

Research Report 2010 – 2014





Welcome to Thames Valley Children's Centre's Research Report!

The Thames Valley Children's Centre's (TVCC) Research Program proudly celebrated its 25th Anniversary this past year! This Report illustrates the scientific inquiry that has taken place here at TVCC during the past four years. Summarizing the work done by many researchers, clients, families, and clinicians is a formidable challenge. Capturing the vision of TVCC and its Research Program is simple: Our Clients at Their Best.

Jointly with Western University's Faculty of Health Sciences, we hosted the inaugural "Child Health Symposium" in 2014, bringing together large numbers of students, clinicians, and researchers to develop collaborative projects distinguished by high levels of academic and clinical expertise. Please find more details about the symposium inside this Report.

At Thames Valley Children's Centre, we seek to bring understanding, inquiry, and innovation to the work we do with children and youth across Southwestern Ontario. And we seek to make a difference in the lives of children and families worldwide through our research activities. In this Report, you will find a variety of research inquiries across different clinical areas. We use research evidence to inform our clinical and everyday practice and to help us in our decision-making processes.

Our research team is exceptionally productive, supporting front-line clinicians, leadership, and other researchers working with our clients. Their contributions are not always as obvious as when they are a named investigator or author – their enthusiasm may be the spark that ignites others' passion for research, and their expertise is behind many, many internal evaluation activities.

We also continue work on a large, multi-year grant from the Canadian Institute for Health Research (CIHR), doing groundbreaking research across the province into Quality of Life for youth with chronic conditions. We take great pride in this balance between supporting the day-to-day work of TVCC and producing original research of the highest academic standards.

Enjoy reading about our accomplishments thus far, and do not hesitate to contact us for more information if anything sparks your interest. Kathryn Hayman, Research Officer can be contacted at 519-685-8700, or at research@tvcc.on.ca.

Director, Quality Management
Thames Valley Children's Centre



Thames Valley Children's Centre is a regional rehabilitation centre for children and young adults with physical disabilities, communication disorders, developmental delays, and autism spectrum disorders, living primarily in Southwestern Ontario.

We are a community-oriented Centre providing assessment, diagnosis, consultation and therapy to help young people reach their potential in terms of independence, self-esteem and participation in society. We serve more than 7,500 children ranging from newborns to young adults, every year.

OUR MISSION:

We will provide rehabilitation services which support participation in all areas of life for children, youth and young adults with physical, communication or developmental needs, and their families, living primarily in Southwestern Ontario by:

- focusing on the strengths of individuals and their families at home, school, workplace and community
- pursuing research, education and advocacy
- partnering in a local and regional system of services

OUR VISION:

Our Clients at Their Best.



OUR VALUES:

- We believe people know themselves and their situations best
- We believe people want the best for themselves and others
- We believe people are unique and deserving of respect
- We believe people function best in a supportive environment

We believe people working in partnership can reach goals that cannot be reached alone



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RESEARCH PROGRAM

Research helps determine effective treatment and delivery of services to children with communication, physical, or developmental needs, and their families. It furthers our understanding of childhood disabilities and the issues they raise.

Research is a method of:

- asking and answering questions
- uncovering facts and causes
- confirming or disconfirming beliefs
- improving reasoning
- adding to knowledge

RESEARCH AT TVCC

According to Thames Valley Children's Centre's (TVCC) philosophy, research and evaluation activities are an integral part of providing quality services and interventions to clients.

Established in 1988, the Research Program at TVCC provides direct services, consultation, education, and resources to TVCC staff members. The Research Program also engages in research activities with TVCC staff members as well as external researchers. Our clients, their families, and staff members also participate in research.

TVCC's approach to research development is a multi-faceted and needs-based approach, with an emphasis on evaluation activities, where clinicians and researchers partner to evaluate services. Other types of research are also supported, including knowledge generation and sharing activities. The model is based on having staff with a high level of research expertise available to work with leadership and staff from across the Centre.

Key Theme Areas

The Research Program's two key theme areas are:

1. Evaluation of programs, interventions, treatments, and aspects of service delivery
2. Investigation of psychosocial aspects of disabilities

Key Goals

The four key goals of the research program are:

- To create a strong research climate that promotes TVCC staff members' awareness, enthusiasm, and participation in research and evaluation, and that fosters ongoing critical appraisal.
- To provide resources and ongoing, individualized support to TVCC staff members doing research.
- To share/disseminate research and evaluation findings internally and externally (e.g., with other children's rehabilitation centres and at professional conferences).
- To develop a reputation for excellence in paediatric rehabilitation research that is an integral part of pediatric services.

RESEARCH PROGRAM FUNCTIONS

The Research Program assists staff with research-related activities through direct involvement, consultation, education, and the provision of resources on how to approach all aspects of the research/evaluation process.

Direct and Consultation Services

Services include providing advice on and carrying out all aspects of the research/evaluation process (e.g., formulating a research question, designing a questionnaire, analysing data, selecting an agency to apply to for funding, selecting a journal for submission of a manuscript, etc.). Networking and collaboration to conduct research studies are encouraged and facilitated with other researchers in London, in Ontario, across Canada, and internationally.

In addition to research and evaluation studies, many in-house quality assurance activities take place at the centre. TVCC researchers also provide support for these activities.

Examples of Quality Assurance Activities

- Assessing caregiver satisfaction with Autism Services
- Creating evaluations for the Autism Program Parent Education workshops
- Developing Solution-Focused Coaching methods for paediatric rehabilitation service providers
- Conducting an assessment of "Getting Started at TVCC"



Education

Information sessions are arranged in which internal and external Principal Investigators share the results of research projects and discuss recently published research findings. These sessions encourage awareness, critical evaluation, and utilization of findings from the research literature. They also provide a forum for Principal Investigators to maximize the impact of findings on clinical practice by sharing outcomes with staff members from other TVCC programs and also external individuals and collaborators from other agencies.

Discovery Series Sessions

The "Discovery" sessions provide researchers with a forum to present the results of their research projects to the TVCC staff.



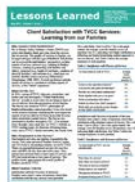
Facts to Go

Facts to Go are one-page information sheets on research topics written by staff members and published and distributed by the Research Program. The goal is to keep families, staff members, and the community updated on recent trends, issues, and future considerations in the area of childhood disability.



Lessons Learned

At TVCC, staff evaluate their practices, programs, and services to learn about what works best, and to enhance service delivery. As part of TVCC's knowledge transfer strategy, our Lessons Learned publication series provides staff an opportunity to communicate their findings, and share their lessons learned.



RESEARCH PROGRAM TEAM

Staffing

The Research Program Team includes:

- A Director
- Centre Researchers
- A Research Officer

The Research Program is part of the Quality Management (QM) Program at the Centre and is under the direction of the QM Program Director.

The Research staff members are funded through TVCC's Research Trust Fund. Project coordinators, data analysts, and research assistants are hired on an "as-needed" basis to work on specific projects and are funded by research project grants.

Team Members

Director

Karen Lowry, M.C.I.Sc (2006-present)

The **Director** provides overall direction to the Research Program, is responsible for the administrative aspects of the Program, and engages in research and writing collaborations with internal and external partners.

Centre Researchers

Janette McDougall, Ph.D. (1995-present)
Michelle Servais, Ph.D. (2000-present)

Centre Researchers consult with staff doing research projects, coordinate and implement research studies, and engage in research collaborations with internal and external partners.

Research Officer

Kathryn Hayman (2009-present)

The **Research Officer** coordinates administrative aspects of the Research Program, organizes the communication of research information, develops resources and information systems, documents and tracks all research activities, and acts as a resource to researchers.

Research Project Coordinators

Nicole Etherington, Ph.D. candidate (2013-present)
Megan Nichols, M.Sc. (2010-present)
Jonathan Schmidt, M.Sc. (2009-2010)

Research Project Coordinators are responsible for the day-to-day operations of a research project including: preparation of materials such as study forms, agendas, and minutes; maintenance of study databases; data collection and entry; data management; data analysis; and collaboration in the writing of articles and presentations.

Volunteer

Susan Readings (2005-2012)


The **Research Program Volunteer** is a valuable and dedicated resource to the

department. The Volunteer completes requested tasks such as mass mailings of publications and maintaining databases. Susan Readings retired in July 2012. Our Research Program thanks Susan for her dedication and commitment.

A LIFE NEEDS MODEL OF SERVICE

In conjunction with others at TVCC, the Research Program has played an instrumental role in the conceptualization of a model of services needed by children with disabilities, their families, and members of the community who play important roles in these children's lives.

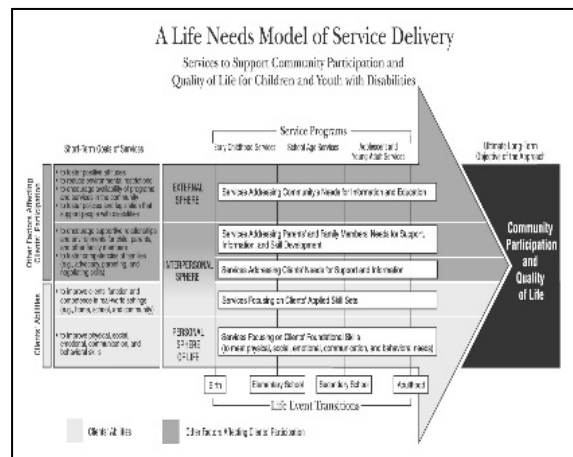
According to the Life Needs Model, the spectrum of services offered by TVCC should be based on the needs of children, their families, and communities. We believe that the family has an important impact on a child's development. We also believe that we must directly intervene at the community level to foster positive attitudes, create understandings, and encourage the development of inclusive legislation.



Research Program Key Facts

Since the creation of the Research Program 25 years ago:

- **155** staff members have been involved in research projects.
- TVCC staff members have been principal investigators on **84** projects.
- Members from all of TVCC's programs and therapy disciplines have been involved in research.
- **50** staff members have been involved in more than one research projects.



The Life Needs Model encompasses the who, what, where, why, and how of service delivery for children with disabilities. It specifies the major types of needs of clients, families, and community members (the “who”), which we believe should form the basis of the services we provide. The model integrates a family-centred approach to service delivery (the “how”) with the idea that services should be structured to meet the recipients’ needs (the “what”). It is a developmental model that focuses on key transitions in children’s lives (the “when”) and is community-based in nature (the “where”).

The key aim of the Life Needs Model (the “why”) is to support clients’ participation in all areas of life, thereby supporting them in “being their best” and being satisfied with their quality of life.

The Life Needs Model has promoted a broad understanding of the needs of children and families by providing a visual map of the types of services necessary to achieve community participation and quality of life.



2014 CHILD HEALTH SYMPOSIUM

On May 22, 2014, the Faculty of Health Sciences at Western University and the Thames Valley Children's Centre presented the first Child Health Symposium entitled, "**Collectively creating connections and collaborations: Research and best practices in child health**".

This successful one day event provided an opportunity for researchers, clinicians, and students from all disciplines to:

- Share their knowledge, ideas and best practices for service delivery
- Present current research interests and questions
- Learn more about the child health research happening in our community
- Network and build relationships and collaborations with other professionals working in the area of child health in the community



Keynote speaker was **Dr. Peter Rosenbaum, MD, FRCP(C)**

Peter Rosenbaum is Professor of Paediatrics at McMaster University and has held a Tier 1 Canada Research Chair since 2001. In 1989, he co-founded *CanChild* Centre for Childhood Disability Research.

Below is a list of the Symposium presentations. TVCC staff members are bold and italicized, former TVCC staff are italicized.

A Review of Physical Activity among Preschoolers in Home-Based Childcare

Presenters: Leigh M. Vanderloo, Olivia J. M. Martyniuk, & Patricia Tucker
Affiliation: Western University

The Influential Role Parents have on their Preschoolers' Physical Activity Levels

Presenters: Alana Maltby, & Patricia Tucker
Affiliation: Western University

Improving Listening Skills through Simulation for Pediatric Rehabilitation Therapists

Presenters: ***Tracy Shepherd***^{1,2}, ***Patricia Baldwin***¹, ***Linda Bolack***¹, ***Michelle Servais***¹, ***Colleen Willoughby***¹, Debbie Strachan⁷, Sheila Moodie³, Kathryn Parker⁴, Diane Savage⁴, Kerry Knickle⁵, Nancy McNaughton⁵, & *Gillian King*^{5,6}
Affiliations: Thames Valley Children's Centre¹, Centralized Equipment Pool², Western University³, Holland Bloorview Kids Rehabilitation Hospital⁴, University of Toronto⁵, Bloorview Research Institute⁶, No Affiliation⁷

A Conceptual Framework of Parent-to-Parent Support for Parents with Children who are Deaf or Hard of Hearing

Presenters: Rebecca Henderson, Andrew Johnson, & Sheila Moodie

Affiliation: Western University

Emerging Therapies in Duchenne Muscular Dystrophy

Presenter: Craig Campbell
Affiliation: London Health Sciences Centre, Western University

Examining Predictors of Exclusive Breastfeeding Initiation and Continuation up to 6 Months Postpartum

Presenters: Shilpa Goel, & Anita Cramp
Affiliation: Western University

Working Memory and Language Intervention for School-Aged Children

Presenters: Laura Pauls, & Lisa Archibald
Affiliation: Western University

Auditory Processing Disorders in School-Aged Children

Presenters: Chris M. Allen, & Prudence Allen
Affiliation: Western University

Disruptive Behaviour Disorders and Youth Justice: Implications for Occupational Therapy

Presenter: Donna Dennis
Affiliation: Western University

A Grounded Theory of the Process of Transition for Adolescents toward the Self-Management of their Hearing Health Care

Presenters: Christine Meston, Mary Beth Jennings, Margaret Cheesman, & Marilyn Evans
Affiliation: Western University

Quality of Life for Youth with Chronic Health Conditions: Exploring Related Factors

Presenters: **Janette McDougall**^{1,3}, Virginia Wright², & Linda Miller³
Affiliations: Thames Valley Children's Centre¹, Bloorview Research Institute², Western University³

Spirituality and Quality of Life: What Youth with Disabilities Have to Say

Presenters: **Patricia Baldwin**¹, **Jan Evans**¹, Virginia Wright², **Nicole Etherington**^{1,3}, Megan Nichols¹, & **Janette McDougall**^{1,3}
Affiliations: Thames Valley Children's Centre¹, Bloorview Research Institute², Western University³

Development of a Self-Efficacy Questionnaire for Aged-Related Activity and Participation for Adolescents with Hearing Loss

Presenters: Sahar Zimmo, Sheila Moodie, & Mary Beth Jennings
Affiliation: Western University

Toward Improvement of Augmentative and Alternative Communication Services for Young People with Complex Communication Needs—Development of an Outcome Measure

Presenters: **Michelle Servais**¹, Steve Ryan^{2,3,5}, Kim Bradley^{3,5}, Michael Hilmer⁴, Shauna Kingsnorth^{2,3,5}, **Carrie Laskey**¹, Anne Marie Renzoni³, **Tracy Shepherd**^{1,3}, Karen Ward³, Madhu Pinto^{2,3}, & **Nicole Etherington**^{1,6}
Affiliations: Thames Valley Children's Centre¹, Bloorview Research Institute², Holland Bloorview Kids Rehabilitation Hospital³, Ontario Ministry of Health and Long-Term Care⁴, University of Toronto⁵, Western University⁶

Developmental Trajectories of Impairments, Associated Health Conditions and Participation of Children with Cerebral Palsy: The 'On Track' Study

Presenters: Doreen Bartlett¹, Sally Westcott McCoy², Lisa Chiarello³, Bob Palisano³, Lynn Jeffries⁴, Alyssa LaForme Fiss⁵, Steven Hanna⁶, & Jan Willem Gorter⁶
Affiliations: Western University¹, University of Washington², Drexel University³, Oklahoma University of the Health Sciences Centre⁴, Mercer University⁵, McMaster University⁶

Functional Classification Systems in Children with Cerebral Palsy

Presenters: Deepa Jeevanantham, & Emily Dyszuk,
Doreen Bartlett
Affiliation: Western University

Outcomes of Infants with Hearing Loss involved with Ontario's Infant Hearing Program

Presenters: Marlene Bagatto, & Susan Scollie
Affiliation: Western University

Does Mom Matter? Examining the Link between Maternal Characteristics and the Emotional and Behavioral Outcomes of Children and Youth with Chronic Conditions

Presenters: **Nicole Etherington**^{1,3}, **Janette McDougall**^{1,3}, & Virginia Wright²
Affiliations: Thames Valley Children's Centre¹, Bloorview Research Institute², Western University³

Concussion in Children and Youth: Tracking the Trends in a Pediatric ABI Program

Presenters: **Janice Gray**, **Sara Somers**, & **Pamela Bailey**
Affiliation: Thames Valley Children's Centre

Responding to Changing Needs: A Support Group Model of Care for Female Adolescents with Persistent Concussion Symptoms

Presenters: **Sara Somers**¹, **Janice Gray**¹, **Mary Ellen Kendall**¹, & **Pamela Frid**^{1,2}
Affiliations: Thames Valley Children's Centre¹, Western University²

The Lived Experience of Concussion Treatment and Management: Return-to-Learn and Return-to-Play

Presenters: Annalise Tichenoff, Jeff Holmes, Paul Echlin, & Andrew Johnson
Affiliation: Western University



Successful School Reintegration for Students Who Have Experienced an Acquired Brain Injury

Presenters: **Janette McDougall**^{1,3}, & Dawn Good²

Affiliations: Thames Valley Children's Centre¹, Brock University², Western University³

Can Eye-Tracking Technology Help Girls with Rett Syndrome Meet their Individualized Goals for Communication?

