for those with disabilities.

The interest shown to date indicates that this manual serves to fill a need that often is just not talked about and where resources are severely lacking. In September 2009, both MacHattie and Naphtalie

Research shows that sexuality is a major rehabilitation priority for clients, and we strongly believe that sexuality is very important to talk about—something that should be respected, celebrated, playful, and PleasurAble! We hope that you and some new ideas inside to improve and expand the sexual options for yourself or your clients.

—Edith MacHattie & Kate Naphtalie

The manual is available on the web for download at: <http://tinyurl.com/yznccao>. There are also plans to disseminate print copies to each major rehab centre. MacHattie and Naphtalie are also available for speaker engagements. They are hoping that professionals will address sexual health more in their practices to help close the awkward silence surrounding this topic by initiating dialogue with their clients. They are suggesting that practitioners ask themselves, "Do I talk about sex with my clients? Why don't I? What is my obligation to my clients?" If you are interested in learning more, please e-mail them at dhrnmanual@gmail.com.

DHRN Graduate Student Travel Subsidy—Round 4 Deadline December 1, 2009

The Disabilities Health Research Network understands and appreciates that conference participation and presentation is an integral part of building research capacity and partnerships.

We are excited to announce our latest DHRN Graduate Student Travel Subsidy for International and National conferences. These subsidies are offered to graduate students and honours senior undergraduate students for travel to national and international conferences.

The next round of subsidy applications are being accepted until December 1, 2009. The application can be downloaded from <http://tinyurl.com/ydpxbzg>

Please note that conferences must take place prior to March 31, 2010 in order to qualify for this funding.



Researcher Connections

by Beth DeVolder

Removing Barriers and Enabling Individuals: Ethics, Design, and Use of Assistive Technologies

Co-sponsored by Peter Wall Institute for Advanced Studies (UBC) and The Disability Health Research Network

In what Peter Wall Institute for Advanced Studies director Diane Newell describes as an “innovative, creative and courageous model exploratory workshop,” an internationally renowned and interdisciplinary team of scientists assembled July 22-24, 2009 at the University of British Columbia to analyze the problems and hypothesize solutions concerning the ethics, design and use of assistive technologies. Conference organizers Dr. Meeko Oishi (Electrical Engineering—hybrid control theory), Dr. Machiel Van der Loos (Mechanical Engineering—rehabilitation technology), and Dr. Ian Mitchell (Computer Science—numerical method for hybrid systems) believe that “The gaps between engineering design, clinical evaluation, and actual use represent an inherently multidisciplinary challenge that must be forcefully and creatively addressed if assistive technologies are to better succeed in enhancing people’s lives.”



There is no question that this workshop tackled that task in earnest, spanning three days, with eight invited speakers and four small group discussion sessions and bringing together researchers from computer science, engineering, social science, humanities, medicine, rehabilitative and clinical fields. Three key recommendations for improving assistive technologies emerged from the discussions. 1) The user’s experience is crucial to both engineering design and the clinical evaluation process and must be central to and fully integrated in both. 2) Services models (such as The Tetra Society of North America,

CanAssist University of Victoria and YokyWorks.org) are important vehicles for academic outreach in that they provide customized assistive technology solutions for individuals and ground the researcher in real-world applications. 3) In developing and commercializing assistive technologies, the issues that need to be addressed are improving standards/regulations, limiting liability through mechanisms that pool risk and promoting investment in small, niche markets.

Dr. Oishi is delighted that there is a growing, “critical mass” of researchers who are committed to improving assistive technology and “bringing to market new devices, such that they incorporate ethical, social and clinical concerns by design.” Further, the workshop succeeded in fostering working relationships between UBC researchers from different departments on assistive technology-related projects and grant proposals. With common context established, the hope is that collaborations that produce grants, articles, and products will soon follow. Many workshop participants are members of multidisciplinary team, led by Dr. William Miller (Occupational Therapy), that has just recently received a CIHR Team Start-up Grant for CanWheel, a 6-year project in Mobility in Aging. In addition, participants are crafting journal papers and an edited volume based on the workshop discussions.

For more information about this workshop visit their website: <http://www.removingbarriers.pwias.ubc.ca>

Dr. Meeko Oishi’s Bio

Dr. Meeko Oishi is an Assistant Professor Electrical and Computer Engineering University of British Columbia. Some of Dr. Oishi’s current work focuses on improving the safety of the indoor operation of power wheelchairs through verification techniques based on hybrid control theory. This is an extension of her analysis involving the human-automation interface in aircraft autopilots. A major challenge, Oishi acknowledges, is the heterogeneity of wheelchair users and the kinds of human input that could compromise the safety of the system. This is in contrast to the behaviours of pilots which, due to intensive training, are more homogenous. Oishi hopes to develop a general algorithm for verification that can be used to inform the design of a user-interface which would communicate to the user the safety level of their input.



