



The PEP Talk*

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

CLINIC STAFFING CHANGES

Dear families,

It is with mixed emotions that I am announcing my retirement. I have worked at the hospital for over 29 years, the last 8½ working at the Cystic Fibrosis and Biochemical Diseases Clinics. The progression of medicine and technology over the years has been incredible. I feel fortunate to have worked with so many wonderful families, witnessed the resiliency of individuals, had the opportunity to watch children grow into incredible adults, been able to support families during challenging times and have had the opportunity to be part of celebrations. I am grateful for the wonderful and enriching experiences and wish you all the very best in the future.

Sincerely,
Tami Kolb (Social Worker)

Congratulations Tami! All the best in your retirement!

In other happy news, our dietician Christine Loong will be on maternity leave starting June 1 and Dr. Kelly Luu's maternity leave will start March 30. Enjoy the 'diaper daze' Christine & Kelly!

All positions will be filled with new staff which we will inform you of when we know who will be joining us!

FYI

- Check out our website for newsreel and up to date information:
<http://www.bcchildrens.ca/our-services/clinics/cystic-fibrosis>
- **Outreach Clinics** to Prince George and Kelowna are organized throughout the year. Unfortunately we cannot accommodate every family every time. The clinic will contact you if you will be offered an appointment at an Outreach Clinic in your area.
- **Clinical Research** – there is a new clinical trials finder on the CF Canada website if you're interested in what trials are going on in Canada.
- Questions/Comments/Ideas?
Email: cfqjproject@cw.bc.ca

SPRING BREAK TRAVEL TIPS

Jetting away to the sun? Crossing the border for shopping? CF Canada has useful travel tips.

1. **Plan for temperature changes:** Just because it's cold in BC doesn't mean it's not sunny elsewhere. Temperature sensitive medications include: enzymes, pulmozyme, insulin and some antibiotics.
2. **Don't forget your ice packs:** If you are going through airport security your ice pack will be checked and swabbed. You may need to inform them that you have them for medical reasons.
3. **Request a Travel Letter:** If you're flying or crossing the border, request a travel letter that outlines the medications you need so you won't have any trouble at the airport.
4. **Plan ahead** Have travel insurance in advance.
5. **Bring extras:** You can't always anticipate delayed transportation or an unexpected spill, so an extra day or two worth of medications is very helpful.

For the full document, visit:

<https://www.cysticfibrosis.ca/about-cf/living-with-cystic-fibrosis/resources>

PATIENT EXPERIENCE MAPPING

In November 2018, three families participated in our first Patient Experience Mapping focused on the care received in between clinic visits. Parents felt that it was an opportunity to be heard and advocate for parents of children with CF.

"I am so glad to be here, if you can stand up for yourself then you are also standing up for other people as well."

Many topics were discussed but some of themes that were identified were:

1. Length of clinic and redundancy in clinic.
2. The desire for parental expertise to be acknowledged and shared.
3. Challenges of receiving care in the community.
4. Feelings of being judged and of guilt.
5. The need for inspiration and hope.
6. Challenges with admissions (PICC, fear, home IV, family disruption).

Our improvement goals from this project will be focused around:

1. Optimizing clinic appointments.
2. More parental involvement in CF education
3. Improved communication regarding research and clinical trials.

Many thanks to those who took the time to share their perceptions and suggestions.

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

Five Feet Apart: A Review

By Melissa Richmond (Physio)

No spoilers here! I took some time to read the book *Five Feet Apart* which features CF (it will be released as a movie later in March) and I wanted to add some thoughts. First, I'm not telling you to run out and read it. If you aren't interested, I would say there are many other books out there to consume on your spring break holiday! But, if you're a teen reading it thinking it's going to tell you about your life or a parent wondering if this is what the teenage years will be, I need to let you in on a few issues. The book brings up some important conversations we need to have about CF care and perspectives on it. Please remember that this book is fiction and a dramatization.