Presenters: **Kelli Vessoian**¹, **Gill Steckle**¹, **Barb Easton**¹, **Janette McDougall**^{1,3}, Victoria Siu^{2,3}, & **Carrie Laskey**¹

Affiliations: Thames Valley Children's Centre¹, London Health Sciences Centre², Western University³

A Meta-Analysis of Receptive and Expressive Language in Autism Spectrum Disorder (ASD)

Presenters: Rachael Smyth, Elaine Kwok, Heather M. Brown, & Janis Oram Cardy
Affiliation: Western University

The Transition to Adulthood: Teaching Life Skills to Young Adults with Autism Spectrum Disorder through a Community Based Occupational Therapy Summer Program

Presenters: Kaity Gain, Jessie Wilson, & Angie Mandich

Affiliation: Western University

The Use of iPadR Technology and Concept Mapping in Facilitating Independence in Adolescents with Autism Spectrum Disorder

Presenters: Jessie Wilson, Kaity Gain, & Angie Mandich

Affiliation: Western University

Driving Characteristics of Teens with Attention Deficit Hyperactivity Disorder or Autism Spectrum Disorder

Presenters: Sherrilene Classen, & Miriam Monahan

Affiliation: Western University

A special "thank you" goes out to the Child Health Symposium Organizing Committee Members!

Andrew Johnson^{2,3}
Chair of the Health and Rehabilitation Sciences Graduate Program

Carrie Connell¹
Education and Program Coordinator

Doreen Bartlett²
Professor, School of Physical Therapy

Gordon MacDonald²
Research Officer

Helene Berman²
Associate Dean (Research)

Helen Kerr²
Administrative Assistant

Janette McDougall^{1,2}
Researcher

John LaPorta¹
CEO

Karen Lowry^{1,3}
Director of Quality Management

Kathryn Hayman¹
Research Officer

Kimberly Simpson²
Research Coordinator

Michelle Servais¹
Researcher

Ruth E Martin²
Professor, School of Communication Science Disorders

Sherrilene Classen²
Director, School of Occupational Therapy

Shauna Burke²
Assistant Professor, School of Health Studies

Trish Tucker²
Assistant Professor, School of Occupational Therapy

Thames Valley Children's Centre¹; Faculty of Health Sciences, Western University²; CHS Organizing Committee Co-Chairs³

RESEARCH PROJECT APPROVAL PROCESS

At Thames Valley Children's Centre, all internal and external research and evaluation projects involving TVCC clients and/or their families and requiring informed consent must be approved by:

- A university ethics review committee, and
- TVCC's Research Advisory Committee.

Informed consent is required if:

- The participants will be asked to complete any measures or questionnaires that they would not normally complete in the course of intervention or for quality assurance purposes;
- Participants will be randomly assigned to therapy conditions or waiting lists; and/or
- The researcher intends to present or publish the results.

Thames Valley Children's Centre has guidelines regarding: collaborative endeavours between outside investigators and TVCC staff members, the approval process for proposals originating within the Centre, and the approval process for proposals from outside the Centre that involve TVCC clients and their families.

Guidelines also exist to ensure client confidentiality in research studies and to ensure that TVCC staff members make the initial contact with parents and clients when their participation is sought in a research study.

The approval process ensures that the proposed research fits with TVCC's Vision and Mission. It also ensures that the many ongoing projects at the Centre do not burden the clients/participants and that the investigator has received agreement/approval from the appropriate TVCC Program Director. Outside investigators also require the cooperation of a Centre staff member as a Research Contact.

Investigators are required to complete TVCC's form "Application for Approval of a Research Study." Approximately every two months, TVCC's Research Advisory Committee reviews the proposals and decides whether to approve them.

RESEARCH ADVISORY COMMITTEE

The Research Advisory Committee (RAC) was established in 1988 to review and approve protocols for all internal and external research studies involving TVCC clients and/or their families. The Committee also acts as a resource with respect to the strategic direction of the Research Program.

The RAC ensures that all research projects meet the criteria for project approval before being allowed to approach TVCC clients through the Research Contact.

The Committee consists of a minimum of five members:

- A TVCC researcher (Chair),
- TVCC's medical director,
- A TVCC medical consultant,
- Faculty members from the Western University, and
- Members of a rehabilitation discipline.

Research Advisory Committee 2010-2014

Dr. Craig Campbell (*Member: 2007-2013*)
Pediatric Neurologist
Children's Hospital, London Health
Sciences Centre

Dr. Megan Cashin (*Member: 2014-present*)
Paediatric Orthopaedic Surgeon
Children's Hospital, London Health
Sciences Centre

Dr. Allyson Dykstra (*Member: 2012-present*)
School of Communication Sciences and
Disorders
Western University

Dr. Pamela Frid (*Member: 2003-present*)
Medical Director
Thames Valley Children's Centre

Dr. Robert Gardner (*Member: 1995-2014*)
Department of Psychology
Western University

Dr. Marilyn Kertoy (*Member: 1992-2012*)
School of Communication Sciences and
Disorders
Western University

**Research Advisory Committee
Continued
2010-2014**

Jamie Kneale Fanning (*Member: 2003-2014*)

Neonatal Intensive Care Unit
St. Joseph's Health Care London

Dr. Angela Mandich (*Member: 2007-2010*)

School of Occupational Therapy
Western University

Dr. Janette McDougall (*Chair: 2005-present*)

Centre Researcher, Research Program
Thames Valley Children's Centre

Dr. Jamie Seabrook (*Member: 2014-present*)

Assistant Professor
Brescia University College

Dr. Trish Tucker (*Member: 2011-present*)

School of Occupational Therapy
Western University

Thank You!

We would like to acknowledge the contributions of the many individuals who make sure that research at TVCC is meaningful and of high quality.

Sincere thanks are extended to:

- The **investigators on staff** - who contribute time, energy, and commitment to finding the answers.
- The **clients and families** - who share their experiences and provide their valuable time and insights.
- Our **collaborators** - who contribute their expertise and important new perspectives.
- The TVCC Board of Directors, Chief Executive Officer, and Program Directors - who provide their support to research.
- The **Research Advisory Committee** - who ensure that our research is of the highest quality.

PROJECTS APPROVED BY RAC

The following **24 studies** were reviewed by the Research Advisory Committee between **April 1, 2010 and March 31, 2014**, and approved to proceed. The names of current TVCC staff members are italicized and bolded. Names of former TVCC staff are italicized only.

June 2010

Understanding sexuality among adolescents with physical disabilities: A narrative inquiry (Lauri East).

Examining occupational identity: Perspectives of children and their parents (Elizabeth Kinsella, Shannon Phelan, Angela Mandich, & Lilian Magalhaes).

September 2010

The effectiveness of intensive behavioural intervention in children with autism over the age of six years (Jennifer Dunn Geier, Adrienne Perry, & Ksusha Blacklock).

An open-label extension study of the long-term safety, tolerability, and efficacy of GSK2402968 in subjects with Duchenne muscular dystrophy (Craig Campbell, Sharan

Goobie, ***Cheryl Scholtes, Wendy McDonald, Rhiannon Hicks, & Ashrafunissa Janmohammad***).

November 2010

School, home and neighbourhood accessibility: Physical disabled children's assessments (The ScHaN Project) PHASE 2 (Patricia McKeever, Susan Ruddick, James Dunn, Nancy Young, Nicole Yantze, & Sean Doherty).

Collaborating with parents and therapists to develop dissemination products: The MOVE & PLAY study (Doreen Bartlett).

January 2011

Physical activity and active lifestyle program for youth with cerebral palsy: A STAY-FIT pilot study (Jan Willem Gorter, Brian Timmons, Peter Rosenbaum, Bob Palisano, & Virginia Wright).

March 2011

Measuring postural control in young children with cerebral palsy and understanding associations with the Gross Motor Function Measure (Kate Randall, & Doreen Bartlett).

June 2011

Constructing a new clinical measure of fatigue for adolescents and young adults with cerebral palsy (Laura Brunton, & Doreen Bartlett).

September 2011

How do parents use information with the aid of a knowledge broker when living with a child with cerebral palsy? (Stephanie Lagosky, & Doreen Bartlett).

Effectiveness of motor speech intervention for children with speech disorders (Aravind Namasivayam, Pascal Van Lieshout, Robert Kroll, & Margit Pukonen).

January 2012

Validating a new measure of fatigue for adolescents and young adults with cerebral palsy: The fatigue impact and severity self-assessment (Laura Brunton, & Doreen Bartlett).

Childhood hemiplegic cerebral palsy integrated neuroscience discovery network "CP-NET" (Craig Campbell, Ravi Menon, Darcy Fehlings, **Pamela Frid, Jennifer McLean, Jacqueline Ogilvie, & Erin Cecchini**).

March 2012

An exploration of factors associated with response to an intensive behavior intervention program for children with autism spectrum disorder (Eugenie Steyn, & Robert Sandieson).

September 2012

Monitoring development of children with cerebral palsy or gross motor delay (Doreen Bartlett, Lisa Chiarello, Robert Palisano, Sally Westcott McCoy, Lynn Jeffries, Alyssa LaForme Fiss, Steve Hanna, & Jan Willem Gorter).

Duchenne muscular dystrophy: Double-blind randomized trial to find optimum steroid regimen (Craig Campbell, Ashrafunissa Jammohammad, Rhiannon Hicks, **Cheryl Scholtes**, Teresa Rooney, & Lisa Coutu).

May 2013

A phase 3 efficacy and safety study of Ataluren (PTC124) in patients with nonsense mutation (Craig Campbell, Sabeeh Alvi, Ashrafunissa Janmohammad, **Cheryl Scholtes, Wendy McDonald**, Rhiannon Hicks, & Theresa Rooney).

A randomized, double-blind, placebo-controlled, phase 3 trial of Tadalafil for Duchenne muscular dystrophy (Craig Campbell, Sabeeh Alvi, Ashrafunissa Janmohammad, Rhiannon Hicks, Teresa Rooney, **Cheryl Scholtes, & Wendy McDonald**).

September 2013

Toward improvement of augmentative and alternative communication services for young people with complex communication needs (Steve Ryan, Kim Bradley, Michael Hillmer, Shauna Kingsnorth, **Carrie Laskey**, Anne Marie Renzoni, **Michelle Servais, Tracy Shepherd**, & Karen Ward).

January 2014

Childhood cerebral palsy integrated neuroscience discovery network CP-NET (Craig Campbell, **Pamela Frid, & Jennifer McLean**).

Stacking exercises aid the decline in forced vital capacity (FVC) and sick time (STEADFAST) in boys 6-16 years with Duchenne muscular dystrophy (Craig Campbell).

March 2014

Health endpoints and longitudinal progression in Congenital myotonic dystrophy (HELP-CDM) (Craig Campbell).

Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences for families and rehabilitation (**Gillian King**, Heidi Schwellnus, **Patricia Baldwin, & Michelle Servais**).

Can eye-tracking technology help girls with Rett syndrome meet individualized goals for communication? (**Janette McDougall**, Victoria Siu, **Barb Easton, Gill Steckle, Kelli Vessoyan, & Carrie Laskey**).

PROJECTS

There were **46 research projects** that involved TVCC clients, their families, and TVCC staff members as participants underway between **1 April 2010 and 31 March 2014** that went through a formal ethics review process. The studies are separated into two categories: Internal Projects and External Projects.

Internal Projects are those projects on which TVCC staff members were involved as principal investigators or co-investigators.

External Projects are those projects that only have external researchers and did not have any TVCC staff members as investigators.

INTERNAL PROJECTS

The following is a list of the **21 internal research projects underway between 1 April 2010 and 31 March 2014** that involved TVCC staff members as named investigators. Names of current TVCC staff members are bolded and italicized. Names of former TVCC staff members are italicized only.

1. School role participation: Perspective of the child, the parents, and the teachers

Investigators: *Jacqueline Specht*¹, *Gillian King*², ***Michelle Servais***³, Marilyn Kertoy¹, & Terry Spencer⁴

Affiliations: Western University¹, Child and Parent Resource Institute², Thames Valley Children's Centre³, Catholic District School Board⁴

Status: Completed, 2006-2010

Funding: Social Sciences and Humanities Research Council of Canada (SSHRC; \$109, 563)

Participation has been shown to be key to healthy development. Students who are more actively engaged in school tend to have higher academic achievement, drop out less, and have increased involvement in activities during early adulthood. Increased participation has shown to protect the mental health of individuals. Unfortunately children with disabilities have been shown to participate less than children without disabilities, thus increasing their risk for depression and anxiety. Reasons for this decreased participation are lacking. The current study attempted to investigate the lack of participation from the perspective of role theory. Roles are defined as socially expected

behaviour patterns determined by a person's status in society and refer to clusters of meaningful activities that are expected of, and assumed by, individuals in various contexts of their lives. The research on adult roles has found that multiple roles in adulthood were related to overall life satisfaction and a decrease in social isolation. These multiple roles had an enhancing or protective effect on physical and emotional health. Although there has been a considerable amount of research about roles in adulthood, little is known about the roles of children. Research to date has not examined children's perceptions of their school participation in terms of their involvement or engagement in different types of roles.

Fifteen teachers were interviewed about the roles in which children participate in school and 24 students in grades 4 through 7 were observed in order to determine the roles in which they engaged. Overall, students with disabilities engaged in less positive roles (Challenged Learner; Victim; Bully), while students without disabilities engaged in more positive roles (Independent Learner; Nurturer; Friend).

Publications:

*Specht, J., King, G., Servais, M., Kertoy, M., & Spencer, T. (2011). School roles: A way to investigate participation. *Exceptionality Education International*, 21(1), 2-14.*

Presentations:

*Specht, J., Young, G., Kertoy, M., Servais, M., Spencer, T., King, G., Puskarich, M., & Pompeo, M. (2010, August). *Participation in school roles: The importance of opportunity*. Presented at the Inclusive and Supportive Education Congress, Belfast, UK.*

*Spencer, T., Specht, J., Servais, M., Kertoy, M., King, G., Pompeo, M., Young, G., & Puskarich, M. (2010, February). *Elementary school roles: Making sure all participate*. Presented at the 5th Annual Ontario Education Research Symposium, Toronto, ON, Canada.*

2. **Effective listening and interactive communication skills in the delivery of services to children and families**

Investigators: Gillian King, **Michelle Servais**, **Colleen Willoughby**, **Tracy Shepherd**, & **Linda Bolack**

Affiliation: Holland Bloorview Kids Rehabilitation Hospital

Status: Completed, 2007-2010

The intent of this project was to study the nature of effective listening and interactive communication skills of paediatric rehabilitation therapists. The project has provided useful information that can raise therapists' self-awareness, encourage insight, and motivate therapists to improve their listening and communication skills.

The project (a) summarized the literature on what is known about effective listening and communication skills in the health and social service field, (b) proposed an innovative framework outlining the nature of six core listening and interactive communication skills that underpin the effective delivery of services to children and families, and (c) provided a qualitative analysis of focus group data from two groups of therapists: a group selected based on the nomination of their peers as "expert listener-communicators" and a self-selected group with interest in the topic area. The project also provided data on the utility and validity of a preliminary version of a self-report measure of effective listening and communication skills.

This work can inform the delivery of clinical services to children and families.

Publications:

King, G., Servais, M., Bolack, L., Shepherd, T., & Willoughby C. (2012). Development of a measure to assess effective listening and interactive communication skills in the delivery of children's rehabilitation service. *Disability and Rehabilitation*, 34(6), 459-469. doi:10.3109/09638288.2011.608143

Shepherd, T., King, G., Servais, M., Bolack, L., & Willoughby, C. (2014). Clinical scenario discussions of listening in interprofessional health care teams. *International Journal of Listening*, 28, 47-63. doi: 10.1080/10904018.2014.861295

Presentation:

Bolack, L., Shepherd, T., Servais, M., King, G., & Willoughby, C. (2009, November). Reflecting on effective communication and listening skills in therapeutic practice.

Presented at the 2009 Ontario Association for Children's Rehabilitation Services (OACRS) Conference, Toronto, ON, Canada.

3. **Examining the development of professional expertise in children's mental health, rehabilitation, and education services**

Investigators: Gillian King¹, Jacqueline Specht², Doreen Bartlett², **Michelle Servais**³, Michelle Gilpin⁴, Shannon Stewart¹, & Patricia Petersen¹

Affiliations: Child and Parent Resource Institute¹, Western University², Thames Valley Children's Centre³, Thames Valley District School Board⁴

Status: Completed, 2007-2010

Funding: Social Sciences and Humanities Research Council of Canada (SSHRC; \$18,210)

Expertise in the delivery of social, health, and education services to children and their families is growing in importance as the complexity of service delivery increases. More complex physical and mental health difficulties, rising consumer expectations, and increasing interest in evidence-based practice have served to highlight the importance of expertise in the provision of effective, client-centred services. Expertise in managing the clinical encounter or the classroom experience is at the heart of service delivery: It is where the qualities, skills, and procedural knowledge of effective professionals enable them to optimize service delivery or the classroom learning experience.

