



The PEP Talk*

Fall 2020

A seasonal newsletter to keep you up to date about
CF Clinic and Research News

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We recognize the huge emotional and financial burden that the COVID-19 pandemic has placed on so many Canadians. Below are some resources that may help. Feel free to reach out for more information and we will do our best to support you.

Cystic Fibrosis and COVID-19

<https://www.cysticfibrosis.ca/about-cf/covid-19-qa-for-cf-community/general-covid-19-questions-answers>

Free online counselling and mental health resources for caregiver, children, young people (16+) and adults

- 'Here to Help' online mental health screening: <https://www.heretohelp.bc.ca/screening/online/>
- **Kelty's Key:** Free COVID-19 related psychologist support through Cognitive Behavioural Therapy (CBT) Sessions <https://www.psychologists.bc.ca/keltys-key>
- **UBCO Virtual Walk-in Wellbeing Clinic** <https://www.psychologists.bc.ca/ubco-virtual-walk>
- <https://here2talk.ca/> resource for post-secondary students.
- Supporting Children throughout Covid-19 Pandemic <https://childmind.org/coping-during-covid-19-resources-for-parents/>
- **Guide to Living With Worry And Anxiety Amidst Global Uncertainty (for adults)**
- <https://www.psychologytools.com/articles/free-guide-to-living-with-worry-and-anxiety-amidst-global-uncertainty/>
- Individuals in immediate crisis should dial **911** or contact a 24-hour crisis line: **1-800- SUICIDE (1-800-784-2433)** or the **Interior Crisis Line (1-888-353-2273)**. Children and youth can contact the **Kids Help Phone (1-800-668-6868 or text to 686868)**

Financial Support Resources

Canadian Emergency Response Benefit (CERB) Benefit

<https://www.canada.ca/en/services/benefits/ei/cerb-application.html>

BC Emergency Benefit for Workers

<https://www2.gov.bc.ca/gov/content/employment-business/covid-19-financial-supports#BCEBW>

BC Hydro- up to \$600 one-time payment

<https://app.bchydro.com/accounts-billing/bill-payment/ways-to-pay/customer-crisis-fund.html>

Renters, homeowners and Homeless

- Talk to your mortgage provider about mortgage deferral options as a result of job loss due to covid-19.
- Information of BC Housings Temporary Rent Supplement: <https://www.bchousing.org/BCTRS>

FYI

Check out our 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

Information about the COVID Testing Clinic at BCCH

- Open 7 days a week from 08–18:30 hrs for children and adults
- The clinic can only be entered from outside, at Entrance 17.
The interior connection has been blocked.
- Patient/caregiver should call 604-875-2154 prior to going to the clinic.
Only symptomatic patients, however mild, will be tested. A nurse will screen and register the patient and then the patient can attend the clinic.
- Patient/caregiver should bring their Care Card.
- There are designated parking spots outside the COVID clinic entrance for patient parking.
- Nurses are available by phone between 08 – 18 hrs for screening and booking appointments.



NOTE: For individuals ages 11 years and older*, the test is a new “Swish/Gargle/Spit” test instead of a nasal swab
(*currently being validated for children younger than 11).

Dr. Henry recently announced that this gentler test is now available province-wide, for children.

To help children who require an NP (nasal) swab, please visit our hospital website:

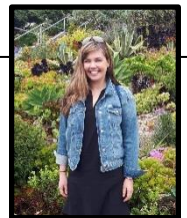
<http://www.bcchildrens.ca/about/news-stories/stories/helping-children-through-a-covid-19-test>

CF Clinic Staff Changes

Staffing Changes in the Newborn Screening Office

Starting September 7th, 2020, Vanessa McMahon will be taking a one year leave of absence to complete the Nurse Practitioner Program through the University of Victoria. We will really miss Vanessa but wish her many happy hours of studying. Dorothy (Dot) Chow will temporarily transfer from the main CF Office to cover Vanessa's role. Dot will work Tuesday, Thursday, Friday and Caroline Burgess will continue to work Monday, Tuesday, and Wednesday. In addition, Paula Howorth will provide intermittent nursing coverage to support the program.

Welcome Emily Worden, CF Clinic Nurse
Emily has joined our team as the CF Clinic Nurse as Dot Chow transitions to the Newborn Office.



I have been working at BC Children's Hospital since 2016. I started out on the Inpatient Nursing Resources Team and then I took a position as a surgical nurse on T6. In 2018 I joined the Ambulatory Nursing Resource Team, working mostly in the Endocrine and Gender clinic. I am excited to now be joining the CF team and looking forward to getting to meet our clinic patients and families. In my spare time I enjoy getting outside for hikes and making pottery.

Welcome to our New Fellows!



Dr. Bobby Ruge: I have been a general pediatrician with an interest in respirology for 5 years in a busy district hospital in South East London. Prior to that I completed my core pediatric training in North London, where I have lived for 10 years. I am originally from the North West of England, famous for its football club which I support. I enjoy going out for walks, reading and spending time with my family. I also have an interest in cinema and in the past have made numerous short films. I am excited about joining the team and learning more about pediatric respirology, as well as embracing the Canadian way of life.



Dr. Rica Dela Paz: I come from the Philippines. I spent my early years down south where the beaches are lovely. Grew up surrounded by pineapple fields but ended up loving the city more. I've been a general pediatrician for the past 4 years. In that time, my practice has revolved around kids presenting with respiratory symptoms. I learned a lot from my observership here back in 2018 and I'm very excited to be back to complete this fellowship. It has not been the easiest getting here with the pandemic, but like everyone stuck at home I have been trying to learn a few life skills (i.e cooking). I am very excited to experience the outdoors and hopefully get to ski while I'm here.

