



# Simcoe Muskoka Regional Cancer Program Patient and Family Advisory Council (PFAC) Newsletter

The Spring 2022 Edition

## Meet a PFAC Member: Debra

Written by Debra Poss, PFAC patient member



My name is Debra and I was diagnosed with stage 3 endometrial in December 2014. I underwent emergency surgery in January 2015, followed by radiation treatments and chemotherapy at RVH, and then another round of a different type of radiation therapy at Princess Margaret. I was fortunate enough to continue working full time (wearily) throughout the entire course of treatment. Beyond that I remember little, short of knowing I had excellent care.

In the spring of 2016, I applied to join the Cancer Program's Patient and Family Advisory Council. Being a part of the team, still to this day, I find we all bring something to the table with our own unique perspectives. We brainstorm, we laugh, we cry. I'm most proud of our group as we've been part of some really great things at the Cancer Centre. It's such a great feeling that I can use my experience to help others along the cancer journey and make it better for the future.

Aside from my involvement with PFAC, I'm also a business owner in the medical equipment and supplies industry. Over the last 3 decades, I've witnessed the struggles that patients and loved ones face after receiving a life-changing diagnosis. Living life while needing medical assistance or medical equipment outside of hospitals/nursing homes is a VERY different world. The amount and the variety of medical supplies that a patient needs are often overwhelming. I've been privileged to offer my expertise and compassion to help those who are struggling to make these decisions.

I felt by joining PFAC I would be able to provide a different perspective when discussing the challenges families face when attempting to keep their loved ones comfortable at home. Patients and their loved ones are truly their own best advocates; through my roles as a business owner and on PFAC I strive to bring this important concept to light.

## Cancer Centre Update: Your Voice Matters

Written by Susanna Wong, PFAC staff member

In October 2021 we've started sending emails to patients to ask for their experience at their most recent visit. We have collected 509 responses from October to December 2021, which is a very impressive number of completed surveys. **A big thank you to those who have completed the survey** and provided your valuable feedback!

## From the Your Voice Matters survey results, here's what you've told us:

### What we're doing well:



Waiting area was comfortable and clean.  
Reception was polite.  
Virtual care visit was in your preferred language.

### What we can improve on:



Have options to involve your friends and family at your in-person and virtual visits.  
Have options on whether your visit can be in-person or virtual.


With COVID-19 restrictions lifting, we are working on providing more options for your visits to provide a better experience for you and your loved ones. Stay tuned for details!

Got questions or ideas for improvement? Email [nsmsscreening@rvh.on.ca](mailto:nsmsscreening@rvh.on.ca), or contact the Patient and Family Experience Office at (705) 728-9090 ext. 44510.

## A Few Words of Inspiration: Blessings and Laughter

Written by Willa Hart, PFAC caregiver member

If someone had told me that one day my partner would be diagnosed with palliative lymphoma and I would be looking after him at home during a pandemic, I would have panicked. Sadly, that really did happen, but the great surprise to us both were all the blessings that came our way those 8 months. I did not panic as I had feared. The saying “you don't know what you don't know” truly applied. Despite many roller coaster days and weeks, we were surrounded by so many amazing health care professionals, friends and family that we were able to focus on our new normal and make it into something we never expected.

 Our strength came from a few different inspirations and routines. First and most important we dropped all unrealistic expectations and lived one day at a time. Meals were simple and nutritious and often cooked by others. We never said ‘no thank-you’ when help was offered. We tried to have something to look forward to every week. We ate too much ice cream. Music was our inspiration and joy. We turned the music up most days and yes you can dance with a walker and a foley catheter. It might not have been ballroom dancing, but it was our ballroom. We were fortunate to have friends come once a week and set up a stage on the deck outside with guitars and microphones. It wasn't Roy Thomson Hall, but it might have been better. We posted videos of the ‘band on the deck’ on YouTube and felt like stars. The grandchildren provided unbridled enthusiasm and love with their frequent visits. Their art and love cards still cover the walls. We laughed often, held hands, and lived in the moment. It wasn't always easy, but with a little imagination and a lot of love we made it work.