This study examined the workplace factors and experiences considered important by individuals providing education or mental health services to children, with one group working within an interprofessional team approach (service providers) and the other working in a discipline-specific manner (teachers). Two focus groups were held involving 5 elementary or secondary school teachers and principals, and 9 therapists providing specialized children's mental health services. Information arising in these discussions was used to develop themes reflecting key elements. The findings point to the importance of establishing a collaborative, learning-oriented workplace culture, including opportunities for varied work experiences, peer interaction and dialogue, and feedback. Implications include adopting relationship-oriented and collaborative service delivery models, and ensuring that workplace settings encourage natural learning opportunities

involving interaction, dialogue, and feedback, as well as professional development experiences of value.

Publications:

King, G., Specht, J., Petersen, P., **Servais, M.**, Bartlett, D., Stewart, S., Young, G., & Brown, H. (2014). The development of expertise in children's mental health therapists and teachers: Changes in perspective and approach. *Educational Research, 56*(3), 277-294. doi: <http://dx.doi.org/10.1080/00131881.2014.934553>

King, G., Specht, J., Bartlett, D., **Servais, M.**, Petersen, P., Brown, H., Young, G., & Stewart, S. (2010). A qualitative study of workplace factors influencing expertise in the delivery of children's education and mental health services. *Journal of Research in Interprofessional Practice and Education, 1*(3), 265-283. Retrieved at www.jripe.org/index.php/journal/article/download/25/31

Presentations:

Specht, J., King, G., Bartlett, D., Stewart, S., Gilpin, M., Petersen, P., **Servais, M.**, Brown, H., Young, G., & Kessler, N. (2009, May). Facilitating the development of professional expertise in children's mental health, rehabilitation, and education services. Presented at the 2009 Conference on Engaging Reflection in Health Professional Education and Practice, London, ON, Canada.

4. Understanding the impact of exercise participation for children with a disability

Investigators: Angela Mandich, **Kim Simpson**

Affiliation: Western University-School of Occupational Therapy

Status: Completed, 2008-2010

This study aimed to explore the impact of participation in a fitness program for youth with a physical disability. Due to the individualized nature of childhood disability and participation, semi-structured parent and youth interviews were used to understand health impact of participating in a fitness program for youth with a disability using a qualitative interview guide created by the researcher.

This study also included two other phases of research; following the interviews, participants and therapists used Goal Attainment Scaling to evaluate the impact of fitness participation on motor skills and video analysis using the Performance Quality Rating Scale to evaluate

the quality of motor improvement of client fitness goals.

Presentation:

Simpson, K. (2011, July). Understanding the impact of exercise for children with a disability. Presented at the International Symposium of Adapted Physical Activity (ISAPA), Paris, France.

5. The impact of personal, interpersonal, and environmental factors on changes in quality of life for youth with chronic conditions



Investigators: **Janette McDougall**, Virginia Wright¹, & Linda Miller²

Affiliations: Bloorview Research Institute¹, & Western University-School of Graduate and Postdoctoral Studies²

Status: Underway, 2009-2016

Funding: Canadian Institutes of Health Research \$742,340

Optimizing quality of life for children and youth is a key goal of the Ontario Association of Children's Rehabilitation Services (OACRS) centres. Many supports and interventions are directed toward this goal. It is important for clients, families, service providers, and policy makers to understand the key factors that influence changes in life quality throughout childhood and adolescence for children and youth with chronic conditions. To this end, researchers will examine the impact of personal, interpersonal, and environmental factors on changes in quality of life for youth with chronic conditions.

This research endeavour includes a longitudinal survey-based study and a qualitative study. The survey-based study will address two unexplored research areas: 1) the changing nature of quality of life for youth with chronic conditions over a three-year period, and 2) the factors that influence change quality of life for youth. Four hundred and thirty-nine youth aged 11 to 17 years (and one of their parents) who receive services from eight OACRS centres across Ontario are participating. Youth and parents each complete a brief questionnaire at four time points that include questions about quality of life and the factors that research and conceptual thinking suggest influence changes in life quality for youth with chronic conditions. Some of the factors to be explored are: youths' physical and emotional functioning, self-determination, social participation, and family and environmental supports. Advanced statistical analysis procedures will be used to evaluate changes in

quality of life and to determine the factors related to change.

Eighteen youth from TVCC participated in the qualitative study. The youth took part in individual interviews and focus groups to consider what "quality of life" means to them and what aspects of life they feel are most important for enhancing their life quality. These findings will be examined alongside those of the survey-based study.

Findings from this research will help us to understand more about quality of life from the perspectives of youth and their families, and can help guide program and policy development toward optimizing life quality for youth with chronic conditions!

Publications:

McDougall, J., Wright, V., DeWit, D., & Miller, L. (2014). ICF-based functional components and contextual factors as correlates of perceived quality of life for youth with Chronic Conditions. *Disability and Rehabilitation*. Early Online doi: 10.3109/09638288.2014.892642.

Etherington, N., & **McDougall, J.** (2014). Understanding the mental health needs of children and youth with chronic health conditions. (*Facts to Go, Volume 10, Issue 2*). London, ON: Thames Valley Children's Centre.

Bedell, G., & **McDougall, J.** (2013). The Child and Adolescent Scale of Environment (CASE): Further validation with youth who have chronic conditions. *Developmental Neurorehabilitation*. Early Online. doi: 10.3109/17518423.2013.855273.

McDougall, J., Bedell, G., & Wright, V. (2013). The youth report version of the Child and Adolescent Scale of Participation: Assessment of psychometric properties and comparison with parent report. *Child: Care, Health, & Development*, 39(4), 512-522.

McDougall, J., Wright, V., **Nichols, M.**, & Miller, L. (2013). Assessing the psychometric properties of both a global and a domain-specific perceived quality of life measure when used with youth who have chronic conditions. *Social Indicators Research*, 114(3), 1243-1257.

McDougall, J., Wright, V., Miller, L., & **Nichols, M.** (2012). Evaluation of two measures of perceived quality of life when used with youth with chronic conditions. [Abstract] *Developmental Medicine & Child Neurology*, 54(6): 34-35. (Suppl.).

McDougall, J., Wright, V., **Schmidt, J.**, Miller, L., & **Lowry, K.** (2011). Applying the ICF

Framework to study changes in quality of life for youth with chronic conditions.

Developmental Neurorehabilitation, 14(1), 41-53.

McDougall, J., Wright, V., & Miller, L. (2009). What is "quality of life" and how can research identify the factors that optimize life quality for children and youth with chronic conditions? (*Facts to Go, Volume 5 Issue 1*). London, ON: Thames Valley Children's Centre.

Presentations:

McDougall, J., & Wright, V. (2014, October). *Perceived quality of life for youth with chronic conditions: Exploring related factors*. Presented at the 91st Annual American Congress of Rehabilitation Medicine Conference, Toronto, ON, Canada.

McDougall, J. (2014, July). *A positive focus for pediatric rehabilitation research*. Presented at the 2nd Annual Canadian Positive Psychology Conference, Toronto, ON, Canada.

Bedell, G. & **McDougall, J.** (2014, June). *Further validation of the Child and Adolescent Scale of Environment (CASE)*. Presented at the World Federation of Occupational Therapy Congress, Yokohama, Japan.

Etherington, N., **McDougall, J.**, DeWit, D., & Wright, V. (2014, May). Emotional and behavioral difficulties among children and youth with chronic conditions: What role for mothers' mental health? Presented at the Canadian Sociological Association Annual Meeting, St. Catharines, ON, Canada.

Bedell, G., & **McDougall, J.** (2014, April). *Further validation of the Child and Adolescent Scale of Environment (CASE)*. Presented at the American Occupational Therapy Association Annual Conference, Baltimore, MD.

Bedell, G., & **McDougall, J.** & Wright, V. (2013, June). Youth Report Version of the Child and Adolescent Scale of Participation (CASP): Psychometric properties and comparisons with the Parent Report Version. Presented at the World Federation of Occupational Therapy Congress, Yokohama, Japan.

Bedell, G., **McDougall, J.**, & Wright, V. (2013, April). Youth Report Version of the Child and Adolescent Scale of Participation (CASP): Psychometric properties and comparisons with the Parent Report Version. Presented at the annual meeting of the American Occupational Therapy Association, San Diego, California.

McDougall, J., Bedell, G., & Wright, V. (2012, November). Youth Report Version of the

Child and Adolescent Scale of Participation (CASP): Psychometric properties and comparisons with the Parent Report Version. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

McDougall, J., Wright, V., Miller, L., **Nichols, M.** (2012, September). Evaluation of two perceived quality of life measures when used with youth with chronic conditions. Presented at the 66th Annual Meeting of the American Academy of Cerebral Palsy and Developmental Medicine, Toronto, ON, Canada.

McDougall, J., Wright, V., Miller, L., & **Nichols, M.** (2012, July). *A positive focus in research for pediatric rehabilitation.* Presented at the 7th Biennial International Meaning Conference, Toronto, ON, Canada.

McDougall, J., Wright, V., Miller, L., & **Nichols, M.** (2012, April). Identifying the personal, interpersonal and environmental factors associated with changes in quality of life for youth with chronic conditions and disabilities. Presented at the 33rd Annual International Young Adults Institute Network Conference, New York, NY.

McDougall, J., Wright, V., & Miller, L. (2009, November). Changes in quality of life for youth with chronic conditions: The impact of personal, interpersonal and environmental factors. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

6. An evaluation of an occupational therapy mentorship program

Investigators: Gillian King¹, Cynthia Tam¹, Linda Fay², Martha Pilkington², **Michelle Servais³**, & Hasmik Petrosian¹

Affiliation: Bloorview Research Institute, Holland Bloorview Kid's Rehabilitation Hospital, Thames Valley Children's Centre

Status: Completed, 2009-2010

There is growing interest in understanding the usefulness of mentorship programs for children's rehabilitation service providers. This evaluation study examined the effects of an occupational therapy mentorship program on the skills and behaviors of 8 new and 17 experienced occupational therapists practicing at a regional children's rehabilitation center. Self- and peer-report measures of family-centered behavior, critical thinking ability, listening/interactive communication skill, and clinical behavior were

collected before and after an 11-month facilitated, collaborative group mentorship intervention. Significant pre-post changes associated with intervention were found on 9 of 12 outcome measures, including information provision, respectful treatment, self-confidence, and listening and clinical skill. Changes were not found on the more trait-like variables of open-mindedness, interpersonal sensitivity, and interpersonal skill. Experienced therapists had higher scores than new therapists on most variables, including family-centered behavior, listening skill, and clinical skill. This study has implications regarding the utility of mentorship programs in children's rehabilitation centers.

Publication:

King, G., Tam, C., Fay, L., Pilkington, M., Servais, M., & Petrosian, H. (2011). Evaluation of an occupational therapy mentorship program: Effects on therapists' skills and family-centered behavior. *Physical & Occupational Therapy in Pediatrics.* 31(3), 245-262.

Presentations:

Fay, L., Pilkington, M., *King, G., Tam, C., Servais, M., & Petrosian, H.,* (2010, November). *Evaluation of an occupational therapy mentorship program.* Presented at the 2010 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Niagara Falls, ON, Canada.

7. The validity of alternative response formats for the Test of Aided-Communication Symbol Performance (TASP):Symbol size and number subtest

Investigators: *Stacy McDougall, Brent Duncan, & Kelli Vessoayan*

Status: Completed, 2009-2011

Individuals who use augmentative and alternative communication (AAC) often have physical difficulties accessing standardized assessment materials. The Test of Aided-Communication Symbol Performance (TASP, Bruno, 2003) assesses use of Picture Communication Symbols (PCS) by individuals who directly access their AAC systems. Using computerized presentation, equivalency between adapted access response methods for the TASP Symbol Size and Number Subtest and a traditional response method was examined, using a Repeated Measures Experimental Design.

Participants included children who use AAC and had direct access. It was hypothesized that performance results on the subtest will be equivalent regardless of access condition.

Presentation:

McDougall, S., Duncan, B., & Vessoian, K. (2010). Alternative presentation and response formats for the Test of Aided-Communication Symbol Performance (TASP). Presentation at the 14th biennial conference of the International Society for Augmentative and Alternative Communication, Barcelona, Spain.

8. School reintegration for children and youth with acquired brain injury

Investigators: Dawn Good¹, Peter Rumney², **Janette McDougall**, Carol DeMatteo³, Patricia McKeever², Denise Guerriere⁴, Sue Loyst⁵, Rhonda Martinussen⁶, & Sheila Bennet¹, John Kumpf⁶

Affiliations: Brock University¹, Holland Bloorview Kids Rehabilitation Hospital², McMaster University³, University of Toronto⁴, Georgian College⁵, & Ontario Brain Injury Association⁶

Status: Completed, 2009-2013

Funding: Ontario Neurotrauma Foundation
\$360,000

Partnering with Children's Centre's and schools across Ontario, this study investigated individual, academic, and system-related factors that related to the successful return to school of children and youth with acquired brain injury (ABI). Using questionnaires and standardized testing, this study identified and examined the impact of the important factors involved in returning to school (e.g. academic and social adjustment).

The results of this research contributed to the understanding and advancement of the academic, social, and environmental features supporting successful school reintegration for students with ABI.

Publications:

Good, D., Rumney, P., McDougall, J., Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2009) School reintegration for children and youth with Acquired Brain Injury. [Abstract] *Journal of Head Trauma Rehabilitation*, 24(5), 399.

Good, D., McDougall, J., Rumney, P., & Bennett, S. (2012). Successful scholastic

reintegration for students who have experienced ABI. [Abstract] *Archives of Physical Medicine and Rehabilitation*, 93(10): E28.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., DeMatteo, C., & McCormick, A. (2012). Successful scholastic reintegration: Academic, social and behavioural success for students with ABI. [Abstract] *Journal of Head Trauma Rehabilitation*, 27(5): E35-E36.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., DeMatteo, C., Martinussen, R., & DeCourville, N. (2012). School-based factors contribute to successful school reintegration of children and youth with Acquired Brain Injury. [Abstract] *Brain Injury*, 26(4-5): 699-700.

Good, D., Rumney, P., Bennett, S., **McDougall, J.**, DeMatteo, C., & Martinussen, R. (2014, May). An investigation of factors that influence socioemotional and academic gains in the classroom for students living with the effects of ABI. [Abstract] *Brain Injury*, 28(5-6): 828-828.

Presentations:

McDougall, J., Good, D., Rumney, P., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, November). *School reintegration for children and youth with Acquired Brain Injury*. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & Decourville, N. (2009, October). *School reintegration for children and youth with Acquired Brain Injury*. Presented at the North American Brain Injury Society 7th Annual conference on Brain Injury, Austin, Texas, United States.

Good, D., Rumney, P., **McDougall, J.**, DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, May). *School reintegration for children and youth with Acquired Brain Injury*. Presented at the 16th Annual Conference on Neurobehavioural Rehabilitation in Acquired Brain Injury, Hamilton Health Sciences, Hamilton, ON, Canada.

Good, D., Rumney, P., **McDougall, J.**, DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S.,

- Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, April). *School reintegration for children and youth with Acquired Brain Injury*. Presented at the 17th Annual Research Day of the Ontario Association for Developmental Disabilities Research Special Interest Group, Barrie, ON, Canada.
- Good, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2010, June). *School reintegration for children and youth with Acquired Brain Injury*. Presented at the 71st Annual Convention of the Canadian Psychological Association, Winnipeg, MB, Canada.
- Good, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., DeCourville, N. (2010, November). *School reintegration for children and youth with Acquired Brain Injury*. Presented at the Toronto ABI Network Conference, Toronto, ON, Canada.
- Good, D., Rumney, P., **McDougall, J.**, DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2011, October) *Social and academic competency in students with ABI*. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.
- Good, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2011, November). *School reintegration for children and youth with acquired brain injury*. Presented at the Acquired Brain Injury 2011 Provincial Conference, Niagara Falls, ON, Canada.
- Good, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2011, November). Predictors of successful school reintegration outcomes for students with acquired brain injury (ABI). Presented at the Children's Mental Health ON, Toronto, ON.
- Good, D., Rumney, P., **McDougall, J.**, Bennett, S., DeMatteo, C., Martinussen, R., & DeCourville, N. (2012, March). *School-based factors contribute to successful school reintegration of children and youth with Acquired Brain Injury*. Presented at the 9th World Congress on Brain Injury, Edinburgh, Scotland.
- McDougall, J.**, Good, D., Rumney, P., Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2012, April). *Factors influencing school reintegration for Ontario students with Acquired Brain Injury*. Presented at the 20th Annual Research Day of the ON Association for Developmental Disabilities Research Special Interest Group, Kingston, ON, Canada.
- Good, D., **McDougall, J.**, Rumney, P., & Bennett, S. (2012, October). *Successful scholastic reintegration for students who have experienced ABI*. Presented at the ARCM-ASNR Conference, Vancouver, BC, Canada.

9. Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem

Investigators: Janice Gray, & Sara Somers
Status: Underway, 2010-2014

Recent research has highlighted the impact of concussion in high school aged athletes (Kirkwood et al 2006; Lovell et al 2003). In addition research has also shown concussion rates for female athletes to be higher than male athletes and for their symptoms to take longer to resolve.

