



IWK Health

Pediatric Rehabilitation
Services

The Village News

March's Special Dates

1 – St. David's Day

10 – Daylight Saving Time Starts (1 hour forward)

11 – Ramadan Start (tentative)

11 – Commonwealth Day

17 – St. Patrick's Day

19 – First Day of Spring

24 – Palm Sunday

24 – Purim

29 – Good Friday

31 – Easter Sunday

March 2024

-Parents of Complex Children
Support Group

-Brigadoon Camp Dates

-Recruiting for F-words
Foundation Course

-Autism Education Series

-Recruitment Flyer--Transition
Framework Co-Design

-McMaster University
Research Study

-Manual Wheelchair Study

-Transition Tips

-Interplay Research Study

-Parasport

-Rehab Kids Patient
Recruitment Study

-Pediatric Power Wheelchair
study

-CP Pain Survey

-Recruiting Caregivers of IWK
Rehab patients

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5850/5980 University Ave
Halifax, NS B3K 6R8
www.iwk.nshealth.ca



Support Group for Parents of Children with Complex Care Needs

Next Virtual Meeting
Thursday, March 21st, 2024
7:00-8:30pm

**This is a journey that does not have to be taken alone.
We can do this together!**

If you are interested in attending, please contact Jackie Pidduck
jacklynn.pidduck@iwk.nshealth.ca

BRIGADOON

VILLAGE

2024
Camp
Programs



WEEK 1

June 30th - July 5th

Camp Silly-Yak
Celiac Disease

**Summer Leadership
Program**

WEEK 2

July 7th - July 12th

Camp Whatcha Say
Deaf or Hard of Hearing

Camp Lots-a-Wata
Kidney Disease

Camp Braveheart
Heart Conditions

Camp Trailblazers
Craniofacial Differences

WEEK 3

July 14th - July 19th

Camp JoinTogether
Juvenile Arthritis

WEEK 4

July 21st - July 26th

Camp Solace
Family Bereavement

Camp BELIEVE
Parental Mental Illness

WEEK 5

July 28th - August 2nd

Camp Treasure Chest
*Asthma, Anaphylaxis,
Lung Conditions*

Camp Clots-of-Fun
Bleeding Disorders

WEEK 6

August 4th - August 9th

**Canadian Cancer Society's
Camp Goodtimes**
*Living with
or Beyond Cancer*

WEEK 7

August 11th - August 16th

Camp Guts & Glory
IBD & Ostomies

Camp Got2Go (ON+QC)
IBD & Ostomies

WEEK 8

August 18th - August 23rd

Camp Carpe Diem
Epilepsy

Camp See-Ya
Blind or Visually Impaired

Camp Brainiac
Neurosurgery Conditions

Giving extraordinary kids a chance to be ordinary

Visit our website to learn more and apply!

1-888-471-5666 | camp@brigadoonvillage.org

www.brigadoonvillage.ca

Recruiting for F-words Foundations Course

Are you a service provider to, or a family member (parent/caregiver) of, someone with a developmental concern in Canada?

If so, we would like to invite you to be part of our F-Words Foundations Course study! The 'F-words for Child Development' (Functioning, Family, Fitness, Fun, Friends, Future) provide a family-centred, strengths-based, holistic approach to child health and development.

For the study, you will choose to complete one of two versions of the online F-words Foundations Course: (i) the self-paced version; or (ii) an online facilitated version that involves the self-paced version plus weekly one-hour online discussion groups with other caregivers and service providers.

You will also be asked to complete a questionnaire at baseline, program completion, and three months post-completion. A subset of parents and service providers will be asked if they would like to participate in an optional interview upon of completing the program.

Please contact Sarah, hopmansn@mcmaster.ca, if you would like more information about the study.

Thank you!



Autism Education Series

Explore resources to support your family in learning more about autism.



Scan here with your smartphone camera to learn more and access the Autism Education Series:



[Visit the IWK Health Website](#)



Autism Education Series:

The resources below have been created to support families with preschool-age children to learn more about autism.

Understanding Autism / Comprendre l'autisme

EN: Learn about the features of autism, support services, and autism acceptance.

FR: Découvrez les caractéristiques de l'autisme, les services de soutien, et l'acceptation de l'autisme.

Making Sense of Behaviour

Understand the meaning of behaviour and strategies to teach skills.

Parent Perspectives

A Parent and Family Advisor shares their family's autism journey.

Exploring Play

Explore ideas for playing together with your child.

Engagement

Set up the stage for your child's communication.

Social Communication

Build your child's social communication skills.

Positive Behaviour Support

Respond to behaviours of concern and teach your child new skills in daily routines.

Toileting

Prepare to teach toileting, practice the skills, and show your child that they are successful.

Self-Care for Parents and Caregivers

Reminders about how important it is to ask for help and to take care of yourself.

