



# GETTING TO KNOW YACC

*A program guide to lead young adults through and beyond their cancer journeys*



## YOUNG ADULT CANCER CANADA

We know cancer is different for young adults. That's why we're here! Young Adult Cancer Canada (YACC) is a registered charity that works with and for young adults diagnosed with cancer between 15 and 39.

Our mission is to build a community of young adults diagnosed with cancer that provides information, support, skills, and opportunity. YACC provides a number of programs for young adult survivors and supporters to help connect them with others who 'get it.' We know that young adult survivors and supporters are facing huge challenges that are very specific to their age group—fertility, finances, relationships, and independence are only a few. These issues are a lot different for a young adult than they are for children and older adults; someone in their 60s doesn't have the same concerns about fertility as someone in their 20s.

Keep reading to learn more about YACC's face-to-face programs and online community. If you want to ask questions on any aspect of YACC, please email [connect@youngadultcancer.ca](mailto:connect@youngadultcancer.ca).

## FACE-TO-FACE PROGRAMS

YACC events are all about coming together with a bunch of people who know what you're going through. The weekends are free to young adult cancer survivors (including people in treatment and remission) and one supporter (a friend, sibling, or partner, but not parents). The participants are responsible for their travel to the event, though we do offer travel assistance for those who need it.



## RETREAT YOURSELF

Come and share your story, learn different strategies to navigate the crazy road that is cancer, and leave with an army of friends.

Retreat Yourself is tailored to survivors in or recently out of treatment, or anyone who hasn't yet connected with other young adults dealing with cancer.

What Hannah, leukemia survivor, had to say about Retreat Yourself:

*Each day at the Retreat consisted of a lot of sharing, in small and large groups. I expected that. There was even sharing during the free time and I loved it! I just kept thinking to myself, 'How have I not been doing this?' It was so natural to share thoughts and feelings about what each one of us was going through. I found comfort in that. Jokes about having 'chemo brain' and being challenged with short-term memory was the norm; people in the room would laugh with you because they too know what it's like. I've never experienced that, and I still laugh about it now.*

What Reggie, Hannah's husband and supporter, had to say about Retreat Yourself:

*Initially, I didn't want anything to do with this weekend, for many reasons, like not wanting to express myself emotionally to a group of strangers. I didn't think we 'needed it.' All I could hear was a small voice in my head saying, 'Sit down and shut up, no one wants to hear from you. They are all here for Hannah.'*

*But this weekend was also for me, Hannah's supporter. YACC made that clear. Although we live the same life, my story was different from Hannah's, and this weekend was very much an opportunity for me to tell it.*

*Trying to express what this weekend did for us is overwhelming. I really do feel as though we took on this journey together. At first, I didn't want to be there, and when it came time to go, I didn't want to leave.*



## RETREAT YOURSELF ADVENTURE

Challenge yourself both physically and mentally while you address survivorship issues on a once-in-a-lifetime adventure!

Retreat Yourself Adventure is perfect for those survivors who want to learn more about themselves, and crave a physical challenge. This program empowers survivors to keep moving forward by increasing their confidence in one's body and mind post-treatment/cancer.

What can you expect from Retreat Yourself Adventure? Here's a recap from the first one ever from program director Karine Chaliflour.

*Each day of our adventure was themed and paired with a unique activity. Day one was about conquering our theme of Fear with ziplining—everyone brought trust and self-confidence with them and faced their fears like champions. The second day was all about “change” as we took to the Atlantic for a day of sea kayaking. We faced wind, sun, and rain, and sang through it all. As we know, young adult cancer survivors go through so many changes and they have to adapt and find the good in there. The third day was a big day as we took on Gros Morne Mountain. Our theme for the day was “believe,” and whether people hiked the intense trail to the base of the mountain or all the way to the top, it was a wonderful and enlightening experience. We are so grateful for this group to have had the courage to push their limits or to stay within. It takes a lot of strength to do both.*



## **SURVIVOR CONFERENCE**

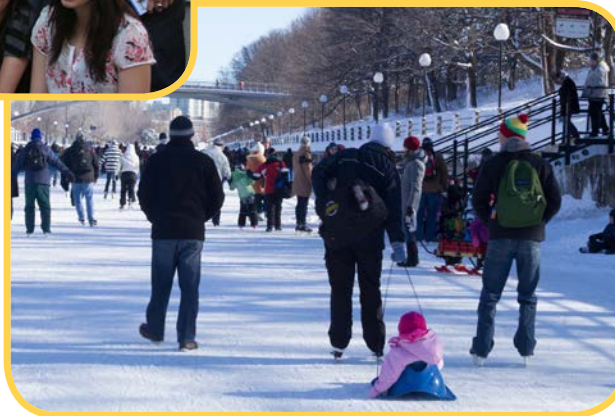
Take part in the biggest reunion of young adult cancer survivors and supporters in Canada.