The present study will investigate the incidence of concussion and duration of symptoms for referrals to the PABICOP Program over the past two years. This population is not restricted to high school aged athletes. By identifying possible trends in our referrals, we hope to be able to provide a more proactive targeted approach to supporting children and youth in their recovery from concussion.

Publication:

Somers, S., Gray, J., & McDougall, J. (2010). Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem. [Abstract] *Brain Injury* 24(3), 51-52.

Presentations:

Somers, S., Gray, J., & McDougall, J. (2010, March). Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem. Presented at the 8th World Congress on Brain Injury, Washington, DC, United States.

Somers, S., Gray, J., & McDougall, J. (2010, November). Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem.

Presented at the Toronto ABI Network Conference, Toronto, ON, Canada.

10. Myoblast transplantation in Duchenne and Becker muscular dystrophy patient

Investigators: Craig Campbell¹, Shannon Venance¹, Guido Filler¹, Daniel Skuk², **Cheryl Scholtes** Rhiannon Taranik¹, Ashrafunissa Janmohammad¹, **Linda Bolack**, Jacques Tremblay², & Jack Puymirat²

Affiliations: London Health Sciences Centre-The Children's Hospital of Western Ontario¹, & CHUL-University of Laval²

Status: Underway, 2010-2015

Funding: Jesse's Journey/ Canadian Institutes of Health Research, \$540,000

At the molecular level, Duchenne and Beckers Muscular Dystrophy (DMD and BMD) are caused by a severe deficiency of dystrophin. Dystrophin deficiency causes skeletal muscle degeneration that is clinically expressed by a progressive generalized paresis in childhood, leading to paralysis in the adolescence and death around the age of 25 years.

In this study, participants with Duchenne and Becker Muscular Dystrophy will be injected with donor myoblast cells in a single skeletal muscle to evaluate the safety and efficiency of myoblast transplantation to increase muscle strength and dystrophin protein expression under immunosuppression using Tacrolimus). The contralateral muscle will be injected with saline.

11. An open-label extension study of the long-term safety, tolerability, and efficacy of GSK2402968 in subjects with Duchenne muscular dystrophy

Investigators: Craig Campbell¹, Sharan Goobie¹, **Cheryl Scholtes**, **Wendy McDonald**, Rhiannon Taranik², & Ashrafunissa Janmohammad¹

Affiliations: London Health Sciences Centre-The Children's Hospital of Western Ontario¹, & Western University²

Status: Discontinued, 2010-2014

Funding: Glaxo-Smith Kline, \$197,100

Participants with Duchenne muscular dystrophy will receive subcutaneous injections of Antisense oligonucleotide (AON)-induced exon skipping drug. This study is being done to assess the safety and efficacy of GSK2402968 versus placebo. This study was discontinued due to a trial sponsorship decision.

12. Childhood hemiplegic cerebral palsy integrated neuroscience discovery network "CP-NET"

Investigators: Craig Campbell¹, Ravi Menon², Darcy Fehlings³, **Pamela Frid**, **Jennifer McLean**, **Jacqueline Ogilvie**, & Rhiannon Taranik¹

Affiliations: London Health Sciences Centre-The Children's Hospital of Western Ontario¹, Western University², & Holland Bloorview Kids Rehabilitation Hospital³

Status: Underway, 2012-2014

Funding: ON Brain Institute, \$1,500,000

Participants with hemiplegic cerebral palsy (CP) will be assessed under four experimental platforms. General information will be gathered from neonatal, obstetrical, and health records. Brain scans will be reviewed to identify when/how cerebral injuries occurred. This information will be paired with the patient's developmental profile and genetic markers to better understand the associations between cerebral lesions, risk factors and developmental patterns.

The experimental testing of constraint induced movement therapy in two groups of children will be assessed with the novel use of functional MRI. This enables treatment strategies to be matched to patterns of brain injury, and allows effective treatments to be started at appropriate stages of development to improve functioning.

This study aims to generate a registry of health information of patients with hemiplegic CP in order to improve the understanding of CP and accelerate the development of new treatment strategies. The ultimate goal is to improve the lives of children with hemiplegic CP and their families.

13. Examining collaboration between augmentative and alternative communication and autism service providers

Investigators: Michelle Servais, Stacy McDougall, & Pamela Frid

Status: Completed, 2012-2012

The Autism service at TVCC identified the need for an Augmentative and Alternative Communication (AAC) specialist to work with Autism staff to build coordinated services for clients who have Autism.

In this study, the 15-month collaborative initiative was evaluated: AAC and Autism service

providers involved in the initiative were invited to participate in a focus group to provide their feedback about their perceptions of the level of success with the various knowledge exchange activities and with the degree to which a relationship was built between the two services. Participants also discussed factors that facilitated interdisciplinary collaboration, implications for best practices for future knowledge exchange activities, and next steps for sustaining interdisciplinary collaboration.

Publication:

McDougall, S., & Servais, M. (2012). AAC and Autism service providers collaborating for communication: An evaluation of a knowledge exchange framework. *Facts To Go*, 8(3). London, ON: Thames Valley Children's Centre.

Presentations:

McDougall, S., & Servais, M. (2012, November). AAC and Autism service providers collaborating for communication: Organizational lessons learned from using a knowledge exchange framework. Presented to the 2012 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON, Canada.

McDougall, S., & Servais, M. (2012, July). AAC and Autism service providers collaborating for communication: A knowledge exchange framework. Presented at the 2012 International Society for Augmentative and Alternative Communication (ISAAC) 15th Biennial Conference, Pittsburgh, Pennsylvania, USA.

14. Duchenne muscular dystrophy: Double-blind randomized trial to find optimum steroid regimen

Investigators: Craig Campbell, Ashrafunissa Janmohammad, Rhiannon Hicks, **Cheryl Scholtes**, Teresa Rooney, & Lisa Coutu

Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario

Status: Underway, 2012-2017

Funding: United States National Institute of Health
\$3,393,979

Duchenne Muscular Dystrophy (DMD) is the most common childhood muscular dystrophy with a birth incidence worldwide of 1 in 3,500 live male births. It is an X-linked recessive disorder, affecting almost exclusively boys. Corticosteroid therapy has demonstrated the ability to increase muscle strength in boys with

DMD, slowing the progression of the disease, and allowing boys to maintain ambulation longer than those not receiving corticosteroid treatment. Although accepted as standard of care there is great variation among prescribing physicians regarding dose, frequency and which steroid is prescribed.

This study will compare 3 steroid regimens for 3 years to establish which steroid regimen has the best results, while minimizing the undesirable side effects that are common with corticosteroid use. The age range for this study of 4-7 reflects the population for which advice on corticosteroid treatment is of maximal clinical relevance.

15. Development of a Listening Skill Simulation Intervention for Pediatric Rehabilitation Therapists

Investigators: Gillian King, Michelle Servais, Tracy Shepherd, Sheila Moodie, Kathryn Parker, Colleen Willoughby, Linda Bolack, & Patricia Baldwin

Affiliation: Holland Bloorview Kids Rehabilitation Hospital

Status: Underway, 2013-2015

Funding: Ontario Simulation Network's Simulation Research & Innovation Grant
\$24,855

Listening and communication skills are core competency areas for all health professionals. Although pediatric rehabilitation therapists' listening skills are essential to children's and parent's satisfaction with services, and the quality of children's outcomes, few simulation interventions have targeted training of listening skills in rehabilitation. The project objectives are (1) to develop a DVD of simulated therapist-client interactions exemplifying problematic listening-related situations in the pediatric intervention context, and (2) to conduct a pilot study using these simulations in a comprehensive, state-of-the-art intervention that includes repeated exposure to a series of listening skill simulations, guided debriefing in interprofessional discussion groups, and individualized coaching designed to move skills into practice. This pilot study will enable the research team to conduct a randomized controlled trial of the simulation intervention. The outcomes of the present project also include the development of a series of listening skill simulations ready for dissemination and use in educational interventions.

Presentation:

Servais, M., Shepherd, T., Bolack, L., Willoughby, C., Strachan, D., **Baldwin, P.,** Moodie, S., Parker, K., Savage, D., Knickle, K., McNaughton, N., & **King, G.** (2013, December). *Developing authentic clinical simulations for effective listening and communication.* Presented at the 2013 Ontario Simulation Exposition, Toronto, ON, Canada.

and safety of Tadalafil once daily in boys with DMD who are already receiving treatment with corticosteroids. DMD is a muscular dystrophy that causes muscle degeneration in boys leading to the loss of ambulation as well as a decline in cardiac and respiratory function.

There is currently no cure for boys with DMD, only therapies to slow the progression of the disease such as corticosteroids.

16. A phase 3 efficacy and safety study of Ataluren (PTC124) in patients with nonsense mutation dystrophinopathy

Investigators: Craig Campbell, Sabeeh Alvi, Ashrafunissa Janmohammad, Rhiannon Hicks, & Teresa Rooney, **Cheryl Scholtes, Wendy McDonald**

Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario¹

Status: Underway, 2013-2016

Funding: PTC Therapeutics, \$85,730

Duchenne Muscular Dystrophy (DMD) is a muscular dystrophy that causes muscle degeneration in boys leading to the loss of ambulation as well as a decline in cardiac and respiratory function. There is currently no cure for boys with DMD, only therapies to slow the progression of the disease such as corticosteroids.

This study aims to evaluate the safety and efficacy of Ataluren PTC124. Boys with DMD have a mutation in the dystrophin protein causing them to produce incomplete dystrophin proteins. Ataluren is a drug that promotes read through of nonsense mutations, which restores a full length dystrophin protein, which theoretically should improve the muscle physiology and ultimately the strength of boys with DMD.

17. A randomized, double-blind, placebo-controlled, phase 3 trial of Tadalafil for Duchenne muscular dystrophy

Investigators: Craig Campbell, , Sabeeh Alvi, Ashrafunissa Janmohammad, Rhiannon Hicks, Teresa Rooney, **Cheryl Scholtes, & Wendy McDonald**

Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario

Status: Underway, 2013-2015

Funding: Elli Lilly, \$221,316

This is a phase 3, global, multicenter, randomized, double-blind, placebo-controlled, parallel, 3-arm study to determine the efficacy

18. Toward improvement of augmentative and alternative communication services for young people with complex communication needs

Investigators: Stephen Ryan¹, Kim Bradley², Michael Hillmer³, Shauna Kingsnorth¹, **Carrie Laskey,** Anne Marie Renzoni², **Michelle Servais, Tracy Shepherd,** & Karen Ward²

Affiliations: Bloorview Research Institute¹, Holland Bloorview Kids Rehabilitation Hospital², & Ontario Ministry of Health and Long-Term Care³

Status: Underway, 2013-2014

Funding: Canadian Institutes of Health Research
\$181,682

The alliance of researchers and clinicians developed a health measurement scale for parents called the Family Impact of Assistive Technology Scale for Augmentative communication (FIATS-AAC).

The purpose of the questionnaire is to detect the effect of communication interventions on the lives of children and their families. Fifty parents of children with speech problems will take part in the study. Parents will complete the questionnaire twice before and twice after their child gets a new communication device.

19. Childhood cerebral palsy integrated neuroscience discovery network CP-NET

Investigators: Craig Campbell, **Pamela Frid,** & **Jennifer McLean**

Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario

Status: Underway, 2014-2018

Funding: ON Brain Institute, \$384,615

CP-NET will create a population-based database of Cerebral Palsy (CP) that integrates detailed information about risk factors, neuropathology, neurodevelopmental and psychosocial status and genomics. PC-NET will recruit a population-based cohort of children

with CP born after Jan. 1, 2009 from 8 children's treatment centres across Ontario. Data will be gathered initially at baseline, confirmed at 5 years of age, and additional data will be collected again when the child is 7 years of age (if applicable).

The core element of CP-NET is the Clinical Database Platform consisting of five clinical database platforms. Neuroimaging exams that have previously been done for clinical purposes will be obtained, read, coded, and analyzed to create the Neuroimaging Platform. Saliva samples will be obtained and DNA stored for the creation of the Genomic Platform. Standardized developmental outcome measures including a neurological exam, identification of co-morbidities, cognitive profile, pain assessment, and gross motor, fine motor, and communication classifications will be administered to create the Neurodevelopmental Platform. Finally, assessment of mental health, sleep, quality of life and participation will comprise the Psychosocial & Participation Platform.

20. Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences for families and rehabilitation practitioners

Investigators: Gillian King, Heidi Schwellnus, Patricia Baldwin, & Michelle Servais

Affiliation: Bloorview Research Institute

Status: Underway, 2014-2016

Funding: Institute of Coaching, \$26,930

The use of coaching within pediatric rehabilitation is growing. Coaching is a goal-oriented way to work with families. Solution-focused coaching (SFC) is a form of coaching that highlights family's strengths and their solutions for their situation. There is little research on how SFC works with families and clinicians. This study fills that gap. This study will help us understand how SFC affects both clinicians and families. Fifteen families and 15 clinicians will be asked some open-ended questions about what they think about SFC. The findings from this study will help us understand the SFC-peds approach better.

21. Can eye-tracking technology help girls with Rett syndrome meet individualized goals for communication?

Investigators: Janette McDougall, Victoria Siu¹, Barb Easton, Gill Steckle, Kelli Vessoyan, & Carrie Laskey

Affiliations: London Health Sciences Centre-
The Children's Hospital of Western Ontario¹
Status: Underway, 2014-2016

Rett syndrome is a severe, genetically-based, neurodevelopmental disorder with profound impairments related to speech, dexterity, and mobility. The disorder is characterized by typical development in children, followed by regression between the ages of 6 to 18 months.

The primary objective of this multiple case study is to use Goal Attainment Scaling to assess whether eye-tracking technology can help children with Rett syndrome meet individualized communication goals. Perceived facilitators and barriers of using eye-tracking technology to meet goals will be explored. Two secondary objectives of the study are to examine: a) the psychosocial impact on children of using the technology and; b) families' satisfaction with using the technology.

EXTERNAL PROJECTS

External projects are projects that do not have any TVCC staff members named as investigators. These projects, however, do involve TVCC clients, their families, and/or TVCC staff members as participants.

All external projects are reviewed and approved by the Research Advisory Committee before being allowed to approach potential participants. A TVCC staff member is assigned as a Research Contact to liaise with the external research and make the first contact inviting potential participants to take part in the research.

The following is a list of the **25 external research projects** underway between **April 1, 2010** and **March 31, 2014**. Abstracts of the projects are located on the listed pages. The names of the TVCC Research Contact are bolded and italicized. Names of former TVCC staff are italicized only.

1. Study to determine the transition needs of adolescents and adults with Duchenne muscular dystrophy (DMD)

Investigators: Shannon Venance¹, Ricardo Viana², Kori LaDonna¹, W.J. Koopman¹, Craig Campbell¹, & Valerie Schulz¹

Affiliations: London Health Sciences Centre-
The Children's Hospital of Western Ontario¹,
& Western University²

TVCC Research Contact: Linda Bolack

Status: Completed, 2007-2010

The last 20 to 30 years has seen significant advancement in the management of cystic fibrosis and Duchenne muscular dystrophy (DMD) as they enter adulthood, these individuals have evolving needs, which may not be fully addressed in a child-centred program. In addition, the disease specific management may be unfamiliar to adult oriented health care professionals, who are most comfortable managing adult diseases. These are a few reasons that the transition to adult oriented care can be difficult for the individual, his or her family, and the health care teams involved. The main objective of this study was to explore care transition from Thames Valley Children's Centre (Pediatric Neuromuscular Clinic) to the London Health Sciences Centre-Adult Neuromuscular Clinic in the (DMD) population. A pilot study involving a needs assessment and gap analysis was performed.

The services offered and goals and objectives from the perspective of the young men with DMD and their caregivers were explored. The study also incorporated a neuromuscular specific quality of life instrument.

Presentations:

Viana, R., LaDonna, K., Koopman, W., Campbell, C., Schulz, V., & Venance, S. (2007, October). *Pilot study to determine the transition needs of adolescents and adults with Duchenne muscular dystrophy.*

Presented at the 12th International Meeting of World Muscle Society, Italy.

LaDonna, K., Koopman, W., Viana, R., Campbell, C., Schulz, V., & Venance, S. (2008, June). *Pilot study to determine the transition needs of adolescents and adults with Duchenne muscular dystrophy.*

Presented at the 39th Annual Scientific Sessions of the Canadian Association of Neuroscience Nurses, Victoria, BC, Canada.

2. Cohort study of children age 3-6 years with cerebral palsy at high risk for bone morbidity (Pilot study)

Investigator: Craig Campbell

Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario

TVCC Research Contact: Cheryl Scholtes

Status: Incomplete, 2007-2012

Cerebral palsy (CP) is a common disorder that affects a child's strength and movement. Many children with CP have other problems including learning difficulties, seizures and bone problems. Bone problems include broken bones,

scoliosis (curvature of the spine) and joint dislocations. These problems all cause significant suffering for affected children and their families when they occur. Also, a great deal of health care resources is frequently required to diagnose and treat these problems.

The causes of the bone problems in children with CP are due partly to abnormal muscle tension but may also be due to low bone strength as well.

The purpose of this study was to find out risks for low bone strength and the relationship to bone complications in children with CP. The aim was to establish temporal relationships between risk factor and outcome. Due to physical relocation of clients and difficult logistics with traveling to London Health Sciences, this study was discontinued February 2012.

