



# Customizing an App to Foster Communication Between Researchers and Families of Children with Autism Spectrum Disorder

by Ellen Kuwana

## Ongoing NIH study has national and international reach

Until relatively recently, researchers and clinicians diagnosed ASD, addressed research questions, came up with a treatment plan and often grouped children based on behavioral criteria. But in recent years, diagnosis and treatment has become far more sophisticated, taking into account results from genetic testing, imaging and other assessments. These advances, combined with the American Academy of Pediatrics recommending screening for ASD at 18 and 24 months of age to promote earlier diagnosis and intervention, have led to an increase in children being diagnosed with ASD and a way to group children based on the same genetic variant.

Raphael Bernier, PhD, University of Washington professor of Psychiatry and Behavioral Sciences and research affiliate and associate director of the Center on Human Development and Disability (CHDD), is piloting the use of an app called Groopt. The app allows families across the globe to connect with other families who have a child who has been diagnosed with ASD with the same genetic variant and also to connect with his research team. The aim is to gain insights into the families' research priorities and to accelerate research.

Bernier and his research team focus on single-gene variants that likely contribute to a child developing ASD. They are studying 30 high-confidence single-gene variants conferring risk for ASD; one of these gene variants is called activity-dependent neuroprotective protein (ADNP). These so-called high-confidence single-gene variants are relatively rare (each gene or genetic event individually accounts for no more than 1% of cases), so Bernier's research by necessity has to have a national and international reach to find enough research participants to power meaningful statistics.

Once a child is diagnosed with one of these gene variants and the family is referred to Bernier, if they consent to participate in research the child and family are flown to the University of Washington (UW) for assessment at CHDD as part of an ongoing study funded by the National Institutes of Health. This approach is costly, and although the family does not pay any of these expenses, flying across the nation or world comes with inconveniences such as time away from other children or missed work. And for some children with significant medical and behavioral problems, getting on a plane is not possible. This led Bernier to think about other ways to make research more accessible to families. "We wanted to see if there was a platform to engage with families and actually drive the research questions that more appropriately fit with the families, and a way we could collect the data we need in a way that is more effective and efficient for families," Bernier said.

## Groopt app customized to engage ASD families

A fortuitous conversation Bernier had about his research with a high-tech executive led to an innovative solution: Groopt, an app that allows families of children with the ADNP gene variant to contribute real-time research data (such as noting that their child had a seizure that day). The scientists can download and analyze the data families contribute. It also allows the families to connect with parents of children with the same gene variant, or to the broader community of ASD families — all without traveling to Seattle.

Tammy Savage, a former Microsoft general manager, helped Bernier customize an already existing app to create a private,



*Raphael Bernier is piloting the use of an app to foster communication between researchers and families of children who have been diagnosed with autism spectrum disorder and to accelerate research.*

by invitation-only online group to serve as a resource for the families and the researchers alike. “GroopIt is a natural extension of patient advocacy and disease-specific groups. This next generation of an online community can move from simply exchanging information to actively working together to achieve specific outcomes,” said Bernier.

The app’s overarching purpose in this project is twofold:

1) GroopIt enables two-way communication that is nearly real time. It gives researchers a way to share results with research participants. And families can post what questions they most want to see addressed in the future, giving researchers insight into what families care about so that scientists can generate research questions that are of perceived value to patients and families also.

2) GroopIt also functions as a registry, allowing the research team to collect information on children with ASD and their families. Within the app, families can record developmental milestones or other events such as sleep issues, share what treatments their child is receiving and participate in surveys that the researchers post, for example. When de-identified information is shared back to the ASD community who are on the app, they can learn, for instance, what other conditions children commonly have who have the same gene variant, such as speech and language issues.

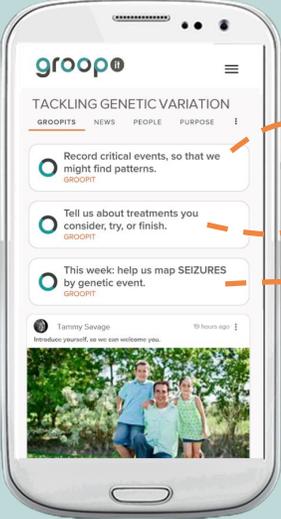
The app is creating a community where families and researchers can share news and information. “We can respond and answer questions almost in real time, and provide information back to the community,” Bernier comments. This last action, represented by the News tab, aligns with mandates by NIH and other funders for researchers to share study findings with research participants.

## Next steps: Studying the app’s effectiveness

With funding from the Research Innovations Award from the UW Institute of Translational Health Sciences that starts in March 2018, Bernier and team will be coordinating focus groups using video conferencing to learn more about what features the families

find valuable. Main collaborators include clinical psychologist Jen Gerdtts, PhD, assistant professor of Psychiatry and Behavioral Sciences, and dissemination implementation scientist Jill Locke, PhD, research assistant professor of Speech and Hearing Sciences. Locke will lead the focus groups.

Bernier and group will be evaluating whether use of the GroopIt app can advance the pace of research in the ASD community, increase the number of families involved in research and the extent to which families interact with researchers and other families via the app. Their engagement will be compared with Bernier’s other two studies: the NIH study where families visit UW, and an online portal (less interactive than the GroopIt app) that gathers information on families who have a child with the ADNP gene variant. Ultimately, they hope to find that GroopIt accelerates research and increases family engagement with researchers and participation in studies.



We take three actions...

- 1 Tell everyone about treatments** and our pursuits for solutions including treatments we are considering, starting, in progress or have finished. We share our insights, questions, or outcomes.
- 2 Record critical events** as they happen including progress, milestones achieved, challenges that are emerging, setbacks and medical events. This helps us map development expectations by genetic event.
- 3 Participate in weekly learning campaigns** to better understand behaviors, characteristics and symptoms by genetic event. We share data and insights about specific topics. Here are examples of the actions we’re asked to take:
  - > This week: help us map [SEIZURES] by genetic event.
  - > This week: tell us one thing researchers & parents should understand about [TOPIC]?
  - > This week: tell us what questions you want answered.

*The app allows families to connect (People tab) and to learn about research results and other news within the autism research field (News tab). The app enables families to: 1) share what treatments their child is getting or has gotten in the past, 2) record events so that researchers can map developmental milestones and expectations and 3) complete surveys so that researchers can learn more about what families care about and want researchers to focus on.*

CHDD is an interdisciplinary center dedicated to the prevention and amelioration of developmental disabilities through research, training, clinical service, and community outreach. CHDD includes the University Center of Excellence in Developmental Disabilities and the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center.

### CHDD Outlook

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