



Research Report

September 2025

Researcher Spotlight: New Provincial Partnership to Transform Neurodivergent Care in Saskatchewan

Dr. Ghita Wiebe, Department of Pediatrics was recently awarded the SHRF Align Grant (\$10K) to establish a Provincial Neurodivergent Advocacy Partnership (PNAP), a community-led collaboration that will reshape how care is delivered for Autistic and Neurodivergent individuals in Saskatchewan. Dr. Wiebe, a Developmental Pediatrician at the Alvin **Buckwold Child** Development Program, is leading this initiative.



In addition to her clinical role, she serves as Division Head of Developmental Pediatrics in Saskatchewan, Physician Lead for the Provincial Autism Strategy and Preschool Diagnostic Fetal Alcohol Spectrum Disorder teams, and Assistant Professor in the Department of Pediatrics at the University of Saskatchewan. There are 19 Co-Investigators including Autistic youth, health researchers, clinicians, educators, nonprofit leaders, and caregivers with lived experience.

Medical student, Julianna Sparks has also been instrumental in supporting this and related projects under Dr. Wiebe's supervision. The project is further strengthened by the backing of seven key provincial and national supporters, including Autism Alliance of Canada, Dept of Pediatrics USask, SHA Maternal & Children's Programs, Greater Saskatoon Catholic Schools, Autism Services of Saskatoon, Children North Early Childhood Intervention Program, and Saskatchewan Prevention Institute. Together, this team is establishing the first-of-its-kind initiative to co-create Neurodiversity-affirming care, informed by those with lived experience and aligned with Canada's national autism strategy. Autism is one of the most common neurodevelopmental conditions, affecting approximately 1 in 31 children.

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Research Spotlight

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In Saskatchewan, over 3,000 children are currently on waitlists for autism diagnosis who are often facing delays that compound medical and mental health challenges. Despite high rates of co-occurring health needs, current healthcare systems too often exclude the perspectives of Neurodivergent individuals, leading to misdiagnosis, caregiver burnout, and poor outcomes.

PNAP aims to change that. PNAP will center the voices of those with lived and living experience in the design of healthcare systems. Through community-based participatory research and inclusive engagement practices, the project will define what neurodiversity-affirming healthcare should look like in Saskatchewan. This initiative is not only about improving care, but it emphasizes the need for equity, dignity, and system transformation. By drawing on human-centered design and national patient engagement principles, the team will co-develop indicators, advocacy tools, and knowledge-sharing resources that reflect the real priorities and values of the Neurodivergent community.

PNAP aligns closely with Canada's Federal Framework for Autism and strengthens Saskatchewan's connections to the National Autism Network. The project will contribute to national priorities such as improved screening and diagnosis, economic inclusion, and public understanding of autism. PNAP is designed to ensure that Saskatchewan voices shape national policy, not just react to it.

The SHRF Align grant will fund the establishment of a governance model co-led by community members, develop Saskatchewan-specific calls to action, and launch a public-facing website to share its work. The team will also begin mapping out ND-affirming care indicators, with input from caregivers, Autistic individuals, healthcare providers, and system leaders.

Future phases will include the co-creation of implementation toolkits, advocacy briefs, and a roadmap for healthcare transformation.

By placing lived experience at the center of system design, PNAP will lay the groundwork for more inclusive, compassionate, and effective care. It will also build lasting infrastructure for collaboration across health, education, and social sectors which in turn will support sustained transformation well beyond the life of this project.

In a province where thousands of families are waiting for answers, PNAP offers a bold and necessary reimagining of what healthcare can and should be for Autistic and Neurodivergent individuals.

Dr. Ghita Wiebe would like to acknowledge her team members:

Co-Investigators:

Dr. Sarah Tehseen, Ms. Desirea Binning, Ms. Karen Olryd, April Griffin, Ms. Haylie Lashta, Bud Spencer, Brad Lawlor, Dr. Gurpreet Binepal, Trinity Lafferty, Ms. Vanessa Bourlon, Ms. Glenda Dmyterko, Ms. Linnea Dmyterko, Ms. Emily MacIntosh, Dr Stacey Lovo, Ms. Catherine Currie, Dr. Faly Golshan PhD, Ms. Lori Mulholland, Dr. Natalie Houser, and Dr. Wendie Marks.