3. An evaluation of the long-term effectiveness of Botulinum toxin in children with spastic cerebral palsy

Investigators: Darcy Fehlings¹, Tim Carey², Peter Rosenbaum³, Virginia Wright¹, Unni Narayanan⁴, & Charles Goldsmith³

Affiliations: Holland Bloorview Kids Rehabilitation Hospital¹, London Health Sciences Centre-The Children's Hospital of Western Ontario², McMaster University³, Hospital for Sick Children⁴

TVCC Research Contact: Linda Bolack

Status: Underway, 2008-2014

Spastic Cerebral Palsy is defined as the presence of persisting increased muscle tone and is further classified into a topography defined according to the type of limb involvement. The presence of spasticity, in addition to impacting on the motor impairment, is associated with poor muscle growth, and the development of joint contractures and orthopedic complications such as painful hip dislocation.

Intramuscular injections of Botulinum Toxin A (BTA) cause both a reduction in spasticity and weakness of the muscle. In the last decade BTA has become a standard of treatment for appropriately selected children with spastic CP. However, evidence is lacking for the impact of BTA on long-term gross motor function, community mobility, and improved ease of care and comfort.

This study will examine the long-term effectiveness of BTA on the gross motor

function, community mobility and participation of young ambulatory children (aged 2.5 – 5 years) with spastic CP over a three-year period. It is hypothesized that children who receive regular BTA injections will have greater improvements in gross motor function, community mobility and participation. The children will be assessed at 12 month intervals on a variety of outcome measures which will fully characterize the nature and extent of impairment, activity, and participation.

4. An open-label study for previously treated Ataluren (PTC124A®) patients with Nonsense Mutation Dystrophinopathy

Investigators: Craig Campbell
Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario
TVCC Research Contact: Jenny Kermer
Status: Underway, 2008-2015

Duchenne muscular dystrophy (DMD) is a disabling and life-threatening X-linked genetic disorder affecting males. A small subset of boys and men (1 out of 10) are classified as having Becker muscular dystrophy (BMD), a phenotypically milder form of the dystrophic muscle disease that is associated with later manifestation of symptoms. Boys with DBMD (Duchenne and Becker muscular dystrophy) develop progressive proximal muscle weakness that leads to deterioration of ambulation, wheelchair dependency, and eventual respiratory and cardiac failure. Only chronic administration of corticosteroids has slowed progression of the disease. However, because of serious side effects, corticosteroids are not always employed. Ataluren (PTC124) is a novel, orally bioavailable, small-molecule drug that promotes ribosomal readthrough of mRNA containing a premature stop codon. Through this mechanism of action, Ataluren has the potential to overcome the genetic defect in patients with nonsense mutation DBMD (nmDBMD). A previous Phase 2a and Phase 2b study have been conducted.

This study comprises a Phase 3, open-label study of Ataluren in patients with nmDBMD who previously received Ataluren at an investigator site in a prior PTC-sponsored clinical study. The primary objective of this study is to assess the long-term safety and tolerability of Ataluren in patients with nmDBMD who had prior exposure to the drug in a PTC-sponsored clinical trial.

5. Mechanostat theory used to understand bone complications in children with Duchenne muscular dystrophy

Investigators: Craig Campbell¹, & Natasha Seemann²
Affiliations: London Health Sciences Centre-The Children's Hospital of Western Ontario¹, Western University- Schulich School of Medicine and Dentistry²
TVCC Research Contact: Linda Bolack
Status: Completed, 2008-2010

This study investigated the relationship between bone density and bone complications in children with Duchenne muscular dystrophy (DMD). In the past, it has been difficult to define osteopenia, or weak bones in children, especially those with chronic diseases, since there is not yet an adequate way to use bone density measurements in children. The Mechanostat theory views bone strength as principally driven by the muscle forces acting on the bone. Using this theory one does not compare children with DMD to age-matched controls without DMD but to those of similar muscle mass.

This study used bone content and muscle mass measurements from dual x-ray absorptiometry, which is a commonly used clinical test but typically analyzed differently, to classify DMD children as having osteopenia and then determining if bone complications occur more commonly in those with osteopenia.

Publication:
McMillan, H.J., Campbell, C., Mah, J.K. (2010). Duchenne Muscular Dystrophy: Canadian paediatric neuromuscular physicians' survey. *The Canadian Journal of Neurological Sciences*, 37(2), 195-205.

Presentation:
Campbell, C. (2012, April). Mechanostat theory used to understand bone complications in children with Duchenne Muscular Dystrophy. Presented at the Discovery Series, Thames Valley Children's Centre, London, ON, Canada.



6. Examining medical and psychosocial morbidity in children with myotonic dystrophy

Investigators: Craig Campbell¹, Rhiannon Taranik², & Ada Ho²

Affiliations: London Health Sciences Centre-The Children's Hospital of Western Ontario¹, & Western University²

TVCC Research Contact: Linda Bolack
Status: Completed, 2008-2011

Myotonic dystrophy type 1 (DM1) is an autosomal dominant disease of unstable trinucleotide repeat expansion. Classic adult onset disease is typically associated with a repeat size of 100-1000, whereas those with childhood or congenital onset (CDM) usually have over 1000 repeats. CDM only occurs in DM1 and has an estimated incidence of 0.08 per 1000 live births. CDM constitutes the third largest group of children in the pediatric neuromuscular clinic at Children's Hospital of Western Ontario. CDM is a disease characterized by progressive muscular weakness and multisystem manifestations. Various studies report muscle weakness and myotonia, respiratory, cardiovascular, gastrointestinal, orthopaedic, and ocular complication in DM1 patients. However, no studies have examined the broad spectrum of medical morbidities involved with the congenital form, which would be useful in determining any differences from adult-onset DM1, establishing practice guidelines and establishing relevant outcomes for clinical trials.

This study recruited subjects ages 5 to 18 years of age. Psychosocial and functional measures were examined as potential outcome measures for childhood DM1.

Publications:

Ho, A., & Campbell, C. (2009). Motor outcome measures in congenital and childhood DM1. *Medizinische Genetik*, 21(3), 442 P4-02.

Ho, A., Bax, K., & Campbell, C. (2009). Quality of life and family impact of congenital and childhood DM1. *Medizinische Genetik*, 21(3), 443 P4-05.

Presentations:

Ho, A., & Campbell, C. (2008, September). *Medical morbidity and mortality in a population based sample of congenital myotonic dystrophy*. Presented at the Muscle Study Group Meeting, Buffalo, NY, United States.

Campbell, C. (2012, November). *Examining medical and psychosocial morbidity in children with Myotonic Dystrophy*. Presented at the Thames Valley Children's Centre, London, ON, Canada.

7. Canadian Neuromuscular Disease Registry

Investigators: Craig Campbell, Shannon Venance, Rhiannon Taranik, & Ashrafunissa Janmohammad

Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario

TVCC Research Contact: Linda Bolack
Status: Underway, 2010-2015

Neuromuscular disorders (NMD) are present in all populations and affect people of all ages. Individual NMDs are often referred to as rare or orphan diseases. A challenge is often the inability to identify and recruit the number of participants needed to complete clinical trials. The Canadian Neuromuscular Disease Registry (CNDR) will provide a tool to connect researchers with potential participants to increase the success of participant recruitment for clinical trials. The CNDR will also provide the ability to collect important information about the distribution of NMDs in Canada.

8. Development of an indicator of the impact of assistive devices on children with disabilities and their families

Investigators: Stephen Ryan¹, Bonita Sawatzky², & Kent Campbell³

Affiliations: Bloorview Research Institute¹, University of British Columbia², & Health Council of Canada³

TVCC Research Contact: Christie Beldom
Status: Completed, 2010-2013

The purpose of this project was to study whether the Family Impact of Assistive Technology Scale (FIATS) could be used to detect the influence of new wheelchair seating systems on the lives of children with mobility impairments and their families. One hundred parents who applied for funding for their child's wheelchair seating in ON, Quebec, and British Columbia took part in the study. Each parent completed the FIATS on four occasions; two times before the introduction of new wheelchair seating, and at 6 weeks and 6 months following its introduction. Parents completed other questionnaires to explore other aspects of family life that may have been affected by the introduction of wheelchair seating.

Presentations:

- Ryan, S.E., Montpetit, K., & Sawatzky, B. (April 2013). *Measuring functional outcomes for adaptive seating interventions in children and youth*. Webinar hosted at Holland Bloorview Kids Rehabilitation Hospital, Toronto, ON, Canada.
- Ryan, S.E., Campbell, K.A., Sawatzky, B., Rigby, P.J., Montpetit, K., Roxborough, L., & McKeever, P. (2012, November). *How do wheelchair seating systems affect the lives of children and youth with disabilities and their families?* Presented at the Health Care Innovations Conference, Toronto, ON, Canada.
- Rigby, P. Sawatzky, B., Campbell, K. & Ryan, S.E. (November 2011). *Construct validity of the Family Impact of Assistive Technology Scale*. Presented at the Bloorview Research Institute Symposium, Toronto, ON, Canada.
- Darlakis, V.B., Montpetit, K., Lafrance, M., Bilodeau, N., Rabzel, M., Campbell, K., Sawatzky, B., & Ryan, S.E. (October, 2011). *Measurement of assistive technology outcomes in children of French-speaking families*. Presented at the Canadian Association of Paediatric Health Centres Conference. Ottawa, ON, Canada. (Received 2011 CAPHC Poster Award for Clinical Research (1st place) from among 100+ posters).
- Rigby, P. Sawatzky, B., Campbell, K. & Ryan, S.E. (2011, June). *Construct validity of the Family Impact of Assistive Technology Scale*. Presented at the Canadian Occupational Therapy Association National Conference, Saskatoon, SK, Canada.
- Sawatzky, B., & Ryan, S.E. (2010, March). *FIATS: An indicator of the family impact of assistive technologies for paediatric seating systems and wheelchairs*. Presentation at the International Seating Symposium 2010.
- Ryan, S.E., Sawatzky, B., Campbell, K.A., Rigby, P.J., Montpetit, K., Roxborough, L., McKeever, P., & Lowe, I. (November, 2009). *The Impact of Assistive Devices on Mobility-Impaired Children and their families: Indicator Development*. Presented at the Bloorview Research Institute Symposium, Toronto, ON, Canada.
- Ryan, S.E., Sawatzky, B., Campbell, K.A., Rigby, P.J., Montpetit, K., Roxborough, L., McKeever, P., & Lowe, I. (November, 2009). *Development of an Indicator of the Impact of Assistive Devices in Children with Mobility Impairments and Their Families*. Presented at the Ontario Association of Children's Rehabilitation Services (OACRS) Conference. Toronto, ON, Canada.

Sawatzky, B., Ryan, S.E., & Campbell, K.A. (November, 2008). *Family impact of assistive devices for children: Focusing on seating and wheelchairs*. Presentation at the CHYRnet 3rd Annual Conference, Vernon, BC, Canada.

9. Understanding the bodily experience of Cerebral Palsy: A phenomenology

Investigator: Laura Brunton
Affiliation: Western University
TVCC Research Contact: Wendy McDonald
Status: Completed, 2010-2012

This study helped understand how adolescents and young adults with cerebral palsy experience their bodies. Youth and young adults with cerebral palsy experience pain and fatigue with activities of daily living.

This study used interviews to gain knowledge about pain, fatigue and exercise. This information is necessary, to help plan physical therapy interventions and for transition from pediatric to adult care. The data gathered from this study helped create a tool to screen people with muscle fatigue to help tailor their physiotherapy services to better manage pain and fatigue experienced on a daily basis.

Publications:

- Brunton, L.K., & Rice, C.L. (2011). *Fatigue in cerebral palsy: A critical review*. *Developmental Neurorehabilitation*, 15(1),54-62.
- Brunton, L., & Bartlett, D. (2012). *Understanding the impact of fatigue on adolescents and young adults with cerebral palsy*. (*Facts to Go, Volume 8, Issue 1*). London, ON: Thames Valley Children's Centre.

Presentations:

- Brunton, L. (2011, November). *Physical activity matters-everyday!* Presented at the Ontario Association of Children's Rehabilitation Services Conference, Toronto, ON, Canada.
- Brunton, L. (2012, March). *The bodily experience of living with cerebral palsy: A phenomenology*. Presented at the Discovery Series, Thames Valley Children's Centre, London, ON, Canada



10. A randomized, double-blinded, placebo-controlled, multiple ascending-dose study to evaluate the safety, tolerability, pharmacokinetics, & pharmacodynamics of ACE-031

Investigators: Craig Campbell, Shannon Venance

Affiliation: London Health Sciences Centre-The Children's Hospital of Western ON

TVCC Research Contact: Cheryl Scholtes

Status: Completed, 2010-2011

This randomized, double-blind, placebo-controlled, drug study was being done to test the safety of ACE-031 (proved in earlier studies to increase muscle mass and strength and reduce intramuscular fibrosis) in subjects with Duchenne muscular dystrophy.

This study had escalating doses of the medication to determine the optimal safe dose. The effectiveness of the drug was evaluated by several outcome measures. Data from this study helped to establish whether ACE-031 was helpful for treating DMD.

11. Understanding sexuality among adolescents with physical disabilities: A narrative inquiry

Investigator: Lauri East

Affiliation: Western University

TVCC Research Contact: Linda Bolack

Status: Completed, 2010-2011

This study explored how adolescents with physical disabilities learned about sexuality and how this experience influenced the way they see themselves as sexual beings.

This project also looked at what types of resources and services should be developed in order to improve sexuality education for these youth. Narrative interviews were conducted with adolescents living with a physical disability, along with focus groups involving teachers, physicians and allied health professionals who are involved in the delivery of sexuality education as well as parents/guardians of youth with physical disabilities.

Publications:

East, L., & Orchard, T. (2011). Understanding sexuality and sex education for adolescents with physical disabilities (*Facts To Go, Volume 7, Issue 3*). London, ON: Thames Valley Children's Centre.

East, L.J., & Orchard, T.R. (2013). Somebody *else's* job: Experiences of sex education among health professionals, parents and adolescents with physical disabilities in Southwestern ON, Canada. *Sexuality & Disabilities*. doi 10.1007/s11195-013-9289-5

Presentation:

East, L. (Producer). (2011, February 9). *Understanding sexuality among adolescents with physical disabilities: A narrative inquiry*. Presented at the Western University- Health & Rehabilitation Sciences Graduate Research Forum. Podcast retrieved from <http://www.youtube.com/watch?v=3NcyPETfTro>

12. Examining occupational identity: Perspectives of children and their parents

Investigators: Elizabeth Kinsella, Shannon Phelan, Angela Mandich, & Lilian Magalhaes

Affiliation: Western University-School of Occupational Therapy

TVCC Research Contact: Linda Bolack

Status: Completed, 2010-2012

The purpose of this research was to examine and develop theory about how occupations contribute to the construction of identity in children with disabilities, with particular attention to the social and cultural factors that shape children's engagement in childhood occupations. Here, the term 'occupations' is defined as groups of activities and tasks of everyday life. Grounded theory methods included: children's occupational profiles, photographs of everyday activities, and in-depth interviews of children and parents. Results contributed to knowledge regarding barriers and facilitators to engaging in childhood activities and how this would influence identity formation during childhood.

Publications:

Phelan, S.K. (2012). Enacting occupation and identity: Perspectives of children and their parents. (*Doctoral thesis, Western University*). Retrieved from <http://ir.lib.uwo.ca/etd/607>

Phelan, S.K., & Kinsella, E.A. (2011). Photoelicitation interview methods and research with children: Possibilities, pitfalls and ethical considerations. In J. Higgs, A. Tichen, D. Horsfall & D. Bridges (Eds), *Creative spaces for qualitative researching. Living research* (pp. 125-134). Rotterdam, The Netherlands: Sense.

- Phelan, S.K., & Kinsella, E.A. (2014).
Occupation and identity: Perspectives of children *with* disabilities and their parents. *Journal of Occupational Science*, 21(3), 334-356.
- Phelan, S.K., & Kinsella, E.A. (2012).
Picture this . . . safety, dignity, and voice-ethical research with children: Practical considerations for the reflexive researcher. *Qualitative Inquiry*, 19(2), 81-90.

