

The Village News

October's Special Dates

- 4 Feast of St. Francis of Assisi
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- 7 Shemini Atzeret
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October 2023

- -Transition Tips
- -Hallowe'en Color Pictures
- -Interplay Research Study
- -Parasport
- -McMaster University Research Study
- -Parent Well Being Study
- -Rehab Kids Patient Recruitment Study
- -Pediatric Power Wheelchair user research study
- -Cerebral Palsy (CPPain) Survey
- -Recruiting Caregivers of IWK Rehab patients
- -Patients with Complex care research

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Getting Ready for Adult Care?

Check out our transition tips!





TALK ABOUT IT

Talking about the transition to adult health care will not likely make it happen any faster, but it may help you to feel more confident and prepared when you do make the move





START EARLY, REPEAT OFTEN

Start thinking about the skills you need early. There are lots of skills to learn, like figuring out how to get medications, knowing your health history, and being an advocate for what helps you.

KNOW YOUR CHAMPIONS

Find people to help--at home, at school or from your health care team.

Look for people who can support you as you take on more responsibility for your health care.





ASK FOR HELP

As you take on more responsibilty for your health, remember, it is ok to ask for help. Your health care team is here to support you.

If you are not sure, ask us!





TRYITON YOUR OWN

Try your new health care skills while you have a support system around you. It is ok to make mistakes, it is how we learn.





You're in Charge is a great way to start the conversation

Register now for our next online session starting this Fall

















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)

sport nova scotia parasport

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!





Para Hockey



Boccia



Para-Canoe



Goalball



Wheelchair Curling



Wheelchair Basketball



Ski & Snowboard



Powerchair Soccer



Map of Programs in Nova Scotia



sport nova scotia parasport

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 ort 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-<u>fund/</u>. 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 <u>parasport@sportnovascotia.ca</u> 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-programloan/ 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 PROJECT 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 questions to tell us about your experiences with healthcare services.

Interested in participating? Want more information?

Contact us at mpoc2@mcmaster.ca





This study has been reviewed by the Hamilton Integrated Research Ethics Board under project #15702 Version #2 Jan 17 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]







RECRUITING PATIENTS & FAMILIES IN IWK KIDS REHAB

Are you currently accessing care at the IWK Kids Rehab Clinic?

Would you like to share feedback about your experience?

We will ask you to complete a 1-1.5 hour interview and you will be compensated \$50 for your participation

Our research study is looking to interview patients and families about their experience with goal setting, the intake interview, and overall functioning of the clinic

To participate in this study you must be a patient or parent/guardian where...

- The patient has been accessing care at the Rehab Clinic for at least the last 5 years
- The patient has not transitioned out of Rehab Clinic
- The patient and/or parent is comfortable having a conversation in English

If you are interested in participating, please contact:

Sarah Jennings Lead Researcher sarah.jennings@dal.ca

Dr. Jordan Sheriko
h Supervising Investigator
jordan.sheriko@iwk.nshealth.ca

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







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!)

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

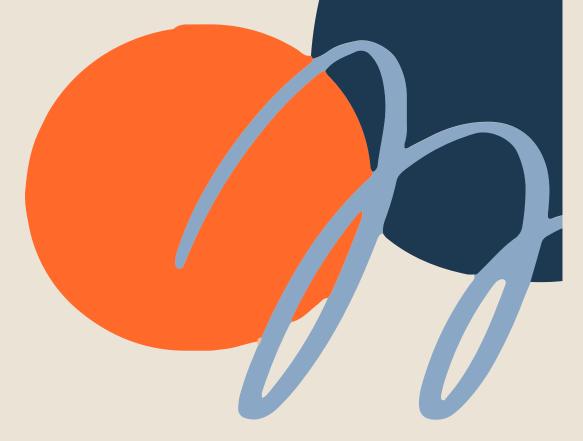
https://tinyurl.com/CPPAINsurvey

Centre for Pediatric Pain Research





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 idenitfy 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

RESEARCH OPPORTUNITY

If you would like to tell us your experiences, please contact:

> Jennifer Lane jennifer.lane@iwk.nshealth.ca (902) 470-2634



Are you a youth with complex care needs?

Are you a parent or caregiver to one?

Did you live and seek care in Nova Scotia between March 2020 and March 2022?

We would like to hear your experiences with public health restrictions and service changes during the COVID-19 pandemic.

Meetings will be virtual and last about 30 minutes.