PATIENTS AND CAREGIVERS INVITED TO DESIGN A TRANSITION STRATEGY FOR THE IWK AND NOVA SCOTIA HEALTH

The transition from **pediatric to adult care** is an important time for youth and their parents and/or caregivers.

To **improve health outcomes** along this transition, a project is underway to create **an implementation strategy** that will help the IWK and Nova Scotia Health to improve the transition to adult care.

Co-design sessions start this November!

Participants will join a **2-hour virtual session** to create practical strategies for the IWK and NSH to use based on their own experiences with the transition process.



Who can join? Patients (14-24 years old) and caregivers of a patient with **one of these health conditions:**

- Sickle Cell Anemia
- Thalassemia
- Complex Care
- Inflammatory Bowel Disease
- Complex Ear Disease
- Tracheostomy



scan to register



To register for a co-design session, please scan the QR code or contact Megan Churchill: Megan.Churchill@iwk.nshealth.ca

PEDIATRIC MANUAL WHEELCHAIR USERS NEEDED

Wheelchair Skills Training Program

Partake in a study evaluate the effectiveness of a program to teach children how to safely and efficiently perform 32 manual wheelchair skills that are essential for everyday activities

Target population


Children who use a manual wheelchair for their everyday mobility




Eligibility criteria

- ✓ Be between the ages of 3 – 21 years old
- ✓ Use a manual wheelchair regularly and be able to self-propel for 10 meters
- ✓ Have your own manual wheelchair
- ✓ Understand 2-step instructions in English
- ✓ Live in (or willing to travel to) the area of Halifax
- ✗ Children using a double hand-rim (one-sided propulsion) for maneuvering their manual wheelchair are not eligible

Description of the study

 12 manual wheelchair skills training sessions held weekly with a trained occupational therapist or research assistant at/near the IWK Health Centre

 3 evaluation sessions each spaced 3 months apart to assess wheelchair mobility

 You will receive a stipend of \$50 after each of the 3 evaluation sessions

Email Pediatric-WSTP@iwk.nshealth.ca for any questions or to partake!

Primary Supervisors: Krista Best, PhD and Jordan Sheriko, MD
(Jordan.Sheriko@iwk.nshealth.ca)



TRANSITION to Adult Health Care

Getting
ready for
adult care

Know your health history and
treatment plan

Find out who to talk to if your health
changes before your adult care
appointment

Make a back-up plan
in case things don't go as you expected

Trust your gut! Speak up
if you are not sure about something

TRANSITION to Adult Health Care

What to
know before
you go to
adult care

Who your new provider will be
and how to contact them

When to expect your first appointment

Look for allied health providers too,
like physio, dietitians or psychology
(if needed)

Have enough medication refills and
supplies to last to your first appointment

TRANSITION to Adult Health Care

Getting
ready for
your
appointment

Invite someone to support you
at your appointment, if you choose

Check what prescriptions to renew
or forms to fill out

Write down your questions
before your appointment

Confirm where you are going
and how to get there

Track your symptoms
to share with your care team

TRANSITION to Adult Health Care

At your
appointment

Go to your appointment
even if you are feeling well!

Ask when to contact your specialist,
your primary care provider/walk-in
clinic or go to the ER.

Find out what happens if you miss an
appointment. Keep the contact
information for the clinic in your phone.

Know the follow-up plan
before you leave.
Ask questions if you don't understand.

TRANSITION to Adult Health Care

Start Early! Tips for Caregivers

Create space for youth to be excited and ready to move into their new role.

Help your youth to prepare for their appointment
Ask what they want to talk about with the team and how you can help

Check in after the appointment
Find out how you can support them for their next appointment

If you will be supporting your youth into adulthood, talk to your team to help you to navigate this transition

You are not alone! If you are worried about transition, talk to the health care team



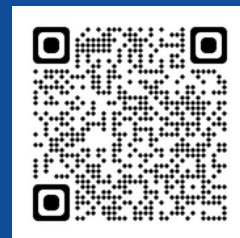
You're in Charge Workshops

Building the skills you need
to care for your health

.....
Register now for our
next online session



Info on the
IWK website





IMPLEMENTATION OF
INTENSIVE THERAPY FOR
EARLY REACH THROUGH PLAY

Share your **experiences** with **HAND THERAPY**

Complete an online survey about things that may influence early intensive hand therapy for young children with cerebral palsy.

Across Canada, we'd like to hear from:

- **Caregivers** of a child with cerebral palsy under 6 years old.
- **Occupational Therapists** who provide therapy for children with cerebral palsy.
- **Leaders** who manage occupational therapy programs.



Take a picture to participate in the survey

Participants will receive \$25

Questions? Ask us at interplay.study@ucalgary.ca

This study has been approved by the University of Calgary Conjoint Health Research Ethics Board (REB22-1692)

Parasport's in Nova Scotia

Para or Adaptive sports are competitive and/or recreational sports that are accessible to everyone, and can be played by anyone whether living with or without a disability!