Presentations:

- Phelan, S., & Kinsella, E. A. (2012, June).
Examining occupation and identity in childhood: A case study approach. Occupations and practice through time. Presented at the Canadian Association of Occupational Therapists Conference, Quebec City, QC, Canada.
- Phelan, S., & Kinsella, E. A. (2012, June).
Photoelicitation: An innovative and occupation-based *method* for researching children's occupations. *Occupations and practice through time.* Presented at the Canadian Association of Occupational Therapists Conference, Quebec City, QC, Canada.
- Phelan, S., & Kinsella, E. A. (2012, May).
Occupation, identity, and disability: Case studies with cOchildren. Presented at the Canadian Society of Occupational Scientists Conference, Edmonton, AB, Canada.
- Phelan, S., & Kinsella, E. A. (2012, May).
Safety, dignity, and voice: Ethical considerations in researching occupation with children. Presented at the Canadian Society of Occupational Scientists Conference, Edmonton, AB, Canada.
- Phelan, S., & Kinsella, E. A. (2011, October).
Ethical considerations in qualitative research with children: The quest for safety, dignity, and voice in the research process. Presented at the 17th Annual Qualitative Health Research Conference, University of Alberta, International Institute for Qualitative Methodology, Vancouver, BC, Canada.
- Phelan, S., & Kinsella, E. A. (2011, October).
Photoelicitation interviews and research with children: Practical considerations from the field. Presented at the 17th Annual Qualitative Health Research Conference. University of Alberta, International Institute for Qualitative Methodology, Vancouver, BC, Canada.
- Phelan, S., & Kinsella, E. A. (2011, October).
Using photoelicitation interviews as a method to study occupation with children: Reflections from the field. Presented at the Annual Research Conference 'Mountaintop Reflections. Learning from Ten Years as a

- Scholarly Community', Society for the Study of Occupation, Park City, UT, United States.
- Phelan, S., & Kinsella, E. A. (2012, October).
Ethical research on occupation with children: A call for reflexivity. *Occupation and place: Sustainability, balance, and occupation.* Presented at the 11th Annual Research Conference of the Society for the Study of Occupation, Portland, OR, United States.
- Phelan, S., & Kinsella, E. A. (2012, October).
Occupation, identity, participation, and social inclusion: Case studies of children with disabilities. *Occupation and place: Sustainability, balance, and occupation.* Presented at the 11th Annual Research Conference of the Society for the Study of Occupation, Portland, OR, United States.

13. The effectiveness of intensive behavioural intervention in children with autism over the age of six years

Investigators: Jennifer Dunn Geier¹, Adrienne Perry², & Ksusha Blacklock²
Affiliations: Autism Intervention Program-Eastern Ontario¹, & York University²
TVCC Research Contact: *Veronica Vanderborght*
Status: Completed, 2010-2011

ON's Intensive Behavioural Intervention (IBI) program is available to all children with a diagnosis of autism regardless of age. Large amounts of public money are being spent on this program. However, the effectiveness of IBI for children older than 6 has not been documented. It was, therefore, imperative to evaluate the effectiveness of IBI for this age group.

Presentation:

Blacklock, K., Perry, A., Dunn Geier, J. (2011, May). *Effectiveness of Intensive Behavioral Intervention in children with autism over the age of 6 years.* Presented at the 37th Association for Behavior Analysis International Annual Convention, Denver, CO, United States.

14. School, home and neighbourhood accessibility: Physical disabled children's assessments (The SchAn Project) PHASE 2

Investigators: Patricia McKeever¹, Susan Ruddick², James Dunn³, Nancy Young⁴, Nicole Yantze⁴, & Sean Doherty⁵
Affiliations: Holland Bloorview Kids Rehabilitation Hospital¹, University of

Toronto², McMaster University³, Laurentian University⁴, & Wilfred University⁵

TVCC Research Contact: Linda Bolack

Status: Completed, 2010-2012

Little is known about the built environments within which children who use mobility devices live, play and learn. Inaccessible environments socially and physically exclude these children and limit their participation. Phase I was completed in 2009 and involved 12 children from across ON who led virtual tours of their homes, schools and neighbourhoods, mapped their daily geographies using GPS and participated in focused interviews.

In Phase 2 (this Phase), a provincial mail survey was sent to 1,000 additional children. The results are used to inform inclusive housing, educational and municipal policies.

15. Collaborating with parents and therapists to develop dissemination products: The MOVE & PLAY study

Investigators: Doreen Bartlett

Affiliation: Western University-School of Physical Therapy

TVCC Research Contact: Dan Judson

Status: Completed, 2010-2011

The MOVE & PLAY Study (Movement and Participation in Life Activities of Young Children) focused on understanding determinants of motor abilities, self-care and play of pre-school children with cerebral palsy and the primary goal in conducting this research was to impact practice. Twelve easy-to-read research summaries of our results were prepared. The summaries had been reviewed by parents of children with cerebral palsy, and therapists who work with these children. They provided feedback via focus groups and the final summaries were posted on the *CanChild* website for access by parents, therapists, administrators and policy makers. The summaries can be found at: www.canchild.ca/en/NewsModule

16. Physical activity and active lifestyle program for youth with cerebral palsy: A STAY-FIT pilot study

Investigators: Jan Willem Gorter¹, Brian Timmons¹, Peter Rosenbaum², Bob Palisano², & Virginia Wright³

Affiliations: CanChild Centre for Childhood Disability Research & Department of

Pediatrics McMaster Children's Hospital¹, McMaster University, CanChild Centre for Childhood Disability Research², & Bloorview Research Institute³

TVCC Research Contact: Karen Faragher

Status: Completed, 2011-2012

The plan of this study was to develop a program that would teach people how to promote physical activity and encourage an active lifestyle in young people with cerebral palsy (CP). Before this program could be developed and evaluated, some pilot work was done to find out the barriers and facilitators to being physically active.

The purpose was to talk to parents and youth with CP to learn what they thought the problems and solutions might be with creating a new program to promote physical activity and encourage an active lifestyle in youth with CP.

Publications:

Claassen, A., Gorter, J. W. (2011). What helps adolescents with cerebral palsy to be physically active? Developing a program to support youth based on focus groups. (*Our Research IN BRIEF*). Hamilton, ON: CanChild Centre for Childhood Disability Research, McMaster University.

Claassen, A., Gorter, J. W., Stewart, D., Verschuren, O., Galuppi, B.E., & Shimmell, L.J. (2011). Becoming and staying physically active in adolescents with cerebral palsy: Protocol of a qualitative study of facilitators and barriers to physical activity. *BMC Pediatrics*, 11(1) Retrieved from <http://www.biomedcentral.com/1471-2431/11/1>.

Presentations:

Gorter, J. W., Jackson, D., Galuppi, B., Shimmell, L., & Wright, M. (2012, November). *What helps adolescents with cerebral palsy to be physically active?* Presented at the OACRS Conference, Toronto, ON, Canada.

Jackson, D., Gorter, J. W., Shimmell, L., & Wright, M. (2012, October). *Social factors determining physical activity in adolescents with cerebral palsy*. Presented at the Cerebral Palsy Conference, Pisa, Italy.



17. Measuring postural control in young children with cerebral palsy and understanding associations with the Gross Motor Function Measure

Investigators: Kate Randall, & Doreen Bartlett
Affiliation: Western University-School of Physical Therapy
TVCC Research Contact: *Liz Lusk*
Status: Completed, 2011-2012

The current literature provides a variety of information on the development of movement in individuals with cerebral palsy; however, there is little knowledge regarding the balance component.

The purpose of this study was to do a head-to-head comparison of two recently developed balance measures to determine their correlation and consistency, and their relationship with a test of movement. The thought of the findings were that the balance measures will be correlated and highly consistent and their relationship to the test of movement will be strong.

Presentation:
Bartlett, D. (2012). Measuring postural control in young children with cerebral palsy and understanding associations with the Gross Motor Function Measure. Presented at Thames Valley Children's Centre Discovery Series. London, ON, Canada.

18. Constructing a new clinical measure of fatigue for adolescents and young adults with cerebral palsy

Investigators: Laura Brunton, & Doreen Bartlett
Affiliation: Western University-School of Physical Therapy
TVCC Research Contact: *Jenny Kermer*
Status: Completed, 2011-2012

This study used the results of a review of available questionnaires used to measure fatigue in neurological conditions and to create a new fatigue measure for individuals with cerebral palsy. Healthcare professionals and individuals with cerebral palsy were asked to help ensure the tool was relevant to the chosen population while remaining easy to complete in a reasonable amount of time.

The general aim of this study was to refine a measurement tool for fatigue to ensure it is specific and feasible to complete by individuals with cerebral palsy.

19. How do parents use information with the aid of a knowledge broker when living with a child with cerebral palsy?

Investigators: Stephanie Lagosky, & Doreen Bartlett
Affiliation: Western University-School of Physical Therapy
TVCC Research Contact: *Monique Van Kessel*
Status: Completed, 2011-2012

The aim of this study was to understand how parents use health information when living with and caring for their young children with cerebral palsy. An interactive workshop was held to introduce research materials to parents. In the subsequent three months, a sample of 12 parents had access to a Knowledge Broker to aid them in the provision and uptake of research materials. After this period, focus groups were held with parents, as well as selected in-depth interviews.

Data was analyzed and a model was generated on how parents use health information.

Presentation:
Lagosky, S. (2012, July). How do parents use health information with the aid of a knowledge broker when living with and caring for their young children with cerebral palsy? Presented at Western University, London, ON, Canada.

20. Effectiveness of motor speech intervention for children with speech disorders

Investigators: Aravind Namasivayam¹, Pascal Van Lieshout¹, Robert Kroll², & Margit Pukonem²
Affiliations: University of Toronto¹, & The Speech and Stuttering Institute²
TVCC Research Contact: *Jennifer Steeper*
Status: Completed, 2011-2012

The purpose of this study was to establish treatment effects and magnitude of treatment effects for specific outcome measures in children with speech sound disorders undergoing motor speech treatment protocol based interventions. It was a large scale multi-centre study aimed at examining the effectiveness of a specific type of (motor) speech therapy for children presented with speech sound difficulties.

The study was organized by the Ministry of Child and Youth Services and 52 specially

trained clinicians from 32 preschool Speech and Language programs in ON, Canada. About 250 children with motor speech issues participated in this study.

This study allowed us to understand and predict how much improvement can be expected from this speech therapy and the factors that improved outcomes.

21. Validating a new measure of fatigue for adolescents and young adults with cerebral palsy: The fatigue impact and severity self-assessment

Investigators: Laura Brunton, & Doreen Bartlett
Affiliation: Western University-School of Physical Therapy
TVCC Research Contact: Linda Bolack, & Jenny Kermer
Status: Completed, 2012-2012

Data on physical activity, pain, life orientation (level of optimism), and the usual mobility were used along with severity level and distribution of involvement to validate a new measure of fatigue for youth and young adults with cerebral palsy (CP). Stability of responses over time were also be determined.

In addition, the data collected in this study was used to explore relationships that may exist between pain, fatigue and physical activity.

22. An exploration of factors associated with response to an intensive behavior intervention program for children with autism spectrum disorder

Investigators: Eugenie Steyn, & Robert Sandieson
Affiliation: Western University
TVCC Research Contact: Catherine Pryor
Status: Cancelled, 2012

Children's progress following participation in an Intensive Behavioural Intervention (IBI) program for children with autism spectrum disorders (ASD) at Thames Valley Children's Centre (TVCC) was to be examined. A file-review of existing data was to be conducted.

This study was cancelled by the Principal Investigator.

23. Monitoring development of children with cerebral palsy or gross motor delay

Investigators: Doreen Bartlett¹, Lisa Chiarello², Robert Palisano², Sally Westcott McCoy³, Lynn Jeffries⁴, Alyssa Laforme Fiss⁵, Steve Hanna⁶, & Jan Willem Gorter⁶

Affiliations: Western University-School of Physical Therapy¹, Drexel University², University of Washington³, University of Oklahoma Health Sciences Centre⁴, Mercer University⁵, & McMaster University⁶

TVCC Research Contact: Michelle Truppe
Status: Underway, 2012-2017

The aim of this research study is to describe the changes in balance (a primary impairment), range of motion limitations, strength, and endurance (secondary impairments), number and impact of health conditions, and participation in self-care and recreation and leisure activities over a one-year period in young children with cerebral palsy

(CP) aged 18 months to 10 years. One hundred and seventy-five children with CP, aged 18 months to 10 years, in each of the 5 levels of the Gross Motor Function Classification System (GMFCS) will be recruited. Trained therapist assessors will measure the primary and secondary impairments (i.e. balance, range of motion limitations and strength) on 2 occasions (12-months apart). Through parental interview, we will track changes in endurance, health conditions, and participation in self-care and recreation activities, at the same data collection points. We will use these two data collection points to develop reference percentiles and we will present the data so that therapists can assist families to determine if other children with CP are developing as expected, better than expected, or more poorly than expected, depending on their functional ability levels.

Rehabilitation services can be altered to ensure optimal motor development, health, self-care abilities and participation in life activities.



24. Stacking Exercises aid the decline in forced vital capacity (FVC) and sick time (STEADFAST) in boys 6-16 years with Duchenne muscular dystrophy

Investigator: Craig Campbell
Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario
TVCC Research Contact: *Cheryl Scholtes*
Status: Underway, 2014-2016

Duchenne muscular dystrophy is complicated by weak breathing muscles and lung infections. "Lung volume recruitment" (LVR) is a method for preserving lung function. It is hypothesized that LVR will slow down the steady loss of lung function, prevent lung infection, and improve quality of life. The study aim is to compare standard care to LVR plus standard of care. Two hundred and fifty-four existing 6-16 year old boys in 14 Canadian tertiary care hospitals will be contacted to participate in the study.

25. Health endpoints and longitudinal progression in congenital myotonic dystrophy (HELP-CDM)

Investigators: Craig Campbell
Affiliation: London Health Sciences Centre-The Children's Hospital of Western Ontario
TVCC Research Contact: *Cheryl Scholtes*
Status: Underway, 2014-2015

Congenital myotonic dystrophy (CDM) is the result of a dominantly inherited disorder caused by a trinucleotide repeat expansion in the DMPK gene. Patients with CDM present at birth with respiratory insufficiency and hypotonia and later have intellectual impairment and motor delay. Currently, there are no published longitudinal or large group cross sectional studies evaluating children with CDM during infancy and childhood. This information is needed to document the rate and variation of progression, identify potential biomarkers, spectrum of manifestations, and individual trends and variation in functional abilities, and quality of life. We propose to longitudinally characterize the symptoms and functional outcomes associated with CDM disease progression in early and late childhood to develop a model for symptom development and progression.

This study will enroll sixty children with CDM and 30 control subjects with stratified recruitment into four cohorts.

QUALITY ASSURANCE PROJECTS

Quality Assurance activities are an integral part of providing quality services and interventions to clients and families. At TVCC, staff members evaluate their practices, programs, and services to learn about what works best, and to enhance service delivery. Selected quality assurance activities that took place between **1 April 1, 2010 and March 31, 2014** are listed below.

1. What early years families tell us about important elements of documentation

Investigators: *Michelle Truppe, Michelle Servais, Patricia Baldwin, Mary Ellen McLean, & Janet Gritzan*

Status: Completed, 2012-2014

The documentation provided to early years families for the Getting Started at Thames Valley Children's Centre (GSAT) service is comprehensive, takes time for clinicians to complete, and is often co-written by multiple clinicians. GSAT clinicians wanted to know whether these reports are useful and responsive to families' needs. Twenty early years families were interviewed to find out their perspectives of the GSAT documentation. These families affirmed the value of the documentation: writing reports does make a difference for these families. This evaluation contributed to the development of best practices for documentation.

2. Evaluation of the Getting Started at Thames Valley Children's Center (GSAT) Service

Investigators: *Michelle Truppe, Michelle Servais, Patricia Baldwin, Linda Bolack, Karen Tjosvold, & Brent Duncan*

Status: Completed, 2011-2013

Getting Started at Thames Valley Children's Centre (GSAT) service, a centre-wide, multi-disciplinary program for welcoming newly referred families to Thames Valley Children's Centre (TVCC) services. GSAT was created in response to lengthy wait times for newly referred clients and families at TVCC. This service was designed to welcome new families in a timely manner, address their priority needs, respond to their questions, and connect families to resources in their communities. Together, a plan is co-created to determine next steps. The GSAT team recognizes that, for families, 'getting it right at the beginning' has a positive impact on their journey. An evaluation was conducted to

examine the GSAT processes to determine what was working well and how this service could be enhanced.

Publications:

Servais, M., Baldwin, P., Truppe, M., Bolack, L., Tjosvold, K., & Duncan, B. (2014). An evaluation of the Getting Started at Thames Valley Children's Centre Program (GSAT, Part 1). *Lessons Learned*, 2(1). London, ON: Thames Valley Children's Centre.

Servais, M. (2012, May). Report of findings. Results from the evaluation of Getting Started at TVCC (GSAT): *Key themes from the GSAT focus groups*. London, ON: Thames Valley Children's Centre.

3. An evaluation of the solution-focused coaching training for pediatric rehabilitation service providers

Investigators: *Patricia Baldwin, & Michelle Servais*

Status: Completed, 2010-2012

Solution-Focused Coaching (SFC) is a method used at Thames Valley Children's Centre to facilitate strengths-based, collaborative partnerships with parents of children with communication disorders, developmental/physical disabilities, and autism spectrum disorders. As part of quality improvement activities, all staff and management received training and ongoing coaching in the use of SFC in their work. A program evaluation was conducted into the effectiveness of SFC and training to: a) examine perceptions of impact on clinical practice and organizational development and b) refine training methods and materials. Seventy-eight Autism staff provided feedback on questionnaires 3 months after training, and 1 year after training. Twenty-three staff and managers participated in a focus group to provide feedback about their training experiences and the impact of SFC on their practice.

Publication:

Baldwin, P., King, G., Evans, J., McDougall, S., Tucker, M. A., & Servais, M. (2013).

Solution-focused coaching in pediatric rehabilitation: An integrated model for practice. *Physical & Occupational Therapy in Pediatrics*, 33(4), 467-483.

doi:10.3109/01942638.2013.784718

Presentations:

Baldwin, P., & Servais, M. (2012, September). Translating solution-focused coaching into practice: An evaluation of solution-focused coaching at Thames Valley Children's Centre. Presentation for the Musing and Munching Series at Thames Valley Children's Centre, London, ON, Canada.

