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*Making BC Disability
 Research a Priority*



Michael Smith Foundation for
 Health Research

Annual Conference & AGM

Evaluation has negative connotations to many and often in a funder-recipient relationship the evaluation process can be extremely frustrating. The DHRN fall conference will help community groups to establish a road map to the evaluation puzzle. Sessions to address the ABC's of evaluation, creating a program logic model, easy information collection strategies and communications will seek to create a more positive and successful evaluation experience. The critical takeaway will be that these easy tools and techniques will also create better client outcomes.

A networking evening wine and cheese will also be held on October 8, 2009 at the Westin Bayshore Vancouver. The agenda will include a preview of the DHRN Video Projects and a Disability Film Festival guaranteed to entertain and educate at the same time. Don't miss this event!

Register now through www.dhrn.ca!

New Member Service

Personalize your profile!

Along with our launch of a new look for our DHRN website, we are pleased to offer our members an opportunity to add a personalized web profile. Shortly, you will be receiving an e-mail from us to invite you to log on to our site and build your own profile. You can add a brief bio, talk about the great work you are doing around disability health and tell us a story about how you became involved in this important work. We also encourage you to upload a photo of yourself.

One of the goals of the DHRN is to ensure that disability health researchers connect with each other to build stronger results around knowledge translation and exchange. We hope that this new tool will assist in you in collaborating with other members. Please be sure to create your profile!

New Website

Layout

We are pleased to present a new look for our website. We encourage and welcome your feedback. Check it out today!

www.dhrn.ca



DHRNLink

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.



Researcher Connections

Dr. Roy Brown and Dr. Jacqueline McAdam were awarded a 2007 Participation, Collaboration and Facilitation (PCF) grant from the DHRN. They were joined by their community partner Vancouver Island Community Support Services, represented by Leif Rasmussen. This DHRN PCF project is titled, "Family Quality of Life for Families with Children who have Intellectual Disabilities".

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Community Connections

David Segal has been working with youth, adults, and families through Power To Be Adventure Therapy. His "Adaptive Recreation Program" and his education in Psychology marries up to provide support for others.

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And more

2009 Graduate Student Travel Subsidy Recipients Angela Scott and Megan MacGillivray share their individual stories and experiences. Learn how their awards are helping them contribute to disability research.

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Upcoming Event

Fall

October 2009
 Vancouver BC

Conference

DHRN 3rd Annual Conference & AGM

This conference will offer attendees an opportunity to demystify the evaluation process through tips, techniques and practical skills.

see page 8 for details

Register now! For more information please visit our web site www.dhrn.ca



Researcher Connections

by Sheila Lewis

Dr. Roy Brown and Dr. Jacqueline McAdam were awarded a 2007 Participation, Collaboration and Facilitation (PCF) grant from the DHRN. They were joined by their community partner Vancouver Island Community Support Services, represented by Leif Rasmussen. This DHRN PCF project is titled, "Family Quality of Life for Families with Children who have Intellectual Disabilities".

Dr. Brown's interest in families with children who have intellectual disabilities has a long history - back to the 1970's. Initially, his interest lay with quality of life for people with disabilities. Dr. Brown and colleagues were amongst the first to research the issues of quality of life as an approach to intellectual and developmental disabilities. Traditionally, the focus has been on the person (child) with the disability, with little attention to the support required for other family members dealing with the challenges of living with a disabled child. This is now changing.

Dr. Brown and his team created workshops for families with children who have intellectual disabilities. The aim of these workshops was to provide a forum for disseminating and discussing research results. They were specifically interested in the results of research that had been conducted internationally and more recently in B.C., in regards to the family quality of life for families with intellectually disabled children. The survey instrument that Dr. Brown and his team used to collect the data is called the, Family Quality of Life Survey (Brown et al, 2006; Isaacs et al, 2007).