Did you know there are tons of Parasport opportunities available in communities all across Nova Scotia? Visit parasportns.com to learn more about all the individual programs that are available across the province!

Examples of Parasport's Available Across Nova Scotia include;

- | | | | |
|--|--------------------|---|------------------------------|
|  | Para Hockey |  | Wheelchair Curling |
|  | Boccia |  | Wheelchair Basketball |
|  | Para-Canoe |  | Ski & Snowboard |
|  | Goalball |  | Powerchair Soccer |

Map of Programs in Nova Scotia



Parasport FAQ's

Do you need to have a specific disability to participate in Parasport programs?

NO! Parasport's are designed to create a more inclusive and accessible sport environment. This means that at a recreational level they are open to participants of all abilities! Depending on your ability, certain sports may provide a better experience than others. You can check out each parasport offered in Nova Scotia at www.parasportns.com to see which sport might be the best fit for you, or you can reach out to parasport@sportnovascotia.ca if you need additional assistance or guidance!

** At competitive National levels and above all Parasport's have classification systems to group similar abilities together for competition*

How do I register for a program?

Parasport programs are not provided directly by Sport Nova Scotia, but by a variety of different organizations across the province! Each organization has their own registration process, but a centralized list of programs, links to register, and contact info can be found at www.parasportns.com! If you are having trouble finding the info for a specific sport or program, you can reach out to parasport@sportnovascotia.ca to get started!

What is the cost?

Cost varies program to program depending on the organization providing the program. Most parasport programs in Nova Scotia are low to no cost to register! If cost is a barrier, there are funding options such as KidSport available - <https://kidsportcanada.ca/nova-scotia/provincial-fund/>. There are also a number of municipalities across the province that offer subsidies for sport registration fees for youth.



I don't know what sport would be a good fit for me/ my child?

You can check out each parasport offered in Nova Scotia at www.parasportns.com to see which sport might be the best fit for you, or you can reach out to parasport@sportnovascotia.ca if you need additional assistance or guidance!

Is there a parasport program in my community?

There are parasport programs offered in communities all across Nova Scotia! You can find a map and list of available programs at www.parasportns.com!

Are there any options if there is no programs in my community?

Yes! Sport Nova Scotia offers the Parasport Program Loan which loans out the equipment, training and resources for a selection of parasports to eligible organizations to trial them in new communities! To find more info on this program visit <https://www.parasportns.com/parasport-program-loan/> or email parasport@sportnovascotia.ca

Do I need to have my own equipment?

It varies program by program depending on the organization providing the program, but for the vast majority of programs, NO! Most programs provide any specialized equipment such as sport chairs, specialized balls, etc as part of the program.





Calling parents of children with disabilities across Canada for a research study



MPOC 2.0: Field-testing the new MPOC

WHAT IS THE STUDY ABOUT?

- Researchers at McMaster University have developed a new questionnaire to measure parents' experiences with healthcare services for their children with disabilities. Now we would like to have parents test it out!

WHO CAN PARTICIPATE?

- Parents of a child/youth who has been receiving developmental, medical, or behavioural services for at least 6 months in the past 5 years.
- Parents who have not previously participated in another phase of the MPOC 2.0 study.

WHAT WILL YOU BE ASKED TO DO?

- Complete a set of surveys to tell us about your experiences with healthcare services.
- Participants will receive a **\$20 e-gift card** for their time.

INTERESTED IN PARTICIPATING?

Contact us at
mpoc2@mcmaster.ca



This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #15702 Version #3 May 18 2023



Weekly Health Letters for Parents of Children with Developmental Disabilities

Facts about 90Second Wellbeing:

- 2 short health letters weekly
- Actionable tips to improve wellbeing
- Evidence-based health information
- Free
- ✓ For all parents of children with developmental disabilities (regardless of age)
- ✓ Flexible time commitment
- ✓ Confidential
- ✓ Complete the study and obtain a \$25 gift card

To learn more about this study, visit:

www.parentwellbeing.ca

Contact us at: Parent.Wellbeing@iwk.nshealth.ca

Phone: 1-877-341-8309 [Ext 6]

SEEKING PEDIATRIC POWER WHEELCHAIR USERS FOR RESEARCH STUDY



Do you have a child that is a current power wheelchair user? Or are you younger than 18 and a current power wheelchair user?

Current pediatric power wheelchair users (aged 4-17) and their caregiver are invited to take part in a research study to help develop a **virtual reality game** for power wheelchair skills training

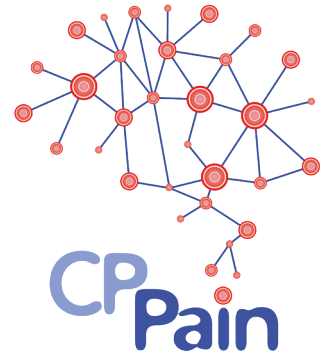
Participants will each receive a \$25 gift card for their time

INTERESTED IN PARTICIPATING OR HAVE QUESTIONS?