Trainee: Ms. Julianna Sparks, 1st Year Medical Student USask

Supporters

Ms. Kim Woycik, Executive Director, Maternal and Children's Programs, SHA / Regina Dr. Terry Klassen, Unified Provincial Department Head Pediatrics, USask Ms. Megan Clark, Research and Evaluation Specialist, Saskatchewan Prevention Institute Ms. Lynn Latta, ED Autism Services of Saskatoon Ms. Daina Lapworth, ED, Children North Early Child Intervention Program / La Ronge Ms. Rosalie Roesch, Coordinator-Learning and Student Services, Greater Saskatoon Catholic Schools

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New Additions to Pediatric Research!



Ally Farrel joins the Department of Pediatrics in the brand-new role of Pediatric
Patient Engagement Navigator

What is your education and work background, and how did this support your new position?

I hold a Master's degree in Biochemistry and Medical Genetics from the University of Manitoba, with a research focus in ovarian cancer. While I originally planned to pursue an academic research path, I discovered the field of patient engagement and was drawn to its unique intersection of research, care, and lived experience. Through outreach efforts with Ovarian Cancer Canada, I helped organize virtual research symposiums in Manitoba, which led to a contract role following graduate studies supporting national research projects, internal grant competitions, and coleading the organization's national patient partner program. These experiences shaped my collaborative, patient-informed approach and reinforced the importance of integrating lived experience into research.

What excites you about supporting pediatric research?

Pediatric research offers a unique opportunity to partner with children and families in ways that are direct, honest, and impactful. I'm excited to see how their lived experiences can shape research priorities and improve care here in Saskatchewan. Coming from a more niche research background, I also appreciate the interdisciplinary nature of pediatrics. It opens the door to a wider range of questions, collaborations, and opportunities to support projects that have real-world impact across the province.

What does your new role consist of?

My position is jointly supported by the Department of Pediatrics and the Saskatchewan Centre for Patient-Oriented Research (SCPOR) and focuses on developing a provincial pediatric patient and family engagement program for research.

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We acknowledge that we live and work on Treaty 6 Territory and the Homeland of the Métis. We pay our respect to the First Nations and Métis ancestors of this place and reaffirm our relationship with one another.

Our Partners



Jim Pattison Children's Hospital Foundation is dedicated to raising funds to enhance maternal and children's health-care in Saskatchewan. As the provincial leader in supporting pediatric and maternal health research, the Foundation plays a key role in driving innovative research opportunities across the province.



The Children's Health Research Trust Fund (CHRTF) was established in 1983 to help raise funds to support child health research at the University of Saskatchewan. As all donated funds are endowed, the CHRTF has continued to grow to become an important part in helping advance research in the Department of Pediatrics. For further information about the CHRTF and to donate: donate.usask.ca/online/chrtf.php

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This includes building a network of patient and family partners, providing training for both partners and researchers, and supporting the integration of engagement across the research lifecycle—from project design and grant writing to recruitment and knowledge translation.

While patient engagement is becoming more common in some areas of health research, it's still emerging in pediatrics and existing frameworks are based on larger centers such as those in Ontario. My goal is to collaborate with national networks while adapting engagement strategies to reflect the realities of prairie communities, contexts that remain underrepresented current frameworks. As we embed patient engagement into pediatric research, we lay the groundwork for more relevant, effective, and community-informed healthcare solutions that reflect the unique needs of Saskatchewan's children and families.

Welcome Ally!

If you would like to learn more about the patient partner program or connect please contact Ally at ally.farrell@usask.ca

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Pediatric Patient Partner Corner: A Voice for Neurodivergent Families



We are excited to showcase a new section of our Pediatric Research Newsletter. Our fist shoutout goes to **Ms. Desirea Binning**. Desirea brings both professional expertise and lived experience to her patient partner role. A former special education teacher with over 15 years in the field, and a parent to two autistic children, she holds a Master's in Educational Psychology and Special Education. Her journey as a patient partner began nearly two years ago when she joined the Provincial Autism Strategy's ECHO HUB team as a Parent Advocate.

What excites her most about pediatric research is the opportunity to help shape more inclusive, neuroaffirming systems of care.

She also champions this work through her own consulting business, Regulate & Thrive Consulting www.regulateandthrive.ca/about. Her work focuses on supporting families, educators, and healthcare professionals in better understanding the needs of neurodivergent children and the gaps in current services.

She is currently collaborating with Developmental Pediatrician Dr. Ghita Wiebe on two exciting projects: "A Provincial Neurodivergent Advocacy Partnership: Developing Responsive, Inclusive Care Systems Led by Communities" which was recently awarded a SHRF Align Grant.