The survey developed from a grant his team received from Human Early Learning Partnership (HELP) and led to the application for the DHRN PCF grant. While working on the HELP project, Dr. Brown and his team attempted two things unique to Quality of Life Studies to date. First they were able to compare survey results based on different disabilities and behaviours in families. Then they were able, through the DHRN PCF grant, to further explore the varying family experiences. For example, how did the different backgrounds of the families shape their perspective about life with a child who has an intellectual disability?

In Family Quality of Life Research, it is accepted that

perceptions play an important part in the functioning of families. External factors, quite often, play a role as well. These factors encompass such things as finances, systems of support, family relationships and values. Through their work, Dr. Brown and his team were able to make some specific insights which included:

- Dental work was initially considered to be a health concern for families, but was in actuality a financial concern for many families.
- Respite care utilization was low due to long wait lists, lack of funding to cover the required hours and times of care, and lack of health care professional knowledge around the potential of respite care to alleviate many issues for these families.
- Many families misunderstood the mission of the survey tool which led to Drs. McAdam and Brown conducting a World Café (<http://www.theworldcafe.com/>) which is a facilitation and research method focused on creating open dialogue. The World Café opened up an opportunity for the families to use their own voice to express concerns and insights in a manner that enabled researchers to be more successful at parlaying perceptions.

Where to go now is the biggest question facing Dr. Brown and his research team. The most obvious answer for them is to make the information that families have been lacking available to them and to provide mechanisms for solving the challenges facing individual families not just the person with the disability.

Dr. Brown and his team are evaluating their next steps. They have uncovered information that can greatly enhance the experience of families who are living with a child who has an intellectual disability. This information includes a range of services, resources, and funding concerns. They are currently working on a DVD as part of an information kit which includes results and recommendations to date. Parents believe that professionals, including frontline personnel, need to enhance services to children with an intellectual or developmental disability and understand the positive impact this support can have on other family members. For example, a parent who can continue their education can eventually help their family become more economically viable. Though there have been attempts to rectify the challenges, it is suggested that this could be more successfully done with greater input from families.

Researcher Connections cont'd

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Dr. Roy Brown's Bio

Dr. Brown has practiced as a Clinical and Educational Psychologist. He started the remedial education clinics in Bristol, UK, where he held the position of Research Fellow at Bristol University. He was appointed to the Department of Educational Psychology, University of Calgary in 1968. During this time he also served as the director of the Vocational and Rehabilitation Research Institute. Later he served as Department Head and Professor, and is now Professor Emeritus of Educational Psychology at the University of Calgary. Dr. Brown also spearheaded the development of the multi-disciplinary Rehabilitation Studies Program and became its Founding Director. From 1994, he was Foundation Professor at the School of Special



Education and Disability Studies, Flinders University, where he served as Dean for 6 years. He is a fellow of the British Psychological Society, the Canadian Psychological Association and The International Association for the Scientific Study of Intellectual Disability.

Publication Review

Cancer as a Contested Illness: Seeking Help amid Treatment

In their chapter, M.E. Purkis and C. Van Mossel set out to explore the linkages between knowledge, decision-making, identity, and power. They follow their exploration through a path already set by Rolland Munro (2004) called the 'demanding relation.' In their study, they worked with participants that had either been through cancer treatment or were in the midst of treatment. The authors were able to identify a clear relationship between the health care practitioner and the patient and the diagnosis of cancer. Once the diagnosis of cancer is made, the patient is positioned as needing help and a cure. The process of treatment



after diagnosis is a heavily negotiated one that often requires the patient to shift identities frequently during treatment. The reason behind this continual shift was the feeling that knowledge about what was happening to them was neither clear nor complete but was always in motion and frequently being revised. Yet, the standard view of cancer is that cancer can be detected, treated, and if not cured, at least managed as a chronic disease. The authors of this paper argue that if the disease was understood as being contentious, patients could engage in the diagnostic process with a better understanding which would allow them to better address treatment plans and choices. In this chapter, the authors work through the negotiation of treatment, monitoring trajectories, identity forming and re-forming, and reflecting on risk and desire.

