



The PEP Talk*

A seasonal newsletter to keep you up to date
about CF clinic and research news

Winter 2018

TIPS FOR TAX SEASON Tami Kolb, Social Work

It's never too early to think about taxes and explore what tax credits your family may qualify for. Here's a list that may be of interest to you:

- 1. The Disability Tax Credit** is a tax credit that helps individuals living with a 'severe and prolonged impairment in physical or mental functions.' The individual or their caregiver can receive credit on their annual personal taxes. Specific requirements need to be met and an application must be submitted. An individual would usually qualify if they are required to complete 14 hours per week of life sustaining therapies (e.g. daily nebulized therapies). <https://bit.ly/2yNovKZ>
- 2. The Medical Expense Tax Credit** is issued by the federal government. The address below provides a list of items that can be claimed and how to submit the claim: <https://bit.ly/2vDmeic>
- 3. The Registered Disability Savings Plan (RDSP)** is a long-term savings plan to help Canadians with disabilities and their families save for the future. The Canadian Government provides a matching Canada Disability Savings Grant. Individuals who open a RDSP may also be eligible to receive a Canada Disability Savings Bond. <https://bit.ly/1D12yze>

For additional provincial and federal tax benefits, visit the **Canada Benefits** website.
<https://bit.ly/2k4oPMX>

FYI

- CF Clinic will be closed on the following dates:
DECEMBER 20 & 27 2018
- Regular clinics will resume on January 3, 2019
- Check out our recently updated website for newsreel and up to date information.
<http://www.bcchildrens.ca/our-services/clinics/cystic-fibrosis>
- Questions/Comments/Ideas?
Email: cfqproject@cw.bc.ca

CLINIC LETTER SURVEY RESULTS

Thank you so much to the 44 families who had a chance to participate in our survey regarding clinic letters. The results were generally positive, with most families reading the letter consistently. Some of the things that have been requested include: long term statistics, BMI, current medication list, test results with explanations, itinerary of next visit, and general CF care tips. To address this wish list, we will try a few things in 2019 (not everything will apply to every family):

1. Review of CF Canada registry data for long term statistics (PFTs and BMI) once a year at clinic.
2. Medication lists are always printed - feel free to take these home with you.
3. We will include relevant tests results in the letter. They are usually best reviewed in clinic, so please ask if we do not remember.
4. Itineraries: Jon emails this information within a week of your next clinic visit. It is logistically not possible to include in the clinic letter.
5. Please check our website regularly – all news and relevant tips will be posted there.
6. Clinic letters via email may be more direct and convenient for some of you while others prefer mail still. Logistically we cannot offer both. We will transition to email when this is requested by a large majority.

INTRODUCING CanACT

What is CanACT?

CanACT stands for the Canadian Accelerated Clinical Trials. It is a new initiative of CF Canada. CanACT is a network of clinical sites across Canada that is committed to CF research and collaboration in clinical trials. At BC Children's Hospital we are part of this network. Other sites include St. Paul's (adults), Montreal and Toronto!

Can my child participate in a clinical trial?

Your CF physician may approach your family if your child is eligible for a clinical trial. Feel free to ask questions. Each clinical trial has specific criteria including: age, genetics, medications, infection status so not all families will be eligible for all trials.

How can I find out the results of a clinical trial?

Your CF clinic visit is the best place to ask about the results of a clinical trial. Sometimes clinical trials take several years so it may take a while to find out the results. We will do our best to keep you updated on the current research.

*Pun Intended. PEP is the airway clearance device used by many children with CF in our clinic.

NACFC HIGHLIGHTS

North American Cystic Fibrosis Conference Research Report Ajay Kevat, Respiratory Fellow, BC Children's Hospital

Results of recent safety trials of two different triple agent CFTR modulators were announced at the most recent North American CF Conference in October. These drugs, VX-659 in combination with tezacaftor and ivacaftor, as well as VX-445 in combination with tezacaftor and ivacaftor, were tested in small numbers of patients with one or two delta F508 mutations, using a range of different dosing regimens. The trials of medication were short, with only four weeks of active therapy, but they were placebo-controlled, with close monitoring for adverse events as well as of lung function and sweat chloride. Results for both new therapies were similar and encouraging. On average, at the optimum doses, lung function improved by about 13% for patients heterozygous for delta F508, and around 10% for those who were homozygous for the same mutation (noting that the latter were already receiving tezacaftor and ivacaftor prior to starting the trial medication). Sweat chloride levels also dropped significantly. Some adverse effects were seen, with the most common being change in cough/sputum, headache, sore throat and fever. Liver-related effects were also noted. Overall however, the tolerability of both triple combination therapies was reported to be quite good, and the medications are now being used in larger Phase 3 trials.

INFECTION CONTROL REMINDER

There is a strict infection control policy in place for CF patients to protect your child.

Here are some reminders:

1. Wear a mask in hospital common areas. This includes Starbucks, waiting areas (PFT lab, lab, radiology), hallways etc.
2. Wash your hands!
3. Stay in your room during clinic visits.
4. All clinic staff must wear a gown and gloves when assessing your child.
5. Inpatients are on Contact Precautions which means staff must wear a gown and gloves. You may speak to staff and ask them to follow this policy if they are not.
6. Inpatients must carry a bandana to identify themselves and should not go within 2 meters of another child with CF. If you are not given a bandana on admission, please ask and one will be given to you.

Please let us know if you have any questions about this policy!

HAPPY HOLIDAYS FROM YOUR CF TEAM!



MAY YOUR DAYS BE MERRY & BRIGHT AS YOU ENTER 2019!