The PEP Talk*

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

Fall 2018

BACK TO SCHOOL LUNCH TIPS

FIBROSIS

For many children heading back to school in the fall, eating enough at lunch can be challenging within the amount of time given and on top of other factors such as distractions or finding school-friendly lunch ideas your child likes to eat. A couple tips to help your child with eating lunch at school:

- ✓ Discuss with your child's school if they are able to support your child with their lunch such as allowing extra time for your child to finish lunch or leave class a few minutes early to wash hands and take their CF medications
- To help spark their interest in eating their lunch, see if your child is able to participate in preparing and/or packing their lunch
- Lunches can also include breakfast foods such as pancakes/waffles or leftovers from dinner. If your child is tired of sandwiches, try using a cookie cutter to create a shape or changing the bread to bagels, croissants, English muffins, pita bread
- To keep foods hot in a thermos, try adding boiling water to the thermos for a few minutes, then drain water before adding hot food
- ✓ For more lunch ideas, visit Chef4cf -<u>https://www.chef4cf.com/recipes/lunch</u> or see our website (link below) for a list of packed lunches (including nut-free)
- ✓ For additional tips on back to school, visit CF Canada's school toolkit: <u>https://goo.gl/RgzLDA</u>

STAY IN THE LOOP

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 for the Newsletter? Email: cfqiproject@cw.bc.ca

FREQUENTLY ASKED QUESTIONS

Q: Thursday does not work for me, can I change my clinic day?

A: While we try to accommodate changes to clinic dates as much as possible, we *cannot* change regular Thursday clinic appointments to Tuesday. Tuesday clinic is reserved for our babies, newborn screen consults and occasional study participants. Thank you for your understanding!

MAGGIE MCILWAINE (PHYSIO) IS RETIRING

Dear CF Clinic,

I wanted to take this opportunity to let everyone know that after working for 37 years with BC Children's Hospital Cystic Fibrosis Clinic, I am retiring (well not really). I feel very privileged to have had the opportunity to work with each of our CF families over the years and to see so many changes in the healthcare of children with CF. It is a pleasure for me to watch as our children with CF grow into young adults and achieve their ambitions.

I mentioned that I am not really retiring, that is because I now have a new and exciting position with CF Canada. CF Canada is launching a Clinical Trials Network to give more people with CF the opportunity to take part in clinical studies which will benefit the whole CF community. I am heading up this Network as the Network Manager. This is an exciting opportunity and one which we will keep you all updated on as we want patient participation in both designing studies and taking part in these studies. Even though I work for CF Canada, I am still based at BC Children's Hospital so will be around to say hello.

If you want any further information on clinical trials we will be setting up a website page on the CF Canada website. Thank you all, once again for allowing me to be part of your CF family!

Maggie McIlwaine

Congratulations Maggie!! Thanks for everything!! We wish you all the best in your next adventures!

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

STAFF CHANGES

WELCOME TO DR. JONATHAN RAYMENT

There's a new face in the CF clinic that many of you have met already! He was interviewed quickly to help you get to know him better! We are very excited to have Dr. Rayment in our clinic!

What is your job? I'm a Respirologist.

Where are you from? I worked in Toronto before I moved to Vancouver.

What are your clinical interests? I am interested in the development of new tools that will help us detect lung disease in children with cystic fibrosis. This includes new, more sensitive breathing tests that will help us measure lung function in children. I am also interested in developing new imaging tests (such as MRI) that will help us see the structure of the lung.

What's your favourite part of Vancouver so far? The mountains! What's your least favourite part of Vancouver so far? The rain!! What's one interesting fact about you? I play the drums. What's your favourite ice cream flavour? Orange Sherbet! Yum!



INTRODUCING THE 2018-19 RESPIRATORY FELLOWS



Dr. Julie Duncan, completed five years of General Pediatric training in Oxford, then completed a Respirology sub-specialty training in London, including a fellows post in sleep and PCD. She then took some time out of training for a two year research degree working with the London CF collaboration. My project was longitudinal monitoring of lung function and imaging in children with cystic fibrosis. She is a keen runner who loves music! She is looking forward to learning to ski this winter!



Dr. Ajay Kevat is our new respiratory fellow who has completed his prior medical training in Melbourne, Australia. He enjoys hiking/backpacking, kayaking and travelling. He is very excited to have moved to Vancouver, BC and was very impressed with the Rockies. This is his first time in Canada.

Delphine Czuba joined the CF clinical team as a Respiratory Research Coordinator in 2016. She completed her Master of Sciences in Cell Bioloav. Physiology and Neurobiology in France. She then went on to work for the clinical trials program at PFIZER France, managing study sites and data collections. She has a 20month-old son who keeps her busy but when time allows it, she enjoys travelling, and horse riding.

MEET THE RESEARCH TEAM

Alam Lakhani, is our new Respiratory Research Coordinator. He completed his Bachelors of Science degree in Cell Biology and Genetics at UBC and has previously worked in the GI division on Inflammatory Bowel Disease research studies and patient outreach and at Bayer on drug development and manufacturing projects. In his spare time he enjoys volunteering with a number of different organizations as well as swimming, hiking and volleyball.

Rodrigo Sandoval recently joined BCCH's CF Research team, as a Research Coordinator. He is involved in several studies. He completed a BSc PT with some international clinical experience (Chile) and an MSc from Simon Fraser University where he had the opportunity to be involved in the invention and development of a diaphragm pacing system, a medical device that aims to aid the weaning process of critically ill mechanically ventilated patients.