My takeaway for those who are reading this is to say, don't be afraid to try the unconventional. Ask for support from friends. People often don't know how to help but if asked will give an enthusiastic yes. Find a few interests that you love and enjoy them when you can. Movies, music, cards, board games. Laugh often and loudly. Some of us have been on the planet for many years and have a lot of memories that provide humour. Laughing at yourself is good medicine. It wasn't always easy, but the joy of hope gave both of us strength when dancing and laughing were too hard.



I hope you too will find inspiration in unlikely places. Roll up the carpet and dance like a teenager. Well maybe not quite like a teenager. That might be a bit too much inspiration.

## Introducing the Look Good, Feel Better Program

Written by Jocelyn Woodcock, PFAC patient member



During treatment for breast cancer, I lost my hair. Why DO we lose our hair when we receive chemotherapy? It happened that the chemo I received for breast cancer targeted the body's fastest dividing cells. That included cancer cells but that also meant healthy cells, like those in hair follicles. Another question I might ask is why were the hairs on my legs the last to go but the first to come back? Ah, but I digress.

I had fairly short hair to begin with, but I was shocked at how rapidly my hair loss progressed. I tried vacuuming my head twice daily. I used a mountain of those sticky lint rollers to no avail. Finally, after ingesting way too much hair while I was having my meals, enough was enough. I shaved my head and left my shorn locks outside. Sure enough, some bird or animal did pick them up and somewhere some babies benefited from my loss.

Upon seeing the new me, the immediate reaction from some friends and family was shock - mostly accompanied by tears. The whole thing was now real. Up until that point one couldn't see the difference between the Jocelyn without cancer and the Jocelyn with cancer. This was what cancer looked like.

### And Then I Attended the Look Good, Feel Better Program

Around that time, I heard of the free program held at RVH called Look Good, Feel Better (LGFB). Since 1992, this program has provided a place to get together with other women to have a time to relax, learn, share and be inspired. Patient participants also received a free goodie bag filled with brand-name skin care products, cosmetics and information on head coverings and wigs. I booked the date and attended with my daughter.



The first thing that I learned when we arrived is that the female presenters were cancer survivors themselves. I felt right at home. My daughter and I settled in to enjoy a few hours of fun while we watched presentations and tried on some scarfs and wigs. I don't normally wear makeup so I learned a lot that day. The last time I had no eyelashes and eyebrows was when I was eleven and had a close encounter with a campfire while roasting marshmallows. I found out the correct way to apply eyebrow pencil so I didn't have a lasting 'surprised' visage. I quickly learned the front from the back of a wig (if you can't see, it's probably on back-to-front!). And I left with a good feeling...about me.

That was a number of years ago. This year is Look Good, Feel Better's 30th anniversary. Because of COVID-19 protocols, the program is currently offered online. Our PFAC members recently spoke to Emily Price, LGFB's Program Manager. Emily mentioned that LGFB is working on resuming in-person sessions as soon as possible.

## Meet Kara Mandel: Team Leader for Look Good Feel Better (LGFB), Barrie

Interview by Stacey LePage, PFAC patient member.



### **1. How did you get started with the Look Good Feel Better program?**

I have always been interested in helping women going through cancer treatments, so I was excited to read about the program in a magazine. I called the number listed and applied to the program in Barrie. Now, 25 years later, I am so glad I did as I have seen how the program has had such a positive impact for women both emotionally and physically. The program is transformative. For me, it has been the perfect volunteer opportunity.

### **2. What is your background?**

I grew up surrounded by makeup artists and hairdressers as my mom was a model, but I hadn't intended to get involved in cosmetics at all. I went to Laurentian University to study Earth Sciences. Soon after, I started a family and chose to focus my attention on my children. As they grew, I decided to get back into the workforce and found a perfect job as a cosmetics representative.