M.E. Purkis, C. Van Mossel. (2008). *Cancer as a Contested Illness: Seeking Help amid Treatment*. In *Contesting Illness: Processes and Practices*. Katherine Teghtsoonian, Pamela Moss (Eds.), University of Toronto Press.

DON'T MISS OUT!

Register today for the 3rd Annual DHRN Conference at www.dhrn.ca

October 8-9, 2009

Westin Bayshore - Vancouver, BC



Community Connections

by Sheila Lewis



DHRN Member Profile David Segal, Power To Be Adventure Therapy

For over 10 years, Dave has been working with youth, adults and families in a wilderness context. He holds a B.A. in Psychology with an emphasis in Environmental Studies and is currently a M.A. candidate with the School of Child and Youth Care at the University of Victoria.

When asked what led him to working with families in an interactive outdoor experience, Dave responded that he wasn't satisfied with traditional office based therapeutic work or as a wilderness guide solely for the able. He felt a need for something more integrative and meaningful. This need for something meaningful led him to Victoria, BC, and ultimately to Power To Be Adventure Therapy (PTBAT), where he approached Tim Cormode, the executive director of PTBAT. He proposed the "Adaptive Recreation Program".

The "Adaptive Recreation Program" provides access to outdoor nature-based recreation for people of all ages living with a disability. The year-round inclusive program provides access to physical activities such as sea kayaking, alpine skiing, indoor rock climbing, gardening and camping. Dave's experience working in the setting of PTBAT has removed some of his perceptions about disability and has allowed him to redefine ability.

Dave and two academic research partners, Dr. Marie Hoskins and Dr. Nevin Harper, received a DHRN Collaboration, Research Exchange Grant for their project titled, "Examining identity loss, ambiguous loss and family functioning following acquired brain injury". In this project, Dave and his team are working with families whose lives have been changed dramatically by Acquired Brain Injury (ABI). Preliminary findings are confirming much of what the literature claims.

ABI provides unforeseen challenges, not only for the person with ABI, but for the entire family relationship and functioning. ABI, as Dave illustrates, places a strain on the family system that often leads to separations or reorganizations of the family structure. ABI also affects family members' identities and their ability to maintain coherent personal narratives. In most cases it is a male parent who is affected directly by ABI. Their identity as a parent and spouse comes into question and is challenged by the effects of ABI. However, there is hope. There are families that are finding strategies to prosper with ABI, through strength and resilience. Dave is focusing on these strategies and hopes they may help other families in the future.

The most significant issue for families whose lives are affected by ABI is the lack of services for the family group. Often, in these cases, there are services for the individual who has ABI, but little support, if any, for the family. Dave's results are supporting the claim that a significant impact comes from a phenomena emerging in the literature labeled as 'ambiguous losses'. Ambiguous loss refers to when it feels as if something has been taking away, but the person cannot say with certainty what that something is. The subtle personality changes experienced by the victim of ABI are often the most difficult for families to deal with.

What has proven most beneficial for the participants of Dave's study, has been their experiences with



David Segal cont'd

PTBAT's family program. Traditionally, outdoor activities have been difficult to pursue, as there are multiple accessibility issues for people with ABI. What PTBAT has been able to do is provide access to outdoor activities that would otherwise be too difficult for these families. As a result, families are able to interact with other families who are fielding the same kinds of challenges. In addition, the children in these families are able to interact with other children and see that their world is not so different. The experience with PTBAT allows families living with disability to return to a sense of normalcy.

For Dave, the experience of working as a community partner with academic researchers has created great benefits. These relationships have allowed him to bring together his experience with Dr. Harper's specialty in Adventure Therapy and Dr. Hoskins specialty in Identity and introduce academic experience and rigor to his work. This has allowed PTBAT to expand and be more effective in their outdoor integrative endeavors.

For more information about PTBAT programs and background, please see www.powertobe.ca



Understanding DHRN Member Needs: DHRN Evaluation Focus Group

On June 19, 2009, DHRN held a focus group at the ICORD facility in Vancouver, BC where DHRN community-based members and disability researchers provided input to inform the upcoming DHRN 3rd Annual Conference agenda. The focus group was facilitated by ASC Applied Solutions and Consulting. In addition to this focus group, ASC will be conducting phone interviews with funding and social policy agencies to bring this lens into the planning for the DHRN fall conference.