DHRN Video Project

A Review



The Disabilities Health Research Network is pleased to announce five completed video projects that were funded recently as part of the DHRN video project. The aim of the project is to fund disability research videos that address both the social and biomedical perspective.

DISABILITY RESEARCH INTEGRATION

Andy Hoffer

The SFU Centre for Disability Independence Research and Education (CDIRE) provides a site where persons with physical disabilities can meet with researchers to analyze ways to improve their performance of activities of daily living and other needs, and to come up with innovative solutions that may be jointly conceived, developed and tested. Our setting encourages participation by and knowledge transfer among researchers, staff, undergraduate and graduate students, educators, clinicians and health professionals.

The CDIRE promotional video was produced by Scionized Media of Port Moody, BC in December 2008/January 2009, hence the wintry scenery. Katrina Hoffer, a third-year SFU communications student, created the script and directed the interviews. Justin Hwang, a third-year UBC film student, shot and edited the video footage. The interviewed subjects are students, faculty, and staff who participated in CDIRE-sponsored activities.

Available on YouTube: <http://tinyurl.com/ybj5ypm>

READY TO ROLL?

Ben Mortenson

For most individuals living in residential care, wheelchairs are their primary means of mobility. Despite their intuitive benefits, however, little research has been done on how wheelchairs are used in these settings.

This video illustrates the findings of research done to learn about the lives of these residents and identify ways to improve their mobility and participation in activity by sharing the stories of three residents. This video emphasizes the pivotal role that wheelchairs play for these residents, reveals institutional procedures that may curtail their mobility and activity, and suggests potential policy and practice changes that may improve the quality of their lives.

Available soon on YouTube: Keyword: DHRN

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Membership

Would you like to become a member of the DHRN?

Benefits of membership include access to DHRN programs as well as real and regular opportunities to network with disability health researchers, community partners and organizations throughout BC. Benefits include the following:

- + Networking Opportunities
- + Research Team Support
- + Workshops
- + Funding Opportunity Updates
- + Funding Application Support
- + Professional Development
- + Student Travel Subsidies
- + Student Conference
- + Internship Opportunities
- + Travel Bursaries
- + Annual DHRN Conference
- + DHRN Website
- + Member Profiles
- + Conduct Your Own Webinars
- + DHRN Link Newsletter
- + E-Newsletter

Please visit www.dhrn.ca for further information and online registration

it's Free

Student Connections

This year's award recipients



Sesath Hewapathirane, MSc and PhD 2009 Graduate Student Travel Subsidy Recipient



I am a PhD candidate working at UBC's Brain Research Centre in Vancouver. With generous support from the Disabilities Health Research Network I was able to attend this year's annual meeting of the Society for Neuroscience conference, held in Chicago USA. Being the largest neuroscience conference, with over 30,000 neuroscientists converging from around the globe, the sheer scale of these conferences is both intimidating and inspiring.

My research interests revolve around epilepsy and seizures, and I was quite happy to see that this field of research was very well represented at this year's conference. I was able to interact with leading researchers in the field, and to hear about the interesting work being done. In addition to receiving

critical feedback on my own research, it was encouraging to hear the many new ideas and suggestions for novel directions in which I could take my work. In fact, some researchers expressed interest in setting up collaborative projects—which is always an exciting prospect.

For me, a central benefit of attending such a large conference is being able to see research sub-fields that I am not often exposed to. I have learned that gaining exposure to diverse research interests in fact broadens one's own work, and often yields new ideas. I therefore also made an active effort to attend talks and chat with poster presenters in various other sub-disciplines. We were also able to hear keynote talks from Nobel laureates and other distinguished neuroscientists. Personally, these experiences re-affirmed my genuine interest in the brain, and also gave me confidence that many bright and motivated individuals are working together to unravel the many mysteries still facing us.

Overall, being able to attend this conference was an excellent experience, and I am very thankful to the Disabilities Health Research Network for facilitating my attendance.

Veronica Schiariti, MD MHS PhD (C) 2009 Graduate Student Travel Subsidy Recipient



I would like to thank the Disabilities Health Research Network for granting me the graduate student travel subsidy. I presented my project at the Canadian Paediatric Society (CPS) conference meeting in Ottawa. Presenting at the CPS meeting provided me an opportunity to disseminate my findings on quality of life on children with Cerebral Palsy (CP).

The aim of this research project was to use the new International Classification of Functioning (ICF-CY) as a standard by which to compare the content of 8 different quality of life (QOL) measures. We found that the ICF-CY provided an international accepted, structured framework for the content comparison of CP QOL measures. The results will provide clinicians and researchers with additional information,

useful when selecting QOL measures.