"From Waitlists to What Matters: Redesigning Autism Systems of Care with Families in Saskatchewan" This proposed initiative focuses on transforming the autism care experience.

In addition to these research collaborations, she remains an active member of the Provincial Autism ECHO HUB team, contributing her voice across multiple rounds of professional development programming. She also participated in SHA Network 8's Maturity Assessment meeting, working with a multidisciplinary team to identify regional trends and improve local healthcare delivery.

Desirea is passionate about championing the collective strength and impact of patient and family partners. She sends appreciation to physicians like Dr. Ghita Wiebe for amplifying the voices of those with lived experience.

Creative works from the Pediatric Research Office — Daislyn Vidal's new Children's book has a focus on healthy eating.



Daislyn Vidal, Clinical Research Coordinator and RareKids-CAN Clinical Navigator, has written "Dedicated Daisy's Goals for Good Health," an entertaining and educational book on healthy practices for children. In the book, we follow Daisy, a small country girl who loves school and dreams of becoming a pianist, who asks her parents for a pink piano as her birthday gift. Her mom, a healthcare worker, wants Daisy to be dedicated to good health and so gives her a list of seven challenging but healthy things to do before her birthday in order for her to get the pink piano. How dedicated will Daisy have to be to complete this list? Will she be able to achieve her goal before her birthday? Follow Daisy on her dedicated journey to good health.

CLICK HERE to visit Amazon.ca where you can buy a copy of the book.

New Pediatric Trials in Saskatchewan

The Division of General Pediatrics was selected as a site for the CIHR funded trial entitled, "National Implementation of Highly Efficient Evidence-Informed Treatment for Youth with Eating Disorders"

PI: **Dr. Ayisha Kurji** CoI: **Dr. Alison Mackland**

The Division of Pediatric Hematology / Oncology was selected as the only Canadian site for the Alexion Pharmaceuticals Inc trial entitled, "A Phase 3 Open-Label Study of Danicopan as Addon Treatment to Ravulizumab or Eculizumab in Pediatric Participants with Paroxysmal Nocturnal Hemoglobinuria Who Have Clinically Significant Extravascular Hemoglosis"

PI: **Dr. Sarah Tehseen** CoI: **Dr. Katie Felton**





Privacy Guidelines: Recruiting Patients for Research within the SHA

These guidelines apply to SHA-affiliated researchers, clinicians, and research personnel conducting studies involving SHA patients or resources. External researchers working cand collaborating with SHA are also required to follow them. The guidelines are designed to ensure that the recruitment of patients for research within the Saskatchewan Health Authority (SHA) is conducted ethically, transparently, and in full compliance with all applicable privacy legislation, including The Health Information Protection Act (HIPA), its Regulations and SHA policies.

Guide-Academics-and-Learning-Privacy-Requirements-for-Research.pdf

Coming Events		
Oct 2 nd	Pediatric Grand Rounds – Dr. Indra Narang	
Oct 17 th	SK-NEIHR First Nations and Métis Research Engagement Day	
Oct 23 rd	Pediatric Grand Rounds - Dr. Jonathan Norton	
Oct 23 rd	REACH Resident Research Day	
Nov 13 th	Pediatric Grand Rounds - Dr. Gordon Broderick	
Nov 27 th	Pediatric Grand Rounds - Dr. Kate Neufeld	
Dec 4 th	Awesome Rounds - Dr. Mahli Brindamour, Dr. Ayisha Kurji, Dr. Janna Brusky, Dr. Daniel Au-	
	Yeung	
Dec 18 th	Pediatric Grand Rounds - Dr. Hasan Merali	



IMPaCT Training Awards applications for the 2026-27 cohort are now being accepted!

Training awards are available for:

- Doctoral Students (\$35,000)
- Post Doctoral Fellows (\$50,000)
- Early Career Researchers (\$70,000)

What is an IMPaCT training award?

IMPaCT training awards facilitate participation in a 1-year immersive learning experience with assigned mentors and deliverables. The IMPaCT program is designed to give you the skills and network to design, conduct, and communicate about clinical trials with pregnant people and children (neonates through adolescents).

Applications will be accepted until 5pm CT on October 17, 2025. The application form and additional award information can be viewed here.

For any questions regarding the application process or IMPaCT program, please contact IMPaCT at impactrials@gmail.com

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Check out the <u>Department of Pediatrics Google Scholar</u> <u>Page</u>. There, you can find publications from all faculty and trainees in the department

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