Evaluation seems to be one of those things that can cause tremendous stress for community organizations and researchers alike. It was clear from the focus group discussion that evaluation experiences are often unpleasant, negative and stressful. Many organizations find it challenging to put aside time to devote to evaluation and feel disconnected from the process. Different funders seem to require the collection of different information or the same information but require it in different formats. Many feel that the data funders collect don't accurately reflect the good work that they are doing in serving their clients. There is considerable frustration and fear among community groups around evaluation. They know it has to be done but it is painful when played out in an environment of low resources.

see page 07

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

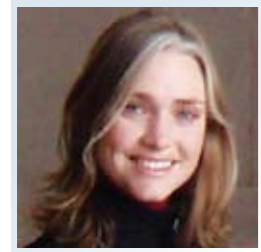
Please visit www.dhrn.ca for further information and online registration

it's Free



Student Connections

This year's award recipients



Angela Scott
2009 Graduate Student Travel Subsidy Recipient

I would like to begin by first extending my gratitude to the DHRN for the opportunity to travel to the 38th Annual Meeting of the Society for Neuroscience, held in Washington, D.C. last November. This is the largest neuroscience meeting in North America and, had it not been for the travel award, I may have missed out on an incredible opportunity and experience. With the recent election of the new American President, Washington was buzzing with energy, and it was a truly exciting environment for the 31,000 people descending in for the conference.

Among those attending, there was a large collection of people that study neural trauma, a theme of research interest that I share. As a senior graduate student in ICORD at the new Blusson Spinal Cord Center, my work is focused on nerve injury and the development of possible recovery strategies, with particular attention to the spinal cord. At the meeting, I presented a study that showed improved nerve regeneration within the spinal cord and functional recovery of sensation following injury to the sensory neurons that connect the periphery to the central nervous system. I received a substantial amount of feedback on the project, including suggestions for future studies and possible collaborations.

During the course of the meeting I made several important contacts, which have since flourished into possible job opportunities. This is particularly important to students, such as myself, that are close to completing their degree, and facing many important decisions and an ever-fluctuating job market. This experience was a great success in many respects, one that not only produced significant benefits to my research, but also helped to brighten a future career path in neuroscience.



Megan MacGillivray
2009 Graduate Student Travel Subsidy Recipient

Traveling to Amsterdam to present at the 4th International State-of-the-art Congress "Rehabilitation: Mobility, Exercise and Sports" was a wonderful experience made possible through the DHRN. The conference explored multiple facets of rehabilitation including the most recent views and research on mobility (in particular wheeled mobility) as well as many elements of exercise and sport. By incorporating mobility, exercise and sport, a broad and interesting

perspective of the importance of integration of each of these three elements was provided. Presentations ranged from cardio respiratory research to the benefits of functional electrical stimulation to studies evaluating quality of life.

To date there has been very little research into the neural control of manual wheeling. One concept is that rhythmic upper limb movement is regulated by a central pattern generator (CPG) and follows a similar pattern of sensory processing as described for walking. My study explored this concept by investigating the modulation of cutaneous reflexes during manual wheeling. Preliminary analysis has provided evidence that manual wheeling exhibits phase dependent cutaneous reflex modulation. Further analysis will look at task specificity between arm cycling and manual wheeling as well as differences in cutaneous reflex modulation based on manual wheeling experience.

It was great to take part in a conference with such a diverse group of researchers from different backgrounds. I feel very fortunate to have had the experience to attend such a wonderful international event. It was great to discuss my project and make connections with people from around the world. Through this experience I learned the benefits of international collaboration and how research is capable of bringing people together irrespective of nationality and language.

The conference provided me with the opportunity to gain experience presenting my project as well as receiving constructive feedback from people with new outlooks. Hearing presentations from several world-known researchers, as well as many students throughout the world, offered a motivating and exciting environment.