My project was accepted for poster presentation, I had the opportunity to discuss with colleagues from different parts of the country about the impact of my study on every day clinical practice. In addition, I had good suggestions regarding how to report my findings and make my results more accessible and applicable at the clinical and research level. I learned a lot about what my colleagues are doing in different centres, and how they are applying the ICF in their centres. I even discussed with some of them the possibility to collaborate on different projects and share what we learned which is very excited.

Again, thanks for your support.

DHRN Student Travel Subsidies—Round 3

Name	Program / School	Conference	Location	Topic
National Applications				
Robin Roots	Department of Physical Therapy, UBC	15th International Qualitative Health Research Conference	Vancouver, BC	Interpretive Description: An Innovative Approach to Understanding the Complexity of Rural Rehabilitation Practice
Shirley C. Wong	PhD, Experimental Medicine, UBC	Canadian Society for Exercise Physiology Annual Scientific Meeting: Ideas Crossing Boundaries	Vancouver, BC	A comparison of cerebral blood flow response during an orthostatic challenge following steady state arm cycle versus hybrid exercise in persons with spinal cord injury and able-bodied individuals
Andrea Bundon	PhD, School of Human Kinetics, UBC	Qualitative Health Research	Vancouver, BC	"Something I Enjoy Doing and That I Can Do": Older Adults with Multiple Chronic Conditions and the Meaning of Physical Activity
Sara Lige	Masters/IGS, UBCO	10th Advances in Qualitative Methods Conference	Vancouver, BC	The challenges of navigating institutional ethics review boards when conducting research with vulnerable populations
Lizette Greyling	School of Exercise Science, Physical & Health Education, UVIC	3rd International Congress on Physical Activity & Public Health	Toronto, ON	Enhancing physical activity participation among adults with intellectual disability: What does the evidence tell us?
International Applications				
Jill Zwicker	Rehabilitation Sciences, UBC	American Physical Therapy Association Combined Sections Meeting	San Diego, CA	Motor Learning of Children with Developmental Coordination Disorder: Insights from Functional Magnetic Resonance Imaging (accepted as platform presentation)
Marie Westby	Rehabilitation Sciences, UBC	ARHP Annual Scientific Meeting	Philadelphia, PA	1) Back to the gym after total hip or knee replacement surgery (90min workshop); 2) Post-acute physiotherapy after primary total hip arthroplasty: A Cochrane systematic review (poster); 3) Post-acute physiotherapy after primary total hip arthroplasty: A Cochrane systematic review (poster).
Lynne M. Feehan	Post doctoral Fellow, Department of Physical Therapy, UBC	2009 ACR/ARHP Annual Scientific Meeting	Philadelphia, PA	Exercise Program Elements Deemed Important by Physiotherapists in Exercise Prescription Following Osteoporotic Fracture. [Feehan L, Li LC, MacIntyre DL, Harris SR, Kirkham A and the OSTEO-Fx Review team]
Xuefeng Liu	PhD in Neuroscience Program, UBC	2nd International Conference on Drug Discovery and Therapy	Dubai, UAE	A peptide based drug candidate for neurological diseases
Megan MacGillivray	Masters of Science, Human Kinetics, UBC	Neuroscience 2009	Chicago, Ill.	Modulation of Cutaneous Reflex Responses During Manual Wheeling
Taryn Klarner	School of Human Kinetics, Master of Science, UBC	Neuroscience 2009	Chicago, Ill.	Tendon vibration modulates the response to Lokomat-applied resistance
Jacquelyn Cragg	Post-graduate Trainee - Zoology, UBC/ICORD	International Symposium on Neural Regeneration	Pacific Grove, CA	Beyond the Glial Scar: Regeneration and Targeting of Axotomized monoaminergic Fibres
Andrew Gaudent	Department of Zoology PhD candidate, UBC/ICORD/VCHRI	13th International Symposium on Neural Regeneration	Pacific Grove, CA	The role of galectin-1 in degeneration and regeneration of sensory neurites
Leanne Ramer	PhD Zoology, UBC	13th International Symposium on Neural Regeneration	Pacific Grove, CA	Impaired Local Vasodilation May Contribute to Cardiovascular Dysfunction Following Spinal Cord Injury
Sarah Chapple	Master of Social Work, UBC	U21 Graduate Conference	Melbourne, AUS	"I Feel Like I Just Don't Quite Fit In": Working-Age Adults with a Physical Disability Share Their Experiences in Residential Care
Bubblepreet Randhawa	MA Rehabilitation Sciences, UBC	Combined Section's Meeting - American Physical Therapy Association	San Diego, CA	Effect of Repetitive Transcranial Magnetic Association on Bradykinesia in Parkinson Disease