FROM THE CF RESEARCH TEAM

Participating in Clinical Trials can be an important part of a Cystic Fibrosis (CF) patient's journey. A clinical trial is a research study to test new medicine. In many cases, it can be a way to access new treatments that may not be otherwise available in Canada. Often times, there is a greater demand for entry into a trial than there are spots available.

This quarter's newsletter will address how our CF Centre selects participants and the factors that contribute to the number of spots allocated for a clinical trial.

How are the number of participants determined for a clinical trial? Who decides it?

The sponsor (drug company) testing the drug determines the number of CF patients in the whole study. Studies can be large (more than 1000 participants) or small (10 in total for the entire trial). Trial size is determined by a number of things, including the phase of the trial (earlier phase trials are smaller), the goals of the trial (safety trials require fewer participants than efficacy trials), the expected magnitude of treatment effect (a less effective drug needs more participants to prove that it works), how many sites are participating and other factors.

Who can be in the clinical trial?

All Clinical trials have rules that determine who will be able to participate in the study. This may include things like CF genetics, age, current medications, lung function and what "bugs" have grown on recent cultures. These criteria are specific to each clinical trial and are determined by what drug is being tested, what impacts of the drug ("endpoints") are being studied, and what is needed to gain approval by the regulatory agencies such as Health Canada (HC) and the US Food and Drug Administration (FDA). Remember: just because you aren't eligible able to be in one study, doesn't necessarily mean you can't be in another!



How many spots does each CF Centre get?

This is determined by the sponsor. Some clinical trials are called Competitive trials, and the number of spots you get is determined by how fast the study can be started. Often the study sponsor will give the site a certain number of spots (for CFTR modulators, this is usually between 1 and 3 spots per clinic). In some cases, if these are filled quickly, the doctor running the study can request another spot. The final number of available slots is often not known until the study is well under way.

How does BCCH select clinical trial participants?

Our goal is to give the opportunity for all eligible children from our clinic to participate in clinical trials, if they and their families are interested. If we have limited spots and trials are competitive, we will usually look at all kids in our clinic who are eligible based on the study criteria. To ensure everyone has an equal chance of being selected, we put all the eligible patient names on a piece of paper and then put them into a box. A CF team member who is not part of the study team will choose as many names as we have spots.

A member of the research team will then contact those individuals to ask if they are interested in being in the study.



What happens if an eligible patient who was randomly selected says no to participating?

If an eligible patient who was selected says no to participating in a study, then another name is selected as above until the spot is filled.

FROM THE CF RESEARCH TEAM

Do we select participants from outside the BCCH CF clinic?

The preference is first to screen our patients and try to fill trial spots with eligible BCCH patients. If there are no eligible patients or if we have more spots than we have eligible patients in our clinic, we may contact other CF clinics to offer them the opportunity to participate in the clinical trial.

Can I do anything to increase my chances of being selected?

As we select potential participants in a randomized way and make sure that all patients are carefully checked for trial participation, there is no way to increase your chance of being selected. Once we have a list of patients who meet eligibility, those who are asked are selected randomly. However, we encourage you to ask your CF physician about ongoing research and possible opportunities and to express your interest in trials. Our team is happy to speak to you about the many ongoing studies and trials-in our clinic.

For more information please contact Alam Lakhani, Research Manager at alam.lakhani@cw.bc.ca



Some things are looking a little different in CF Clinic right now...

You will notice some changes when you come to clinic. Here's what you can expect:

Why are things different? In order to follow pandemic guidelines and keep everyone safe, there are some changes in place.

Where is clinic? For now the CF clinic is in the Respiratory and Allergy clinic space, in the 1982 Building (old hospital). You must enter the hospital using Entrance 53 and make your way through the new Teck Hospital and into the 1982 Building. When you see the gift shop and Second Cup Coffee, turn right and go to the end of the hall, then turn left and go to the end of that hall. This is the same area where kids have their lung function test (PFT lab).

Who will I see? For most visits, you will only see the CF doctor (and possibly one of our fellows) and if your child is old enough they will have their lung function test (PFT). You may see a physio (if not, then the doctor will collect your cough swab or sputum specimen) – please always bring your PEP mask if you use one. To minimize infection control risks, other allied health team members will only see you as needed. Please let us know in advance if you wish to see the dietician, pharmacist, nurse, or social worker (and remember – the allied health team members are always available by phone).

How long will clinic take? We are trying to make clinic visits faster; please plan to stay for 2 hours so you can get all your assessments done.

What tests will I have?

- Lung function test (PFT) if old enough, and cough swab or sputum sample (all patients)
- Chest X-ray if needed (you can request for this to be done in your local community, in advance of your CF appointment)
- If bloodwork is needed, we prefer for you to do this in your local community in order to avoid long waits at BCCH; the exceptions are babies/ small children (with tiny veins) and those with needle anxiety – these children should plan to have their bloodwork done at BCCH where there are specialized lab technicians and support staff (Child Life) if needed. Before clinic the team will review what tests you need to have done.

Who can come? Right now only one parent or caregiver (no siblings) can accompany a patient. There are exceptions (breastfeeding infant siblings, for example) but these require advance permission from hospital administration; you will need to discuss any exceptions with the CF clinic nurse or clerk in advance of your appointment.

****If you are scheduled for clinic and have new viral symptoms (increased cough, fever, runny nose, sore throat, etc.), please let us know before you come.****