



The PEP Talk*

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

CF Team Changes

HAPPY RETIREMENT SHELAGH! THANK YOU FOR EVERYTHING!

For those who have not heard, our CF Clinic Nurse, Shelagh Jenkins, has retired.

Shelagh worked as a nurse at BCCH for 42 years and with the CF clinic since 1996.

We want to thank her for her tireless commitment to each and every family.

Congratulations Shelagh!
All the very best in your retirement!

Pictured below, Shelagh was honoured with a plaque from CF Canada for all her years of service.

WELCOME DOT CHOW! CF CLINIC NURSE!

We would like to introduce Dot (Dorothy) Chow as our new CF Clinic Nurse. She has worked at BCCH since 2005 and comes to us most recently from the emergency department where she worked for over 10 years!

Dot's first patient as a nurse had cystic fibrosis which gave her a clinical interest in this area.

Dot loves a good cup of coffee and keeping up with the latest celebrity news.

She looks forward to getting to know each one of you over the next few months.



Novel Coronavirus (COVID-19) Update

We have had many questions about the novel coronavirus (COVID-19). The risk in BC remains very low. Hand washing and cough etiquette remain the first line defense. As we are made aware of information we will update the CF newsreel. Here is the alert bulletin from Health Canada:

<https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection.html>.

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

RESEARCH NEWS

ASAP – CF

The Respiratory Research team is excited to start the ASAP – CF study at BCCH. The study, which looks into the **A**ntibiotic treatment of **S**taphylococcus **A**ureus in stable **P**eople with **CF** (ASAP-CF), was devised and is being run by Dr. Jonathan Rayment at both BCCH and Sick Kids Hospital in Toronto. This study will investigate whether two weeks of treatment with the antibiotic Cephalexin (also known as Keflex) is beneficial in clinically stable children with CF who have Methicillin-sensitive *Staphylococcus aureus* (MSSA) growth on their airway bacterial culture. The study will use Multiple Breath Washout (MBW) testing, as a way to measure changes in lung function throughout the trial. Eligible participants will be able to be randomized a maximum of two times to receive either Cephalexin or placebo for 14 days.

A few of the key eligibility criteria for this study include:

- Between 3 and 16 years of age
- At least one episode of MSSA growth on airway culture in the past 24 months
- No other infections in the past 12 months
- No chronic daily antibiotic or systemic corticosteroid use within 28 days
- No known severe allergies to cephalexin, amoxicillin, ampicillin, cefadroxil, cefaclor, or cefprozil

If you have any questions or are interested in participating in this exciting study, please contact Research Coordinator Fareeha Khan, at 604-875-2345 ext 2928 or fareeha.khan@bcchr.ca.

Multiple Breath Washout (MBW) Testing

What is MBW testing?

MBW, testing, is a technique of measuring lung function that has existed for decades, and has recently re-emerged in the literature because of its extreme sensitivity to the small airways disease that is seen in early CF lung disease.

What does MBW test?

The lungs take in air, extract the oxygen that keeps us alive, and expel carbon dioxide, which the body cannot use. In people with lung damage, there may be pockets of the lungs that can do this well, and other pockets of the lungs that don't work as well. MBW can measure how effectively gases mix inside the lungs and how evenly this mixing is distributed throughout the lungs. Structural damage and inflammation in lung disease is patchy and results in uneven distribution of gas mixing in the lungs.

Why are we interested in MBW testing?

MBW is a very sensitive test, so it has a lot of potential to help us detect lung damage earlier than traditional tests. While spirometry is the most commonly used pulmonary function in respiratory medicine, many children with CF have evidence of structural lung abnormalities while having a normal FEV1 as tested by spirometry.

How does it work?

MBW testing is performed during quiet tidal breathing on subjects of all ages. Subjects begin the test by breathing in medical air, which consists of the same amounts of nitrogen and oxygen as the air we normally breathe. During the testing phase, the subject breathes in 100% oxygen, while slowly washing out the tracer gas (such as nitrogen) until the tracer gas is a fraction of its starting concentration. This determines how much the subject had to breathe in order to reduce the tracer gas to a target value. The greater the impairment of gas mixing due to lung disease, the slower the rate of tracer gas clearance.