Please contact the Research Coordinator, Sara, at
Sara.Drisdelle@iwk.nshealth.ca

This study has been reviewed and approved by the IWK
Research Ethics Board (#1026934)





Do you have a child (<18 years old) living with cerebral palsy? Or are you younger than 18 and living with cerebral palsy?



Complete an online survey to tell us about pain experiences in cerebral palsy and its impact (those with and without pain encouraged to participate!)

<https://tinyurl.com/CPAINsurvey>

1 in 100 chance to win a \$150 prepaid VISA card

For more information contact cppain@iwk.nshealth.ca

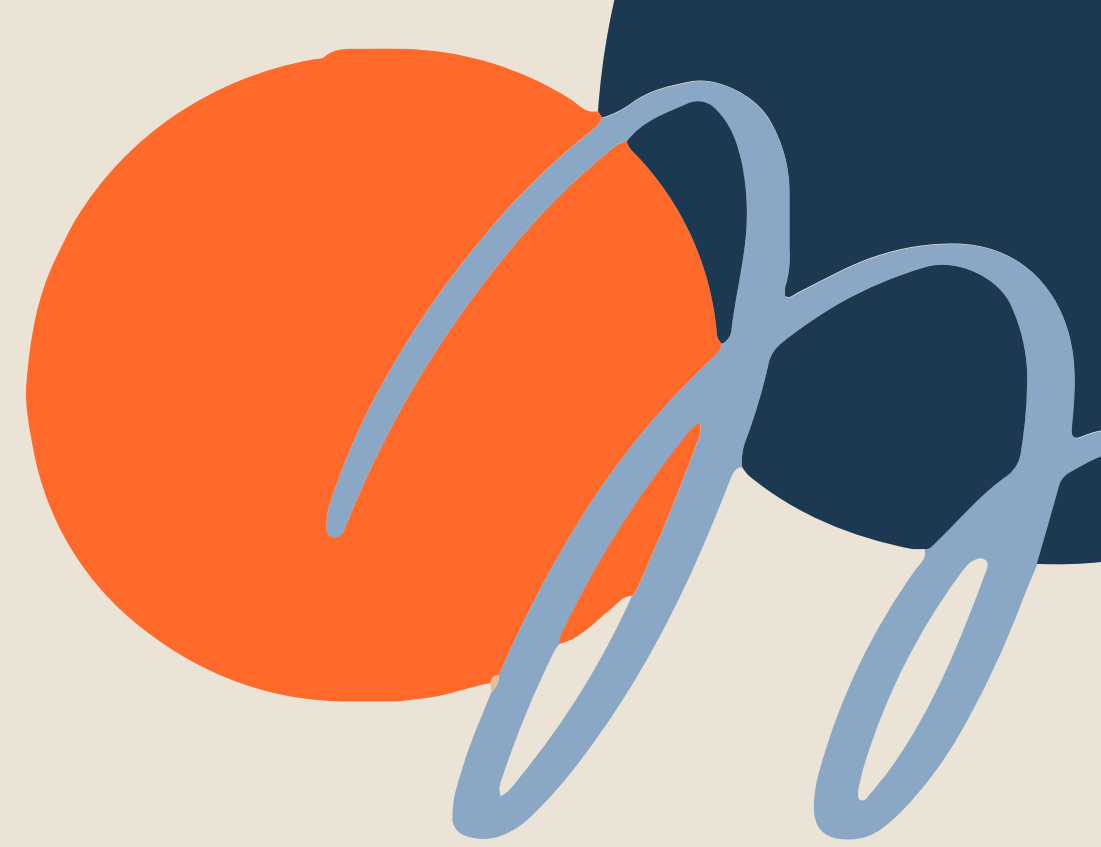
This study received approval from the IWK Health Centre Research Ethics Board

Centre
for Pediatric
Pain Research
SCIENCE HELPING
CHILDREN




 DALHOUSIE
UNIVERSITY

RECRUITING CAREGIVERS OF PATIENTS IN THE IWK KIDS REHAB




Our research study is looking to interview caregivers of children with physical disabilities to understand how disability impacts their risky play behaviours.

Who can participate ?



Caregivers of children aged 8-13 years, who are currently accessing the **IWK Kids Rehab Clinic** and identify with having a **physical disability**.

What you'll be asked to do:



Complete a **1-1.5 hour online interview** that will explore **family demographics** and your child's **risky play experiences**.

If you are interested in participating, please contact:

Maggie Locke
Lead Researcher
mg382955@dal.ca