**3. What do you observe when participants first start the program?** The women are usually quite nervous at first. Many have been dragged in by a friend, a sister, or someone who has been through the program before. Their apprehension is understandable as we all tend to have a fear of the unknown. They are also usually exhausted from treatment and rather reluctant to be back at the hospital when they are not having treatment. Their schedule is full between treatment and life commitments such as work, family and caregiving for others. It is tough to juggle everything and then add on the unknowns that cancer brings.

Then, as people feel more comfortable, there is a 180-degree transformation both physically and emotionally. They talk to each other and form friendships. Most are so thankful and want to stick around to chat or ask questions. There is more of a bounce in their step as they leave. They are more confident. We hear comments like, "I haven't looked this good since my wedding. I've never treated myself, maybe I'll pick my wig today." Going out for lunch is usually on the schedule afterwards. The women laugh and really have fun.

We also help women with head coverings too as many have lost their hair through chemo. We've seen all kinds of heads over the years: bald, baby hair, henna, jewels on the scalp. We've seen bad wigs too. Some women bring in their old wigs looking for suggestions for how to modernize them.

### **4. Is the program also for men? Can I bring my husband/partner with me?**

Men are not allowed in the workshop. This is a decision we made based on patient participant feedback. While this decision may seem offensive towards men, we really need to respect the clients for whom our program has been designed. For 30 years since we have run these programs, we have received the same feedback. The participants said: "for these two hours, we'd like to be with other women, take off our wigs, to not feel self-conscious with someone else's husband or partner there observing".

Having said that, Look Good Feel Better is looking to expand their support resources to men as well as members of the Black, Indigenous and Women of colour who are facing cancer. We are currently looking for feedback from these groups on their experience on the appearance-related side effects.

**Spread the word and let us know on your thoughts!** <https://lgfb.ca/en/surveys/>

## 5. Did the program continue through COVID?

The program was always offered virtually for anyone who lived in remote locations, but during COVID, the entire program was moved on-line. Head office really ramped up the on-line program and invested in videos and other ways of reaching out.

Before COVID-19, each patient participant received a free sample kit. The kits included a variety of skin care products as well as cosmetics that we carefully screen to ensure they meet our criteria of being suitable for dry and sensitive skin and that they are free of synthetic fragrances. The makeup is quite neutral so that it appeals to a wide range of women of all ages and with varied skin tones. We paused on distributing the kits to patients during COVID-19 and look forward to restarting this when we offer the in-person programs.

## 5. How do you teach women to use their cosmetics and skin care products?

We found that it is better to give our ladies their own mirror and teach them how to apply the skin care products and make up themselves. We are there to help and guide, and fix things if they need help, but mostly they do it themselves. Some women struggle with how to put on their eyebrows (sometimes lost during chemo) or what to do without lashes (also sometimes lost during chemo). There is also a manual in the kit which they can refer to when they get home. We do NOT talk about medical issues and we CANNOT give medical advice. This is not about vanity; it is all about wellness. Though the program focuses on appearance, it has definite benefits on your mental health. Looking good, you WILL feel better!

*“(Look Good Feel Better) is not about vanity; it is all about wellness.”*

## 6. Is this program for breast cancer patients only?

No! People often thought our program is for breast cancer patients only because we used to wear pink aprons. The program is open to all women diagnosed with any type of cancer - even if you didn't lose your hair. All are welcome.

## 7. Where do I go for more information?

The LGFB program website can be found at [www.lgfb.ca](http://www.lgfb.ca) or you can call 1-800-914-5665.





## Did You Know?

There are a few different cancer patient transportation services available to patients in North Simcoe Muskoka. We spoke to a few organizations and provided an introduction to their services. Always check if the service is running by calling or visiting their website.

### 1. Canadian Cancer Society (Wheels of Hope) 1-888-939-3333

Website:

<https://cancer.ca/en/living-with-cancer/how-we-can-help/transportation>



Do you need to travel across town — or across the province — to receive cancer treatment? We can help. We will work with you to help you find the best option for travelling to your treatment.