The Survivor Conference is an annual event focused on making the rest of our life the best of our life. It's a time to connect or reconnect, and learn useful tips to live a healthier and happier life. It also works on using the experiences with cancer to help other young adults across the country.

What Lynsey Frangakis had to say about Survivor Conference:

*Attending the 2012 Survivor Conference was the first time I felt normal in a year. No one looked at me funny, said, 'Ooooh, but you look so good,' or stared awkwardly when I said I had cancer. The feelings and worries that I face are normal. Everyone in the group had—or has—these thoughts. We are all there to help each other and share our experiences. I felt a part of something magical, something life-changing, and it brought me out of isolation. It was acceptable to talk openly and honestly about emotional, physical, or any struggles.*

*When I was first diagnosed I thought, 'Cancer at 23 is just a (big) bump in the road, but once I get through the year things will be right back on track.' I have slowly been learning that isn't the case. Cancer is a total redirection. Your life takes a different road all together. My old road was so clear, and I knew where I was headed. But this new road that is slowly unfolding in front of me is very curvy, and I can't see around the next bend. I will soon be moving from cancer patient to cancer survivor. I'm not sure how I will make this transition, but I know that my amazing YACC family will help me though. I am honoured to be a part of this organization and am blessed to have attended the conference.*



## LOCALIFE

Take part in fun activities and connect with other young adult cancer survivors in your own community!

Localife is a peer-led activity-based initiative with groups currently in Edmonton, Calgary, Toronto, and Ottawa. Here's a sampling of some of the things they've been doing!

### **EDMONTON: MOVIE NIGHTS AND PUB HANGS**

With the arrival of spring, Edmonton Localifers took advantage of the warmer weather on May 4 for another awesome event! We indulged in some great conversation, good food, and even better company on a lovely patio off Whyte Avenue prior to taking in some culture and finest popcorn in the city at the historic Garneau theatre.

'While some people were only able to come for appetizers, and some were only able to come for the movie, an enjoyable time was had by all. So much so, that after the movie, great conversation flowed into the lobby of the theatre, so we decided to make our two-part eventing a three-part evening, and those who could stay joined us for some amazing chai tea at a cafe across the street.

'We were stoked with the success of this event and the opportunity to meet some new faces in the Edmonton area.'

### **CALGARY: COMEDY NIGHT**

‘Colin had the great idea to spend an evening at the Loose Moose for our event this month. We were able to enjoy a fun night of improv comedy with 27 people—our largest turnout yet!

‘It was so awesome to get to meet some new people, as well as see some familiar faces. A couple of folks still wanted to hang out and chat after the show so we decided to head to the Hose and Hound pub, though we had some trouble finding our way there. There was a lot of laughter—and confusion—involved, but we were finally able to find our way.

‘Thanks to everyone who attended; it was a killer time!’

### **TORONTO: ICE SKATING**

‘A day after a winter snowstorm hit the city, we woke up to a beautiful sunny morning. It was a perfect day for skating.

‘After a few rounds to test out the ice, we ditched our layers and/or winter jackets. It was like a beach day in the winter with freshly made ice! While some of us hit the ice, the others remained at the Harbourfront Centre Lakeside EATS for food and beverages over some cancer chats. Some shared stories of where they are now, and others shared stories of what they had been through.

‘Despite the venue anticipating it to be a busy weekend, it was not as crowded as it could be, and we sat there chilling enjoying each other’s company until 4 p.m.’

### **OTTAWA: GETTING THE MAPLE SYRUP EXPERIENCE AT BEAN TOWN RANCH**

‘Bean Town Ranch is one of several local sugar bushes around Ottawa. Localifers were treated to an all-you-can-eat pancake breakfast, a horse-drawn wagon ride around the sugar bush, and delicious maple taffy on snow. For some, it was to be their first sugar bush experience.

‘Full with delicious food we sat around the table and chatted for a bit before heading back outside for the horse-drawn wagon ride around the sugar bush grounds. The weather had warmed up considerably by now and it was a perfect day. We all piled onto the wagon and enjoyed the scenery as slowly we made our way through the trees and trails.

‘That led us to a barn where we all hopped off. In the back was a scruffy man who was preparing the maple taffy. He poured out the lines of sweet goodness on the snow and one by one we started to roll it up onto our popsicle sticks and taste the sweet, sweet sugar.’