Baldwin, P., Servais, M., & Tucker, M. A., (2011, November). *Using solution-focused coaching in pediatric rehabilitation.* Presentation for the 2011 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON, Canada.

4. An evaluation of Thames Valley Children's Centre's Autism Program's educational workshops for parents of children with autism

Investigators: Wendy Forster, Cathy Kelday, Jennifer Klingenberg, Patricia Lemon, Charlene Oulds, Sarena Renauld, Marcie Salens, Michelle Servais, Veronica Vanderborght, & Theresa Verspagen

Status: Completed, 2009-2010

The Autism Program evaluated their Parent Education Programs to examine parents' and caregivers': a) overall satisfaction with educational sessions and b) parents' and caregivers perceived impact of educational sessions on personal skills, knowledge, and quality of life. Eighty-five parents and caregivers participating in these educational sessions completed questionnaires at 5 time points. Participants reported a high level of satisfaction with services, and an increase in their skills and knowledge level. Families with less stress reported a higher quality of life than those families under high stress levels. This feedback from families was used to enhance the Parent Education Programs.

Presentation:

Servais, M. (2010, May). *How satisfied are parents with the autism program's parental educational service?* Presented for the Autism Program at Thames Valley Children's Centre, London, ON, Canada.

5. Evaluating Client Satisfaction with Thames Valley Children's Centre's Service Delivery

Investigators: Colleen Willoughby, Linda Bolack, Janette McDougall, Barb Bocking, Dan Judson, Patricia Baldwin, Mary Ann Tucker, Barb Easton, Carolyn Underwood, Carrie Laskey, Monique Van Kessel, Sue Kirkpatrick, Karen Lowry, Mary Ellen Kendall

Status: Completed, 2010-2013

A group of TVCC clinicians, researchers, and leaders met and developed a "Client Satisfaction Survey" in order to assess how we are doing in terms of service delivery from the perspectives of our families. One hundred and sixty-one families responded to the survey. The vast majority of comments from families about TVCC services were positive. Overall, the families that responded to TVCC's Client Satisfaction Survey were very satisfied with the process, structure, and outcomes of services, and services overall. We are focused on enhancing those aspects of services that families told us could be improved.

Publications:

McDougall, J., Willoughby, C., & Bolack, L. (2014). Client Satisfaction with TVCC Services: Learning from our Families *Lessons Learned, 1(1)*. London, ON: Thames Valley Children's Centre.

Presentation:

Willoughby, C., Bolack, L., & McDougall, J. (2012-2013). *Client Satisfaction Survey.* Presented to ECSAAP, Clinics, Parent Advisory Committee, Operational Priority Committee, Leadership, Seating and Mobility Team, and the ACS Team. Thames Valley Children's Centre, London, Ontario.



6. Using the International Classification of Functioning, Disability, and Health - Children and Youth Version (ICF-CY) to Enhance Client Assessment and Outcome Measurement.

Investigators: Linda Bolack, Janette McDougall, Karen Lowry, Colleen Willoughby, Dan Judson, Pamela Frid
Status: Completed, 2010-2012

A group of TVCC clinicians, researchers, and leaders met and developed a clinical assessment tool based on the ICF-CY. ICF-CY codes were also incorporated into TVCC's electronic health records system, Goldcare so that service need and delivery could be tracked on an aggregate basis.

Presentation:

Bolack, L., & McDougall, J. (2012, November). *Using the ICF-CY to enhance client assessment and outcome measurement.* Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

7. Evaluating the interdisciplinary collaboration of a pediatric rehabilitation regional service team

Investigators: Joanne Legros-Kelly, Michelle Servais
Status: Completed, 2011-2014

The regional team consists of service providers from both the Autism Program and Rehabilitation Services. We investigated team members' perceived levels of interdisciplinary collaboration. The Index of Interdisciplinary Collaboration Questionnaire (Bronstein, 2002) was used to measure five critical core components identified in the research literature (Bronstein, 2003) that represent different aspects of interdisciplinary collaboration: interdependence, newly created professional activities, flexibility, collective ownership of goals, and reflection in processes. The results indicate that staff valued their collaboration with colleagues and wanted opportunities to further develop interdisciplinary collaboration. Findings resulted in identifying areas of interdisciplinary collaboration that could be enhanced.



FUNDING FOR TVCC PROJECTS

Between **April 1, 2010 and March 31, 2014** a total of **\$233,467** in funding from granting agencies was awarded to **3** research projects with TVCC staff members as investigators. The names of TVCC staff members who were investigators on the grants are bolded and italicized. Names of former TVCC staff are italicized only.

Canadian Institutes of Health Research **\$181,682**

Toward improvement of augmentative and alternative communication services for young people with complex communication needs, 2013-2014 (Stephen Ryan, **Carrie Laskey**, **Michelle Servais**, **Tracy Shepherd**, Kim Bradley, Michael Hillmer, Shauna Kingsnorth, Anne Marie Renzoni, & Karen Ward)

SIMone Ontario Simulation Network **\$24,855**

Development of a listening skill simulation intervention for pediatric rehabilitation therapists, 2013-2015 (*Gillian King*, **Michelle Servais**, Sheila Moodie, **Tracy Shepherd**, **Colleen Willoughby**, **Linda Bolack**, **Patricia Baldwin**, Kathryn Parker, & Diane Savage)

Institute of Coaching **\$26,930**

Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences for families and rehabilitation practitioners, 2014-2015 (*Gillian King*, **Patricia Baldwin**, **Michelle Servais**, & Heidi Schweltnus)

Between **April 1, 2010 and March 31, 2014** a total of **\$6,125,640** in funding from granting and other agencies was awarded to **6** research projects with TVCC staff members named as site investigators (i.e., TVCC staff were not named on the original grant or funding application). The names of TVCC staff members who were site investigators are bolded and italicized. Names of former TVCC staff are italicized only.

Jesse's Journey & Canadian Institutes of Health Research **\$540,000**

Myoblast transplantation in Duchenne and Becker muscular dystrophy patient, 2010-2015 (Craig Campbell, **Cheryl Scholtes**, **Linda Bolack**, Shannon Venance, Guido Filler, Daniel Skuk, Rhiannon Taranik, Ashrafunissa Janmohammad, Jacques Tremblay, & Jack Puymirat)

Ontario Brain Institute **\$1,500,000**

Childhood hemiplegic cerebral palsy integrated neuroscience discovery network "CP-NET", 2012-2014 (Craig Campbell, **Pamela Frid**, **Jennifer McLean**, **Jacqueline Ogilvie**, Ravi Menon, Darcy Fehlings, & Rhiannon Taranik)

National Institute of Health **\$3,393,979**

Duchenne muscular dystrophy: Double-blind randomized trial to find optimum steroid regimen, 2012-2017 (Craig Campbell, **Cheryl Scholtes**, Ashrafunissa Janmohammad, Rhiannon Taranik, Teresa Rooney, & Lisa Coutu)

Eli Lilly **\$221,316**

A randomized, double-blind, placebo-controlled, phase 3 trial of Tadalafil for Duchenne muscular dystrophy, 2013-2015 (Craig Campbell, **Cheryl Scholtes**, **Wendy McDonald**, Sabeeh Alvi, Ashrafunissa Janmohammad, Rhiannon Taranik, & Teresa Rooney)

PTC Therapeutics **\$85,730**

A phase 3 efficacy and safety study of Ataluren (PTC124) in patients with nonsense



mutation dystrophinopathy, 2013-2016 (Craig Campbell, **Cheryl Scholtes**, **Wendy McDonald**, Sabeeh Alvi, Ashrafunissa Janmohammad, Rhiannon Taranik, & Teresa Rooney)

Ontario Brain Institute

\$384,615

Childhood cerebral palsy integrated neuroscience discovery network CP-NET, 2014-2018 (Craig Campbell, **Pamela Frid**, & **Jennifer McLean**)

Funding Sources

Since 1989, funding for research endeavours taking place at TVCC has been received from the following agencies:

- Apple Canada Incorporated
- Bloorview Kids Foundation
- Canadian Institutes of Health Research
- Canadian Occupational Therapy Foundation
- CanChild, Centre for Childhood Disability Research
- Chedoke-McMaster Hospitals
- Child and Parent Resource Institute
- Children's Hospital of Western ON Foundation
- Easter Seal Association
- Easter Seal Research Institute
- Education Quality and Accountability Office
- Eli Lilly
- Health Canada, Health Policy Research Program
- Hospital for Sick Children Foundation
- Institute of Coaching
- Jesse's Journey
- National Crime Prevention Centre
- National Institutes of Health
- Ontario Brain Institute
- Ontario Health Care Evaluation Network
- Ontario Mental Health Foundation
- Ontario Ministry of Community and Social Services
- Ontario Ministry of Health
- Ontario Neurotrauma Foundation
- Ontario Rehabilitation Research Network
- Ontario Rehabilitation Technology Consortium
- PTC Therapeutics
- Reseau Provincial de Recherche en Adaptation-Readaptation
- Research Alliance for Children with Special Needs
- SIMone Ontario Simulation Network
- Social Sciences and Humanities Research Council of Canada
- St. Mary's Fund from St. Joseph's Health Centre
- Thames Valley Children's Centre
- The Jack and Ina Pollock Foundation
- The Richard and Jean Ivey Fund
- United Cerebral Palsy Foundation
- United States National Institute of Health
- Western University



Research Key Fact: Project Funding

Since 1989 the total amount of funding - **\$7,962,537** for **121 grants with TVCC staff as named investigators on the grants**

- Projects awarded funding - **100**
- Projects receiving more than one grant - **17**
- Funding sources - **38**
- Projects under \$5,000 - **39**
- Projects with funding between \$5001 and \$9,999 - **8**
- Projects with funding between \$10,000 and \$50,000 - **28**
- Projects with funding of \$51,000 and \$250,000 - **21**
- Projects with funding over \$250,000 - **7**

PUBLICATIONS

TVCC produces and transfers knowledge about children with special needs and our research findings through professional publications. Findings have clear implications for enhancing services and therapeutic interventions.

The following is a list of articles and resources that were published between **April 1, 2010 and March 31, 2014**. Names of TVCC staff members are bolded and italicized. Former TVCC staff member's names are italicized only.

BOOK

McDougall, J. (2011). *Social support and health in youth: Examining relationships*. Saarbrücken, Germany: LAP LAMBERT Academic Publishing. (ISBN: 978-3-854-4205-1)

DISSERTATION

Servais, M. (2012). *Understanding teachers' information needs, perceived competencies, and information seeking behaviours for special education information*. Electronic Thesis and Dissertation Repository, Paper 743. Posted at: <http://ir.lib.uwo.ca/etd/743>

PUBLISHED ABSTRACTS

Good, D., **McDougall, J.**, Rumney, P., & Bennett, S. (2012). Successful scholastic reintegration for students who have experienced ABI. [Abstract] *Archives of Physical Medicine and Rehabilitation*, 93(10), E28.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2009) School reintegration for children and youth with Acquired Brain Injury. [Abstract] *Journal of Head Trauma Rehabilitation*, 24(5), 399.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., DeMatteo, C., & McCormick, A. (2012). Successful scholastic reintegration: Academic, social and behavioural success for students with ABI. [Abstract] *Journal of Head Trauma Rehabilitation*, 27(5), E35-E36.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., DeMatteo, C., Martinussen, R., & DeCourville, N. (2012). School-based factors contribute to successful school reintegration of children and youth with Acquired Brain Injury. [Abstract] *Brain Injury*, 26(4-5): 699-700.

Good, D., Rumney, P., Bennett, S., **McDougall, J.**, DeMatteo, C., & Martinussen, R. (2014). An investigation of factors that influence socioemotional and academic gains in the classroom for students living with the effects of ABI. [Abstract] *Brain Injury*, 28(5-6): 828-828.

McDougall, J., Wright, V., Miller, L., & **Nichols, M.** (2012). Evaluation of two measures of perceived quality of life when used with youth with chronic conditions. [Abstract] *Developmental Medicine & Child Neurology*, 54(6): 34-35. (Suppl.).

Servais, M., Shepherd, T., Bolack, L., Willoughby, C., Strachan, D., Baldwin, P., Moodie, S., Parker, K., Savage, D., Knickle, K., McNaughton, N., & King, G. (2014). Developing authentic clinical simulations for effective listening and communication. [Abstract]. In *2013 Ontario Simulation Exposition Presentation Abstracts*. Toronto, ON: SIMone Ontario Simulation Network.

JOURNALS

Augmentative and Alternative Communication

Batorowicz, B., & **Shepherd, T.** (2011). Team work in ACC: Examining clinical perceptions. *Augmentative and Alternative Communication*. Advance online publication. doi:10.3109/07434618.2010.546809.

McDougall, S., Vessoyan, K., & Duncan, B. (2012). Traditional versus computerized presentation and response methods on a structured AAC assessment tool. *Augmentative and Alternative Communication*, 28(2), 127-135.

Child: Care, Health and Development

King, G., Petrenchik, T., DeWit, D., **McDougall, J.**, Hurley, P., & Law, M. (2010). Out-of-school time activity participation profiles of children with physical disabilities: A cluster analysis. *Child: Care, Health, and Development*, 36(5), 726-741.

McDougall, J., Bedell, G., & Wright, V. (2013). The youth report version of the Child and Adolescent Scale of Participation: Assessment of psychometric properties and comparison with parent report. *Child: Care, Health, and Development*, 39(4), 512-522.

Developmental Neurorehabilitation

- McDougall, J.**, Wright, V., Rosenbaum, P. (2010). The ICF Model of functioning and disability: Incorporating quality of life and human development. *Developmental Neurorehabilitation*, 13(3), 204-211.
- McDougall, J.**, Wright, V., Schmidt, J., Miller, L., & **Lowry, K.** (2011). Applying the ICF framework to study changes in quality of life for youth with chronic conditions. *Developmental Neurorehabilitation*, 14(1), 41-53.
- Bedell, G., & **McDougall, J.** (2013). The Child and Adolescent Scale of Environment (CASE): Further validation with youth who have chronic conditions. *Developmental Neurorehabilitation*. Advance online publication. doi:10.3109/17518423.2013.855273.

Disability and Rehabilitation

- King, G., **Servais, M.**, **Bolack, L.**, **Shepherd, T.**, & **Willoughby, C.** (2012). Development of a measure to assess effective listening and interactive communication skills in the delivery of children's rehabilitation service. *Disability and Rehabilitation*, 34(6), 459-469. doi:10.3109/09638288.2011.608143.
- McDougall, J.**, Wright, V., DeWit, D., & Miller, L. (2014). ICF-based functional components and contextual factors as correlates of perceived quality of life for youth with chronic conditions. Advance online publication. doi: 10.3109/09638288.2014.892642.

Exceptionality Education International

- Specht, J., King, G., **Servais, M.**, Kertoy, M., & Spencer, T. (2010). School roles: A way to investigate participation. *Exceptionality Education International*, 21(1), 2-14.

International Journal of Listening

- Shepherd, T.**, King, G., **Servais, M.**, **Bolack, L.**, & Willoughby, C. (2014). Clinical scenario discussions of listening in interprofessional health care teams. *International Journal of Listening* 28(47-63). doi: 10.1080/10904018.2014.861295.

Journal of Research in Interprofessional Practice and Education

- King, G., Specht, J., Bartlett, D., **Servais, M.**, Petersen, P., Brown, H., Young, G., & Stewart, S. (2010). A qualitative study of workplace factors influencing expertise in the delivery of children's education and mental health services. *Journal of Research in Interprofessional Practice and Education*, 1(3), 265-283.

Physical & Occupational Therapy in Pediatrics

- King, G., Tam, C., Fay, L., Pilkington, M., **Servais, M.**, & Petrosian, H. (2010). Evaluation of an occupational therapy mentorship program: Effects on therapists' skills and family-centered behavior. *Physical & Occupational Therapy in Pediatrics*, 31(3), 245-262.
- Reid, A., Imrie, H., Brouwer, E., Clutton, S., **Evans, J.**, Russell, D., & Bartlett, D. (2011). "If I knew then what I know now": Parents' reflections on raising a child with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*. Advance online publication. doi: 10.3109/01942638.540311.
- Baldwin, P. J.**, King, G., **Evans, J.**, **McDougall, S.**, Tucker, M. A., & **Servais, M.** (2013). Solution-focused coaching in pediatric rehabilitation: An integrated model for practice. *Physical & Occupational Therapy in Pediatrics*, 33(4), 467-483. doi:10.3109/01942638.2013.784718.

Qualitative Report

- Tsonis, M., **McDougall, J.**, Mandich, A., & Irwin, J. (2012). Interrelated processes toward quality of life in survivors of childhood cancer: A grounded theory. *The Qualitative Report*, 17(89), 1-18.

Social Indicators Research

- McDougall, J.**, Wright, V., **Nichols, M.**, & Miller, L. (2012). Assessing the psychometric properties of both a global and a domain-specific perceived quality of life measure when used with youth who have chronic conditions. *Social Indicators Research*, 114(3), 1243-1257.

EASY-TO-READ SUMMARIES

"Facts to Go"

Facts to Go are one-page information sheets on research topics written by staff members and published and distributed by the Research Program.



