

Welcome to my thoughts on my family's journey with the DTC - From start to finish. Not as a representative of CanPKU.. Just as a PKU Mom.

Let's Turn the Disability Tax Credit (DTC) into the Prevent a Disability Tax Credit

A label can be a problem and no parent wants their child with PKU to be labelled "disabled". Same with clinics who strive to guide families into preventing disabilities. I understand that you may not want to label an infant "disabled" where you are also wanting to ensure the parents the child will be just fine. **My child was not disabled!** We hated the thoughts of labeling him this way. One reason **we pushed back with John Adams**, CanPKU President, against applying for years.

I know, by the thoughts in our household and from chatting with clinics, especially my own in Toronto - that was **hurtful to some clinicians** to feel that CanPKU, by pushing for the DTC, was also pushing for a disability label. Hurtful, because the clinic **is doing everything they can to prevent the "disability"**. My clinic is as awesome as my son!

As an independent person and mom, **I agree with all of the above statements**. So, I understood why all clinics were not enthusiastic about any perception of a wrong label of disability. My clinic was doing a great job protecting his brain, he wasn't disabled, we didn't need this.

But as a mom and with my limited understanding in early days, I **didn't fully agree that PKU was a qualifier**, if I am being honest. I was certain it was for much worse off children. I am reminded every time I attend a conference or a clinic appointment how lucky we are. These other children may be disabled. **We were not**.

It took me a LONG time (and thankfully John's persistence) to adjust my thinking and apply for this credit for our son. Here's the thing, **none of those above points about a disability label is what the credit is or can be about, at least not in the case of PKU**.

- It's about the fact this child DOES and will have to spend more time than another child eating. It's a hard fact of PKU.
- As infants, it's about mom having to balance her breast feeding with her medical formula feeding.
- It's about having to travel to clinic appointments, spending money on hotel, food, parking, gas, and maybe trying to figure out how to prepare these metabolic foods in a hotel room.
- It's about preparing special foods, making separate meals, balancing their allotment over the course of the day.
- It's about doing blood spots and having to adjust their meals or tolerance based on results.
- It's about making and drinking a formula... multiple times every day... for the rest of their lives (or until the cure is found).
- It's about them never getting to order pizza or hot lunch at school when all the other kids do.

- It's about having to bring your own cupcake to every birthday party you attend.
- It's about hoping that the birthday party has a fruit or veggie tray so you can eat too.
- It's about having to bring your own food to a restaurant, if they allow it
- It's about going to a burger joint and asking for lettuce, tomatoes and pickles on the side, no bun, no patty, no cheese, but thank you.
- It's about ordering a caesar salad – after establishing the sauce is not authentic with anchovies and saying, “No bacon, No Cheese, thank you.” “So just lettuce and dressing?” “Yes, Please”
- It's about going hungry at a family event because someone tried a new recipe that includes bacon and cheese on the brussel sprouts. You were just told the menu included brussel sprouts.
- It's about not being able to go to sleepovers unless your parents feel comfortable with the other parents understanding not to feed you the wrong thing.
- It's about not being able to attend school or summer camp because your parents are afraid of the menu.
- It's about having to take an additional medication just to be able to eat more protein, if you are lucky enough to respond to that medication.
- It's about hearing your parents ask “Have you made your milk yet”
- It's about having a headache, because you have not.
- It's about hearing the nurses explain newborn screening to your aunt/sister/wife/self and them saying “No News is Good News”.
- It's about hanging your head with the feeling they implied, your parents were given “Bad News”.
- It's about knowing you can't have a beer with your buddies after work.
- It's about struggling with a healthy weight as the “diet” beyond fruits and veggies is very carb based.
- It's about having to explain/discuss PKU with a potential friend or partner.
- It's about the struggles women will face when having children.
- It's about broccoli pockets costing \$12 instead of \$1.99 for pizza pockets.

- It's about *preventing* a disability.

Did you know, the law says, that “but for therapy” the person may become disabled. So prevention is included. In fact, in June 2022, the government also changed the wording of the law and the application form to be *more clear and included* the consumption of “Medical Foods and Medical Formula” in the time therapy takes. So, even they are working to make it more *clear* for people with PKU to not struggle with someone misinterpreting what and who the credit is for.

This is not just a “Disability Tax Credit” it is also a poorly advertised a “Tax Credit to Prevent Disability”. It's time that families know that they are being supported in preventing the disability by being able to make claim to the credit. This helping many families with the cost of appointments, food and potential hours lost at work to maintain the therapy as outlined by their clinic to develop and maintain optimum brain health “for life”. Or until the time a cure is found.

We didn't decide that PKU qualified. The government has provided this benefit for people with PKU - they should be advised it is available.