There is, however, much that we don't know about this testing modality: how can/should it be used in a clinical setting? What constitutes a significant change between visits? Should a significant change in MBW outcomes prompt a change in clinical management? Through industry-initiated clinical trials and investigator-initiated studies, we hope to address these questions about this exciting new test. We're working to refine and improve its use for monitoring children with CF and other diseases that affect lung function. If you would like to take part of one of our registries that gathers information about this device, or if you have any questions about this testing, please contact your Respiratory Physician.



A child performing MBW testing



From My Kitchen to Yours... Roasted Veggie Enchiladas

Here is a nutrient rich recipe recommended by our dietician, Alex.



INGREDIENTS

- 3 cups fresh/frozen cauliflower
- 1 large sweet potato
- 2 red bell peppers
- 1 medium, yellow onion
- Extra-virgin olive oil
- 1 teaspoon ground cumin
- Salt
- Freshly ground black pepper
- 2 ¼ cups (18 ounces) red salsa
- ½ cup chopped fresh cilantro
- 9 to 10 corn 4" tortillas, halved
- 1 can (15 ounces) black beans,
- 2 big handfuls baby spinach leaves
- 2 cups shredded Monterey Jack cheese
- Sour Cream (M.F. 14%)

INSTRUCTIONS

1. Preheat the oven to 400°F
2. Chop vegetable (cauliflower, sweet potato, pepper and onion) into 1" pieces.
3. Add cauliflower and sweet potato on one pan and bell peppers and onion on the other. Add olive oil, salt, pepper and cumin to vegetables
4. Bake for ~30 to 35 min or until vegetables are tender, then set aside.
5. Reduce oven temp to 350°F and grease a 9" square baker.
6. Stir chopped cilantro into 2¼ cups salsa.
7. To assemble dish:
 - Spread ½ cup salsa evenly over the bottom of the pan.
 - Add a single layer of halved tortilla pieces, arranging them so they completely cover the salsa.
 - Top with ½ of the beans, ⅓ of the vegetables, ½ of the spinach, and ⅓ of the cheese.
8. Repeat this process 2 more times (pressed down on the mixture a little after each layer to make room for the next).
9. Cover the pan with parchment paper/aluminum foil. Bake for 20 minutes, then uncover and bake for an additional 10 minutes.
10. Before serving, sprinkle with chopped cilantro and sour cream.

<https://cookieandkate.com/vegetarian-enchilada-casserole-recipe/>

NUTRITION TIPS

- If you are trying to boost your calories, add extra olive oil to the baked vegetables or extra sour cream/cheese at the end.
- If you would like to include chicken; add finely chopped, pre-cooked chicken with each black bean layer.
- Get your kids involved in shopping for or cooking new recipes to improve family acceptance.

FYI MENTAL HEALTH RESOURCES

We encourage families to connect with the local mental health practitioner within their clinic for assessment/counselling support. Here are a few useful online resources for your reference.

For information on CF, Anxiety and Depression:

- CF Canada
<https://www.cysticfibrosis.ca/about-cf/living-with-cystic-fibrosis/mental-health>

Other resources on anxiety and children that may be beneficial:

- Mindshift <https://www.anxietycanada.com/resources/mindshift-cbt/>
- Anxiety Canada <https://www.anxietycanada.com/learn-about-anxiety/anxiety-in-children/>
- Kelty Mental Health <https://keltymentalhealth.ca/parents-caregivers>
- The Child Mind Institute <https://childmind.org/>



Prescription Refills 101

Has your usual medication run out? Do you need more enzymes? Here is the most efficient way to get refills for your prescription:

1. Check the bottle for quantity remaining or call your local pharmacy to see if there are any refills on file.
2. If not, ask your pharmacy to fax a refill request to the CF clinic fax 604-875-2349
3. The clinic will send the re-fill prescription to your pharmacy.

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