### 2. Canadian Red Cross Simcoe Muskoka Branch 705-721-3313

Website:

<https://www.redcross.ca/in-your-community/ontario/nutrition-and-transportation/transportation>

The Canadian Red Cross provides transportation service for those in need, such as elderly or disabled in the community, who are unable to use public transportation or private means. Our service keeps people connected in their community by providing affordable transportation to social gatherings, escorts to medical appointments or even for a shopping excursion. With a combination of cars and mid-sized vans, as well as accessible vehicles, we have the transportation service delivery and coordination expertise to meet your community transportation needs.



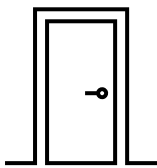
### 3. Helping Hands (Orillia) 705-325-7861

Website: <https://helpinghandsorillia.ca/services/transportation/>

As an enabler for health care, Helping Hands provides our clients with specialized, affordable transportation services, capable of meeting various mobility needs. With access to passenger vehicles, vans and wheelchair vehicles, Helping Hands provides well-trained and knowledgeable transportation service workers, to meet the individual needs of our clients. Service is available for both local and distance destinations for medical appointments, personal errands or social engagements throughout the province. Transportation escorts are welcome to attend at no additional cost.”

### 4. Muskoka Seniors 705-789-6676

Website: <https://www.muskokaseniors.org>



We provide door-to-door transportation for our clients to help them to live more independently. Our staff drivers use our branded vehicles and our registered volunteers use their private vehicles to pick up and drop off clients to do their errands, get groceries, fill prescriptions, go to medical appointments, and conduct day-to-day business with ease. Clients are requested to contact Muskoka Seniors in advance to arrange this service.

## A Little Bit of Humour Helps You Feel Better...



## Say Hola to This Chicken Burrito Bowl Recipe

Written by Kelly Blakely, PFAC patient member

Quick, easy, family pleasing, and healthy! These words pretty much sum up my goals for meal planning on any given day. This recipe is all those things and more!

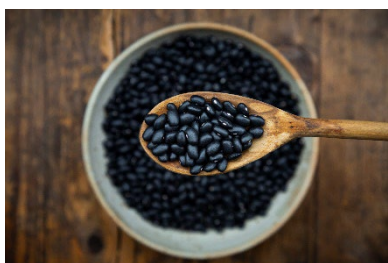


When I was going through treatment, these words were even more important. During chemo, I needed foods with lots of flavour to help with the different tastes in my mouth. I also needed a meal that was no fuss for when my energy levels were low. This meal is easy to make. Even my husband, who is not great in the kitchen, pulled it off and our kids were able to help with prepping the toppings. They were 8 and 10 at the time! My kids loved it because they got to choose their toppings and they always came back for

seconds. For reference purposes, I have a large oval slow cooker and I double this recipe and it fits perfectly in the slow cooker. I also use chicken thighs as they are juicier and easy to shred!

### In your slow cooker, add:

1 cup of chicken broth  
4 chicken breasts or 12 thighs (frozen or fresh)  
1 can of black beans drained  
1 can of diced tomatoes (I often use the ones with Italian seasoning)  
1 can of corn (drained)  
Salt and pepper to taste  
Half a pack of chilli seasoning  
Half a pack of chicken fajita seasoning.



### Directions:

Cook on high for 4 hours or low for 8 hours. When almost ready for dinner make rice of your choice. Basmati is our favorite but instant rice works too! While the rice is cooking, use a slotted spoon and scoop out chicken. Shred it and return it back to the pot. Suggested toppings include shredded cheese, guacamole or chopped avocado, sour cream, salsa, onions, cilantro and lettuce.

When the chicken mixture is ready, put your rice in the bowl, add your chicken mix and top with toppings of your choice! A fun side to this dish is tortilla chips. Use them to scoop up the mixture or crumble some on top. They add a nice crunch! If you double this recipe, you will have great leftovers and it freezes beautifully!

Hopefully you enjoy this recipe as much as we do!

-Kelly