1. **Confidentiality** – We will keep your information private. If you start to talk about another family with CF, you might see us politely nod and smile neutrally but not offer any information. In the book, characters interact with staff and ask them about other patients' lives, infections and health status. Your health information is yours to know and yours to share whether you choose to keep it private or share on social media.
2. **B. Cepacia** – This organism is one of the 'villains' in this book. While we recognize that B. Cepacia is an important organism to be aware of, we have a low infection rate in our clinic. B. Cepacia is an organism that was found to spread rapidly among groups of CF patients which led to strict infection control policy and hence the title of the book.
3. **The 6 Foot Rule** – CF patients are told to stay 6 feet apart from other patients with CF as this is the distance organisms in a cough can travel. Despite this rule, the characters in the book hang out in each other's rooms with masks as long as they follow this rule. This is not acceptable in terms of infection control. A rule that was meant for corridors, elevators and passing each other in clinic has been dramatized to just mean a bubble of space wherever you go. Children with CF should not spend time in the same space as we know surfaces can harbour bacteria. Remember infection control is not keeping you from doing something fun, it is looking out for your best interest.
4. **Hospital Stays** – Code Blues and CPR are not the reality of a pediatric CF hospital stay. When you are admitted to hospital it is often for 2 weeks of IV antibiotics to treat a lung infection and not the level of medical fragility described in this book.
5. **Lung Health** – All the teenagers in the book have low lung function and are lung transplant candidates. In Canada the median lung function (FEV₁) of 18 year olds is over 80%, according to the CF Canada registry.
6. **Physiotherapy & Clinical Trials** – Remember all these are all presented in this book from an American perspective where practices can be slightly different than us!

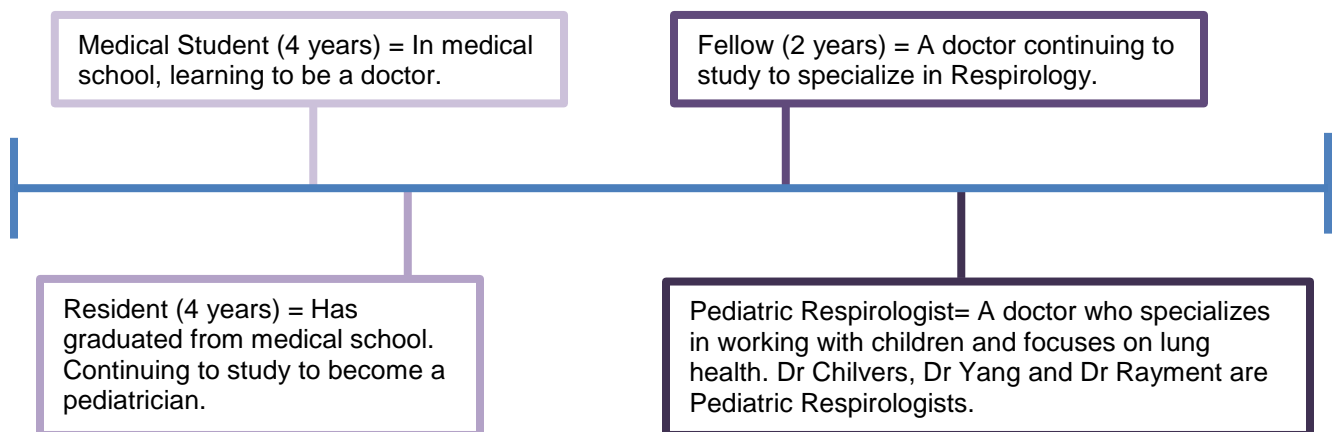


If you have any questions or want to chat more about the book or movie (I plan to see it), let me know!

STUDENTS AND LEARNERS: WHO'S WHO IN CLINIC

BC Children's Hospital is a teaching centre. This means that often you will meet dietetic, medical, pharmacy, physiotherapy, nursing or research students in the CF clinic.

The path to becoming a doctor can seem quite confusing, below are the different "types" of doctors you may meet in the CF clinic.



WORD SEARCH: FUN WITH ENZYMES

Find the **BLUE** words hiding in the word search below:

There are 3 different brands of **COATED** enzymes available in Canada:

COTAZYM, **CREON**, and **PANCREASE**.

Enzyme beads are coated so that they can pass through the acidic environment of the stomach into the small intestine where it helps digest food. Inside the beads there are 3 types of enzymes which help to breakdown and absorb nutrients from the food you eat:

AMYLASE breaks down carbohydrates,

LIPASE breaks down fat, and

PROTEASE breaks down protein. If you

are still learning to swallow pills,

enzymes can be opened up, and the

beads inside can be sprinkled onto a

spoonful of **APPLESAUCE**. Keep your enzymes stored in a **DRY** place and in room temperature. With winter

coming, be mindful of the **TEMPERATURE** which your enzymes are stored, freezing or cold temperatures

may inactivate the enzymes.

