



Alberta Pregnancy
Outcomes and Nutrition

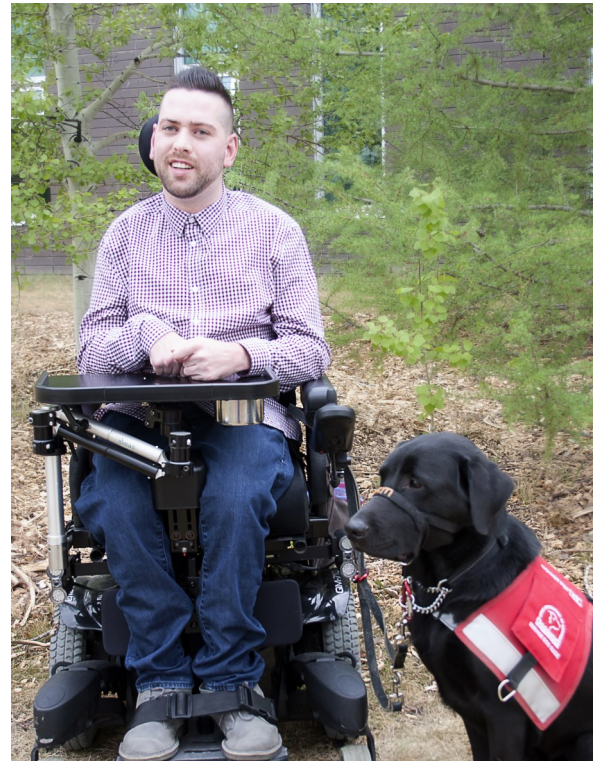
SPRING 2016 Leaflet

What's new with APrON?

Meet David & Jim!

David joined the Owerko Centre team in June of 2015 as an administrative assistant in our new lab at the Child Development Center. David holds a degree in Public Relations from Mount Royal University and spent four years working with Cerebral Palsy Kids and Families prior to joining the team.

David is accompanied by his four-legged friend, Jim, a two-year-old service dog from the Lion's Foundation of Canada. David recently went to Ontario to spend three intensive weeks training with Jim, who assists David with a multitude of tasks in the workplace and at home. Jim even helps David prepare questionnaires sometimes.



If you come into the lab for a visit David is always available to answer any questions, so feel free to stop by and chat with him anytime.

Join APrON's Participant Advisory Committee

Next Meeting June

The APrON team will be running a participant focus group this June and we want you to be a part of it! If you have ideas on how we can keep participants, like you, engaged and interested in our research, we want to hear from you. The session will be 1.5 hours long and will take place at the Owerko Centre at the Child Development Centre in Calgary. If you would like to learn more about this exciting opportunity, please

Send Us Your Feedback!

If you have any comments or questions about the *APrON Leaflet*, we want to hear them! We would also like to hear your ideas for future newsletters. Please contact us at apron@ucalgary.ca
We truly value your feedback!

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All of us here at APrON would like to wish our **AMAZING Mothers** a
Happy & Wonderful Mother's Day!



RESULTS

Study Title: New Study on Parents' Perspectives on Sharing Data

Participant data in the APrON study has potential to be utilized to its fullest extent by sharing the anonymized, non-biological data with the Child Data Centre of Alberta (CDCA). In partnership with APrON, the CDCA could potentially enable other researchers from all over the world to use APrON data to answer new questions. Developing such partnerships is important because it could maximize participants', researchers', and funders' investments in the APrON dataset.

The researchers were interested in knowing if parents would feel comfortable donating their data for further analysis in this way. So they individually interviewed 19 randomly selected parents and conducted 4 group interviews with another total of 18 parents. They found that overall, parents strongly supported the sharing of their own, and their child's, non-biological research data. Parents told us that they also wanted to see the data used to its maximum capacity to answer new questions, just like researchers and funders. They wanted assurance that their privacy would be protected. They also wanted to be assured that procedures would be in place to ensure that data are used responsibly. They wanted assurance that both researchers and their projects would be subject to an approval process.

As we explore the possibility of partnering with the CDCA, we are aware that the privacy and anonymity of data and how researchers access the data must be carefully considered by the CDCA as they develop their services. We are confident that will lead to rigorous safeguards by the CDCA and that parents' opinions will be respected. If you have any questions or concerns about developing a partnership with the CDCA to maximize the benefit of APrON data, please do not hesitate to contact us. We love hearing from our participants!

Authors: Kiran Manhas, Stacey A Page, Shawn Xavier Dodd, Nicole Letourneau, Aleta Ambrose, Xinjie Cui, Suzanne C Tough.

Reference: Manhas, K. P., Page, S., Dodd, S. X., Letourneau, N., Ambrose, A., Cui, X., & Tough, S. C. (2016). Parental perspectives on consent for participation in large-scale, non-biological data repositories. *Life Sciences, Society and Policy*, 12(1), 1-13.

HELP KEEP OUR
FILES UP-TO-
DATE

Staying in touch with our participants is a key part of our work. When we lose touch with people we lose some of our ability to answer important health questions. If you have moved,

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Alberta Pregnancy Outcomes
and Nutrition Study



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