2009 Travel Awards

| Name | Program / School | Conference | Location | Topic |
|---------------------------|--|--|--------------------------|---|
| National Apps | | | | |
| Amanda Hume | School of Psychology UBC | American Psychological Association (APA) Convention | Toronto, ON | Factors Affecting Sustainability of School-wide PBS |
| Courtney (Weiqun) Kang | School of Public and Population Health UBC | 2009 OARSI World Congress of OsteoArthritis | Montreal, QC | Input of total physical activity in younger age on physical & mental health of people with osteoarthritis |
| Kimberly Beirnes | Biology UBC | Canadian Human Genetics Conference | Harrison Hot Springs, BC | SMARCAL1 deficiency: the paradox of phenotypic specificity |
| Robin Roots | Physical Therapy UBC | Research to Action: Improving Health in Rural BC | Prince George, BC | Understanding rehabilitation practice in rural British Columbia: an interpretive description |
| Shalini Lal | Rehabilitation Sciences UBC | Canadian Association of Occupational Therapists Annual Conference 2009 | Ottawa, ON | A Systematic Review of Photovoice |
| Cheryl Walton | Animal Biology UBC | 3rd ASM Conference on DNA Repair and Mutagenesis | Whistler, BC | Defining the Role of Tyrosyl-DNA Phosphodiesterase (Tdp1) in Human Disease |
| International Apps | | | | |
| David Mikhail | Integrated Sciences UBC | 2009 ISCoS Research Meeting | Florence, Italy | Orthostatic hypotension among wheelchair athletes |
| David Segal | School of Child and Youth Care Uvic | 5th International Adventure Therapy Conference | Edinburgh, UK | Examining narratives of loss, identity reconstruction and family functioning following Acquired Brain Injury |
| Grace Boutilier | Experimental Medicine UBC | RehabMove | Amsterdam, Netherlands | The Segway PT as an Alternative Mobility Device |
| Jeanne Yiu | Rehabilitation Sciences Research UBC | IX Conference of the International Society of Quality of Lifestudies | Florence, Italy | Longitudinal Analysis of Balance Confidence in stroke Survivors Using a Hierarchical Linear Model |
| Jill Zwicker | Rehabilitation Sciences UBC | DCD VIII: Developmental Coordination Disorder International Conference | Baltimore, Maryland | Motor Learning of Children with Developmental Coordination Disorder: an fMRI study |
| Jodi Edwards | School of Population and Public Health UBC | 1st International Congress on Clinical Neurology and Epidemiology | Munich, Germany | Are changes in intracortical inhibition following transient ischemic attack associated with increased risk of acute stroke? |
| Karine Duval | Human Kinetics UBC | International Society for Posture and Gait Research International Conference | Bologna, Italy | Curved walking in individuals with stroke |
| Simon Chen | Neuroscience UBC | Society of Neuroscience 2009 | Chicago, IL | The role of neuroligins on dendritic morphogenesis |
| Patricia Branco Mills | Health Care and Epidemiology UBC | International Spinal Cord Society 48th Annual Scientific Meeting (ISCOS) | Florence, Italy | Influence of level and severity of Spinal Cord Injury on cardiovascular outcomes in humans: a meta-analysis |
| Gillian Simonett | Health Care and Epidemiology UBC | International Spinal Cord Society 48th Annual Scientific Meeting (ISCOS) | Florence, Italy | Adverse events during electro-acupuncture for spinal cord related neuropathic pain |
| Leanne Ramer | ICORD/Zoology UBC | Congress on Spinal Cord Medicine and Rehabilitation | Dallas, TX | Impaired local vasodilation may contribute to cardiovascular dysfunction following spinal cord injury |

Focus Group cont'd from page 05

As a result of this first stage of information gathering, the DHRN is planning the fall conference with a focus on creating more success in the area of evaluation. The conference will focus on creating strength through knowledge around the practical skills of evaluation and opening a dialogue between the funder and those that are funded.

To register for the 3rd Annual Conference, go to www.dhrn.ca.