F	E	H	K	U	A	Q	T	V	L	Z	U	A	L	N	A	Y
R	W	X	C	D	Q	P	F	X	A	D	B	S	G	F	U	E
Y	Y	F	F	D	M	V	Z	M	I	H	E	W	Q	N	F	X
S	L	E	Z	R	X	W	Y	Y	J	F	S	T	R	M	O	X
G	X	Q	L	G	T	L	E	E	R	Z	E	Q	A	F	F	T
G	J	Y	A	U	A	I	R	G	E	B	M	P	M	O	T	E
T	Z	T	A	S	N	G	C	Q	F	A	Y	G	C	P	C	C
E	T	L	E	R	H	E	O	Y	B	O	Z	I	R	A	N	U
M	M	I	K	U	D	G	T	F	Y	Q	N	J	E	N	P	A
P	J	Q	D	K	U	A	A	M	Z	V	E	I	O	C	T	S
E	E	X	Y	P	Q	G	Z	V	G	F	S	N	N	R	W	E
R	T	R	G	H	L	F	Y	Y	N	M	X	Y	H	E	Q	L
A	D	W	V	M	H	E	M	U	H	R	W	Q	V	A	A	P
T	C	K	I	L	I	P	A	S	E	G	D	L	T	S	B	P
U	E	S	A	E	T	O	R	P	Z	F	Y	D	T	E	D	A
R	G	X	M	T	J	E	A	M	B	F	K	C	I	T	Y	M
E	J	R	Z	G	M	Y	L	P	S	D	B	F	D	J	S	R



WISH GRANTED: AN INTERVIEW WITH STUART



Hi Stuart!

Thanks for agreeing to be interviewed about your wish!

First of all, how old are you?

I'm 9 years old.

What organization granted your wish?

Make a Wish Foundation.

How did you hear about wishes?

When I was in the hospital my mom showed me a video of a kid with CF that got a wish.

What was your wish?

To go to London to see the Harry Potter Warner Brother Studios and it came true! On the first day I was jet lagged but I went on a VIP tour of Primark Department store and got Harry Potter souvenirs. Then I went to the Warner Brothers Studio. I even went on a muggles walking tour.

When did you go?

We went for 8 days in August 2018.

Who came with you?

Most international trips can only accommodate one parent but luckily both parents were able to go on this

Why is making a wish important?

Because you will have the time of your life!

What was the best part of your trip?

The Warner Brother's Studio! I saw Aragog the giant spider in Harry Potter.

Do you have any advice to kids wanting to make a wish?

It will be a blast! Choose something you like. If you like You Tube you might want to meet a famous You Tuber or if you're a gamer pick a gaming wish.

Thanks for sharing your story and advice Stuart!

Interested in a wish?

Children and youth with CF may be granted one wish before their 18th birthday. For more information, guidelines and other programs offered, please see the following organizations:

Make a Wish Canada: <https://makeawish.ca/>

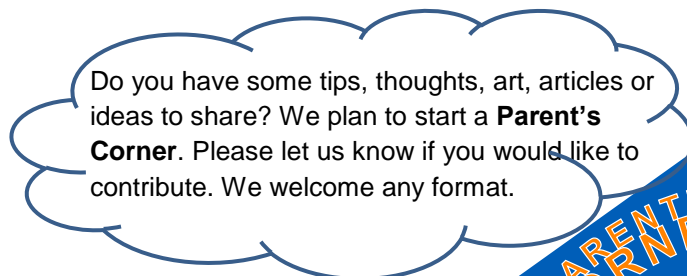
Starlight Children's Foundation (BC Office):

<http://www.starlightcanada.org/about-us/our-team/#bc>

Children's Wish Foundation (BC & Yukon):

<https://www.childrenswish.ca/category/chapters/british-columbia-yukon/>

Did you have a wish granted and want to share your story? Let us know!!



Do you have some tips, thoughts, art, articles or ideas to share? We plan to start a **Parent's Corner**. Please let us know if you would like to contribute. We welcome any format.