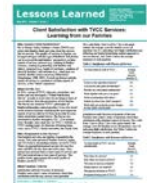
Facts To Go can be requested from the website: www.tvcc.on.ca/

- **Baldwin, P.J., Evans, J., McDougall, S., & Servais, M.** (2010). Solution-focused coaching in paediatric rehabilitation. (*Facts to Go, Volume 6, Issue 3*). London, ON: Thames Valley Children's Centre.
- **McDougall, J., Evans, J., & Baldwin, P.J.** (2010). Self-Determination: Why is it important to youth and young adults with disabilities? (*Facts to Go, Volume 6, Issue 2*). London, ON: Thames Valley Children's Centre.
- **McDougall, J., Baldwin, P., & LaPorta, J.** (2011). A positive focus for service delivery and research in pediatric rehabilitation. (*Facts to Go, Volume 7, Issue 1*). London, ON: Thames Valley Children's Centre.
- **Riggin, C., & Specht, J.** (2011). Using an interactive whiteboard to support a student with autism spectrum disorder. (*Facts To Go, Volume 7 Issue 2*). London, ON: Thames Valley Children's Centre.
- East, L., & Orchard, T. (2011). Understanding sexuality and sex education for adolescents with physical disabilities. (*Facts To Go, Volume 7 Issue 3*). London, ON: Thames Valley Children's Centre.
- **Tucker, M. A., Baldwin, P., LaPorta, J., Lowry, K., & McDougall, J.** (2011). A service delivery model for pediatric rehabilitation. (*Facts to Go, Volume 7, Issue 4*). London, ON: Thames Valley Children's Centre.
- **Brunton, L., & Bartlett, D.** (2012). *Understanding the impact of fatigue on adolescents and young adults with cerebral palsy.* (*Facts to Go, Volume 8, Issue 1*). London, ON: Thames Valley Children's Centre.

- **Servais, M., & Sandieson, R.** (2012). Teachers' special education information needs and source preference by experience level. (*Facts to Go, Volume 8, Issue 2*). London, ON: Thames Valley Children's Centre.
- **McDougall, S. & Servais, M.** (2012). AAC and autism service providers collaborating for communication: An evaluation of a knowledge exchange framework. (*Facts to Go, Volume 8, Issue 3*). London, ON: Thames Valley Children's Centre.

"Lessons Learned"

At TVCC, staff evaluate their practices, programs, and services to learn about what works best, and to enhance service delivery. As part of TVCC's knowledge transfer strategy, our *Lessons Learned* publication series provides staff an opportunity to communicate their findings, and share their lessons learned.



Lessons Learned can be requested from the Research Program: research@tvcc.on.ca

- **McDougall, J., Willoughby, C., & Bolack, L.** (2013). Client satisfaction with TVCC services: Learning from our families. (*Lessons Learned, Volume 1, Issue 1*). London, ON: Thames Valley Children's Centre.



Research Key Fact: Publications

On average **8** articles are published or accepted for publication each year. Since 1989 there have been **216** peer-reviewed publications.

- Peer-Reviewed Articles - **173**
- Book - **2**
- Book Chapters - **9**
- Measurement Tool - **1**
- Research Reports - **22**

PRESENTATIONS

Our research findings have been communicated through presentations at international, national, provincial and regional conferences, and meetings.

TVCC staff members made the following **external presentations** between **April 1, 2010 and March 31, 2014**. Names of TVCC staff members are bolded and italicized. Names of former TVCC staff are italicized only.

INTERNATIONAL

American Occupational Therapy Association, San Diego, CA, USA.

Bedell, G., **McDougall, J.**, & Wright, V. (2013, April). Youth Report Version of the Child and Adolescent Scale of Participation (CASP): Psychometric properties and comparisons with the parent report version. Presented at the annual meeting of the American Occupational Therapy Association, San Diego, CA, United States.

Inclusive and Supportive Education Congress, Belfast, UK

*Specht, J., Young, G., Kertoy, M., **Servais, M.**, Spencer, T., Puskarich, M., & Pompeo, M. (2010, August). *Participation in school roles: The importance of opportunity.* Presented at the Inclusive and Supportive Education Congress, Belfast, United Kingdom.*

International Society of Augmentative and Alternative Communication (ISAAC), Barcelona, Spain.

McDougall, S., Duncan, B. & Vessoian, K. (2010, July). Alternative presentation and response formats for the Test of Aided-Communication Symbol Performance (TASP). Presented at the International Society for Augmentative and Alternative Communication, Barcelona, Spain.

International Society of Augmentative and Alternative Communication (ISAAC), Pittsburgh, PA, USA.

McDougall, S., & Servais, M. (2012, July). *AAC and Autism service providers collaborating for communication: A knowledge exchange framework.* Presented at the 2012 International Society

for Augmentative and Alternative Communication (ISAAC) 15th Biennial Conference, Pittsburgh, PA, United States.

International Symposium of Adapted Physical Activity, (ISAPA), France.

Simpson, K., & Mandich, A. (2011, July). *Understanding the impact of exercise on children with a disability.* Presented at the International Symposium of Adapted Physical Activity, (ISAPA) France.

Young Adults Institute Network Conference, New York, NY, USA.

McDougall, J., Wright, V., Miller, L., & **Nichols, M.** (2012, April). *Identifying the personal, interpersonal and environmental factors associated with changes in quality of life for youth with chronic conditions and disabilities.* Presented at the 33rd Annual International Young Adults Institute Network Conference, New York, NY, United States.



Research Key Facts: International Conferences

Since 1989, TVCC staff members have made **319** presentations. On average, staff members make 13 presentations at conferences in a year. International presentations have been made at the following:

- American Academy for Cerebral Palsy and Developmental Medicine
- American Cleft Palate/Craniofacial Association
- American Congress of Rehabilitation Medicine
- American Educational Research Association
- American Occupational Therapy Association
- American Psychological Association
- American Society for Neurorehabilitation
- American Society for Surgery of the Hand
- American Speech-Language and Hearing Association
- Assistive Technology Industry Association
- Association for the Care of Children's Health
- Australian Academy of Cerebral Palsy and Developmental Medicine
- Australian Cerebral Palsy Association
- Child and Youth Health, Third World Congress
- Child Health Psychology
- College of Occupational Therapists United Kingdom
- Danish Resource Centre of Brain Injury
- Early Childhood Intervention Australia National
- European Congress on Psychology

- European Federation for Research in Rehabilitation
- European Speech Communication Association
- Interdisciplinary Advances in Qualitative Methods
- International Conference on Cerebral Palsy
- International Conference on the Scientific Basis of Health Sciences
- International First Conference on Family-Centered Care
- International Institute for Qualitative Methodology
- International Meeting for Autism Research
- International Paediatric Neuromuscular Rehabilitation
- International Seating Symposium
- International Society for Applied Behaviour Analysis
- International Society of Augmentative and Alternative Communication
- International Symposium of Adapted Physical Activity
- Joint Congress of the Canadian Physiotherapy Association and American Physical Therapy Association
- North American Brain Injury Society
- North American Collaborating Centre Conference on ICF
- North American ICIDH-2 Conference
- North Coast Regional Conference of the Society of Pediatric Psychology
- Second City Disabilities Studies in Education, New York
- Society for Research in Child Development
- Solution-Focus Brief Therapy Association Annual Conference
- University of California San Diego New Frontiers in Pediatric Traumatic Brain Injury
- World Congress on Brain Injury
- World Federation of Occupational Therapists Congress
- Young Adults Institute Network Conference

World Congress on Brain Injury 9th Annual Conference, Edinburgh, Scotland.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., DeMatteo, C., Martinussen, R., & DeCourville, N. (2012, March). *School-based factors contribute to successful school reintegration of children and youth with acquired brain injury*. Presented at the 9th World Congress on Brain Injury, Edinburgh, Scotland.

World Federation of Occupational Therapy Conference, Yokohama, Japan

Bedell, G., **McDougall, J.**, & Wright, V. (2013, June). Youth Report Version of the of the Child and Adolescent Scale of Participation(CASP): Psychometric properties and comparisons with the parent report version. Presented at the World federation of Occupational Therapy Conference, Yokohama, Japan

NATIONAL

American Congress of Rehabilitation Medicine-American Society for Neurorehabilitation, Vancouver, BC.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S. Martinussen R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2012, October). *Successful scholastic reintegration for students who have experienced ABI*. Presented at the ARCM-ASNR Conference, Vancouver, BC, Canada.

Canadian Psychological Association, Winnipeg, MB.

Good, D. Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2010, June). *School reintegration for children and youth with acquired brain injury*. Presented at the 71st Annual Convention of the Canadian Psychological Association, Winnipeg, MB, Canada.

PROVINCIAL

Acquired Brain Injury 2011 Provincial Conference, Niagara Falls, ON.

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2011, November). *School reintegration for children and youth with acquired brain injury*. Presented at the Acquired Brain Injury 2011 Provincial Conference, Niagara Falls, ON, Canada.

American Academy for Cerebral Palsy and Developmental Medicine, Toronto, ON.

McDougall, J., Wright, V., Miller, I., & **Nichols, M.** (2012, September). *Evaluation of two measures of perceived quality of life when used with youth with chronic conditions*. Presented at the 66th Annual meeting of the American Academy for Cerebral Palsy and Developmental Medicine, Toronto, ON, Canada.

Canadian Paediatric Society Conference, London, ON.

Gray, J., Somers, S., Van de Vooren, R. & **Frid, P.** (2012, June). *Concussion in children and youth: Tracking the trends in a pediatric brain injury program.* Presented at the 89th Annual Canadian Paediatric Society Conference, London, ON, Canada.

Canadian Society for the Study of Education (CSSE), Waterloo, ON.

Servais, M., & Sandieson, R. (2012, May). *Understanding teachers' special education information needs and source preferences.* Presented at the 2012 Canadian Society for the Study of Education (CSSE) 40th Annual Conference, Waterloo, ON, Canada.

Specht, J., King, G., **Servais, M.,** Bartlett, D., & Rohatyn, N. (2012, May). *The MPOT: A tool for teacher development.* Presented at the 2012 Canadian Society for the Study of Education (CSSE) 40th Annual Conference, Waterloo, ON, Canada.

Children's Mental Health Ontario, Toronto, ON.

Good, D., Rumney, P., **McDougall, J.,** Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2011, November). *Predictors of successful school reintegration outcomes for students with acquired brain injury (ABI).* Presented at the Children's Mental Health Ontario, Toronto, ON, Canada.

International Meaning Conference, Toronto, ON.

McDougall, J., Wright, V., & Miller, L. (2012, July). *A Positive focus for research in pediatric rehabilitation.* Presented at the 7th Biennial International Meaning Conference, Toronto, ON, Canada.

Oncology Research and Education Day, 8th Annual, London, ON.

McDougall, J. (2011, June). *Quality of life in survivors of childhood cancer.* Presented at the 8th Annual Oncology Research and Education Day, London, ON, Canada.

Ontario Association for Developmental Disabilities Research Special Interest Group, Kingston, ON.

McDougall, J., Good, D., Rumney, P., Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2012, April). *Factors influencing school reintegration for ON students with acquired brain injury.* Presented at the 20th Annual Research Day of the Ontario Association for Developmental Disabilities Research Special Interest Group, Kingston, ON, Canada.

McDougall, J., Wright, V., Miller, L., & **Nichols, M.** (2012, April). *Identifying the personal, interpersonal and environmental factors associated with changes in quality of life for youth with disabilities.* Presented at the 20th Annual Research Day of the Ontario Association for Developmental Disabilities Research Special Interest Group, Kingston, ON, Canada.

Ontario Association of Children's Rehabilitation Services, Niagara Falls, ON.

Fay, L., Pilkington, M., King, G., Tam, C., **Servais, M.,** & Petrosian, H., (2010, November). *Evaluation of an occupational therapy mentorship program.* Presented at the 2010 Ontario Association of Children's Rehabilitation Services Conference, Niagara Falls, ON, Canada.

Ontario Association of Children's Rehabilitation Services, Toronto, ON.

McDougall, J., & Wright, V. (2010, November). *The ICF-CY and Goal Attainment Scaling: Benefits of their combined use for pediatric practice.* Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

Baldwin, P., Servais, M., & **Tucker, M., A.** (2011, October). *Using solution-focused coaching in paediatric rehabilitation.* Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

Good, D., Rumney, P., **McDougall, J.,** DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2011, October). *Social and academic*

competency in students with ABI.

Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

McDougall, J., Baldwin, P., & Evans, J. (2011, October). The importance of self-determination to perceived quality of life for youth and young adults with chronic conditions and disabilities. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

Baldwin, P., Servais, M., & Tucker, M. (2012, November). *Translating solution-focused coaching into practice: An organizational perspective.* Presented at the 2012 Ontario Association of Children's Rehabilitation Services Conference, Toronto, ON, Canada.

McDougall, S., & Servais, M. (2012, November). AAC and Autism service providers collaborating for communication: Organizational lessons learned from using a knowledge exchange framework. Presented at the 2012 Ontario Association of Children's Rehabilitation Services Conference, Toronto, ON, Canada.

McDougall, J., Bedell, G., & Wright, V. (2012, November). Youth report version of the Child and Adolescent Scale of Participation (CASP): Psychometric properties and comparisons with the parent report version. Presented at the 2012 Ontario Association of Children's Rehabilitation Services Conference, Toronto, ON, Canada.

Servais, M., & Sandieson, R. (2012, November). *Teachers' special education information needs: What pediatric therapists need to know.* Presented at the 2012 Ontario Association of Children's Rehabilitation Services Conference, Toronto, ON, Canada.

McDougall, J., & Servais, M. (2013, November). Thames Valley Children's Centre Research Program: 25 years of working toward improving clinical practice and enhancing quality of life for youth with chronic conditions. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

Servais, M., Baldwin, P., LaPorta, J., & McDougall, S. (2013, November). Organizational and professional learning: Best practices in fostering knowledge exchange and uptake. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

Ontario Simulation Exposition, Toronto, ON.

Servais, M., Shepherd, T., Bolack, L., Willoughby, C., Strachan, D., **Baldwin, P.,** Moodie, S., Parker, K., Savage, D., Knickle, K., McNaughton, N., & King, G. (2013, December). *Developing authentic clinical simulations for effective listening and communication.* Presented at the 2013 Ontario Simulation Exposition, Toronto, ON, Canada.

Research in Education Symposium, University of Western Ontario, London, ON.

Servais, M. (2010, April). Understanding teachers' information needs, perceived competencies, and information seeking behaviours for special education information. Presented at the 2010 Research in Education Symposium, University of Western Ontario, London, ON, Canada.

Toronto ABI Network Conference, Toronto, ON.

Good, D., Rumney, P., **McDougall, J.,** Bennett, S. Martinussen R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., DeCourville, N. (2010, November). *School reintegration for children and youth with acquired brain injury.* Presented at the Toronto ABI Network Conference, Toronto, ON, Canada.

Somers, S., Gray, J., & McDougall, J. (2010, November). Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem. Presented at the Toronto ABI Network Conference, Toronto, ON, Canada.

INVITED PRESENTATIONS

International

North American Collaborating Center Conference on ICF

McDougall, J. (2010, July). *ICF-CY applications.* Presented at 16th North American Collaborating Center Conference on ICF, National Institutes of Health, Bethesda, MD, United States.

Provincial

Child and Parent Resource Institute, London, ON.

McDougall, J. (2010, October). *Use of Goal Attainment Scaling to Measure Sensory Intervention Outcomes*. Presented at the Child and Parent Resource Institute, London, ON, Canada.

Western University, Elborn College, London, ON.

McDougall, J. (2013, November). *Applying the ICF/ICF-CY to enhance the health of children and youth*. Presented at Western University, Elborn College, London, ON, Canada.

Ontario Association of Children's Rehabilitation Services, Toronto, ON.

McDougall, S., & Servais, M. (2011, November). AAC and autism best practices: Results and next steps of the OACRS 2011 best practice networking day on Autism and AAC. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

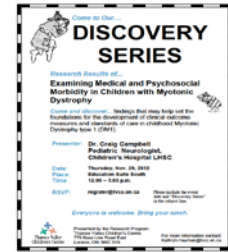
Bolack, L., & McDougall, J. (2012, November). *Using the ICF-CY to enhance client assessment and outcome measurement*. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON, Canada.

Ontario Hospital for Sick Children, Toronto, ON.

McDougall, J. (2010, November). *Using Goal Attainment Scaling to measure transition outcomes for survivors of childhood cancer*. Presented at the Ontario Hospital for Sick Children, Toronto, ON, Canada.

DISCOVERY SERIES SESSIONS

The "Discovery Series" sessions provide researchers with a forum to present the results of their research projects to the TVCC staff members. The following Discovery sessions were held between 2010 and 2014:



- Brunton, L. (2012, March). *The bodily experience of living with cerebral palsy: A phenomenology*. Presented at the Thames Valley Children's Centre, London, ON, Canada.
- Campbell, C. (2012, April). *Mechanostat theory used to understand bone complications in children with Duchenne muscular dystrophy*. Presented at the Thames Valley Children's Centre, London, ON, Canada.
- Bartlett, D. (2012, October). *Measuring postural control in young children with cerebral palsy and understanding associations with the Gross Motor Function Measure*. Presented at the Thames Valley Children's Centre, London, ON, Canada.
- Campbell, C. (2012, November). *Examining medical and psychosocial morbidity in children with myotonic dystrophy*. Presented at the Thames Valley Children's Centre, London, ON, Canada.

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