FAQ – Provincial Neurodivergent Advocacy Partnership (PNAP)

Who are we and what are we doing?

Our current healthcare system is not designed to support the unique needs of neurodiverse individuals, resulting in reduced healthcare access and quality of life for these patients and their families. As such, our group of pediatric healthcare providers, researchers and educators have come together with a passion for improving the lives of young neurodiverse people by making system level changes. Through the development of the Provincial Neurodivergent Advocacy Partnership (PNAP), we aim to utilize the lived experience of healthcare providers, pediatric patients and their caregivers to build stronger, more inclusive supports and tools for families and pediatric healthcare providers in Saskatchewan. By utilizing real-world experiences shared by our patient partners, our volunteer-based initiative aims to improve healthcare for neurodivergent pediatric patients in a way that is relevant, respectful, and guided by lived experience.

Who can get involved?

We invite individuals across Saskatchewan with lived experience, such as parents, caregivers, children and youth with lived experience related to neurodivergent healthcare. People from all backgrounds are welcome. While we are prioritizing individuals living in Saskatchewan, we also welcome expressions of interest from those with relevant lived experiences in other provinces who want to contribute. Our goal is to create a diverse, equitable, and supportive network of patient partners.

What will I do as a volunteer partner?

Your involvement advances the quality, relevance, and impact of PNAP, leading to systemic neurodivergent healthcare improvements in Saskatchewan. You'll collaborate with researchers by sharing your voice and experiences, which will help to shape the tools and supports we create together.

Other ways you might contribute include:

- Sharing your lived experience
- Participating in committees and/or special projects
- Helping co-design and facilitate training sessions or workshops
- Providing feedback on online tools, presentations, or other healthcare supports/materials

Your level of involvement is both flexible and customizable. You can share your experience, thoughts, and suggestions virtually, in written or recorded format or attend and participate in the meetings.

We are trying to create a space where various styles of communication are supported and honored.

Do I need experience or training?

Your lived experience is your expertise and it's exactly what will guide our project outcomes. We'll provide any training or support you need, including a flexible orientation to help you get started. For example, we offer access to various interactive online training modules co-developed by parents, caregivers, and researchers.

Who will support me as a patient or family partner?

The Department of Pediatrics has a dedicated Patient Engagement Navigator whose role is to support and strengthen partnerships between volunteers, researchers, and clinicians. This navigator provides the tools, resources, and space needed for meaningful collaboration. Whether it's offering training, sharing helpful resources, or simply being someone that you can check in with, support is always available. We recognize that this work can sometimes be emotionally complex, so your well-being and time are a priority. You're encouraged to ask for additional support or take space whenever needed.

What is the time commitment?

There is currently no minimum time commitment, as we're still in the early stages of co-developing this partnership. Right now, we're focused identifying community needs and priorities together. While some research projects may span several months or even years, we understand that families lead busy lives and invite patient and family partners to participate as much or as little as your capacity allows, and we're committed to finding ways to collaborate that feel flexible, accessible, respectful, and manageable for you.

When would I start?

Our first meeting will take place November 20th from 12:30-3pm in room GD04 in the Health Sciences Building at the University of Saskatchewan. Video conferencing will be available for those who prefer to attend virtually. During this first meeting we hope to gain clarity on the over-

arching areas of our healthcare system that can be better adapted to the needs of Saskatchewan's pediatric neurodiverse community; all suggestions are welcome.

Interested or want to learn more?

We're currently collecting expressions of interest to gauge community interest. Submitting an expression of interest is not a commitment to participate, but a way for us to connect with you. To submit your expression of interest, please email PNAP@usask.ca or scan the QR code on the accompanying flyer.

Once you express interest, a member of our team will reach out via your preferred method of contact with next steps. No research background is needed — just your voice, your experience, and your willingness to make a difference.