## ONLINE COMMUNITY

We know not everyone is able or interested in attending a support program in person, and our vast geographical area means the internet is a valuable tool for building a community. If you want to dive into the YACC community, or simply check it out at a distance, our online community is a great way to get introduced.

- **Survivor Profiles** The YACC web community started in 2004 when young adult cancer survivors and supporters submitted Q&A-style recaps of their cancer experiences. Since then, approximately 200 people have shared their stories on our website, and the community profiles section continues to be the most popular section of [youngadulthoodcancer.ca](http://youngadulthoodcancer.ca). Please email [connect@youngadulthoodcancer.ca](mailto:connect@youngadulthoodcancer.ca) if you are interested in learning more about submitting your own profile.
- **Social Media** Stay up to date with what's happening at YACC through Twitter (@yacancercanada) and Facebook ([facebook.com/youngadulthoodcancercanada](https://facebook.com/youngadulthoodcancercanada)). We also have closed and secret groups on Facebook where survivors and supporters can connect with the community in general, or just with alumni from events they attend, or who find themselves in similar situations. Email [connect@youngadulthoodcancer.ca](mailto:connect@youngadulthoodcancer.ca) for more information.
- **Up To Here** is our monthly e-newsletter. You can register on our website. Up To Here gives you an update of the latest news and some information on our activities and programs.
- **Goaltender** is a program designed to help facilitate survivorship. It is useful for keeping track of medical appointments, sharing resources, setting goals, and connecting with peers. Visit [cancergoaltender.ca](http://cancergoaltender.ca) to register.



# SURVIVOR PROFILES

## COLIN ANDERSON

Colin Anderson had just returned from his honeymoon when his wife showed him a positive pregnancy test. Later that day, he was diagnosed with a brain tumour. After submitting his profile in June 2011, he has become an integral part of the YACC community, and has attended Retreat Yourself events, multiple Survivor Conferences, and is a Localife leader in Calgary. Read on to learn more about him.

**WHAT SCHOOL DID YOU ATTEND?** BCIT Aerospace Campus (Richmond BC)

**DO YOU WORK?** As an Aircraft Maintenance Engineer

**WHAT ARE YOUR CAREER GOALS?** My short-term goal is just to get back to work, after that I guess we will see.

**HOW DID YOU FIND OUT YOU WERE SICK? WHAT LED TO THE DIAGNOSIS?**

Within two weeks of returning from our honeymoon to Peru in May 2010, I started experiencing strange problems including extreme thirst, excessive urination, weird headaches, loss of appetite, and low energy, to name a few. Four or five trips to the family doctor had them stumped, the thirst had them thinking diabetes, but I tested negative every time. I was referred to an infectious disease specialist thinking that I picked up some weird bug in Peru. He did another battery of tests, including a CT scan of my head. The CT scan revealed a 3.8 cm tumour in the pineal region of my brain. Further tests revealed secondary tumours in the pituitary area and lower spine. I was admitted to the Foothills Hospital in the neurology ward, where I had a biopsy done on the tumours in the lower spine. The biopsy revealed the germinoma diagnosis. The process took over three months from the onset of symptoms and I was diagnosed in September.

**WHAT IS YOUR DIAGNOSIS?** Germinoma, with the primary tumour in the pineal gland region of my brain, secondary tumours in the pituitary gland and lower spine.

**IN WHICH HOSPITALS ARE/WERE YOU TREATED?** Foothills Hospital, Rockyview Hospital, and Tom Baker Cancer Center.

**WHAT WERE YOUR FIRST THOUGHTS WHEN DIAGNOSED?** I felt relieved because we had been searching for answers for three months, and this meant we could move forward with treatment. I was also scared for my life.

**HOW DID YOUR FAMILY REACT?** It was pretty hard on everyone; I had only been married for four months and it was quite the shock. My dad had also had cancer surgery recently and the family wasn't really recovered from that yet. My parents both flew out from Vancouver to be with me during my biopsy and diagnosis stage. It was really hard on my younger brother too; he had to be so strong throughout my dad's cancer, and me getting sick too was the last thing he expected.

**HOW DID YOUR FRIENDS REACT?** Everyone was shocked, of course. If I was treated any differently, I have not really noticed. I realize that it's not always easy for people to relate. My co-workers have been amazingly supportive, they even took up a collection to help us out financially.



Colin Anderson, 32, Calgary, AB

## SURVIVOR PROFILES CONTINUED

**WHAT DID YOUR TREATMENT CONSIST OF?** Medical side: A biopsy done through my spine to confirm the germinoma diagnosis, which took over four hours and was quite painful to recover from; three rounds of chemotherapy (cisplatin/etoposide); a five-day stay in hospital with a fever caused by low blood counts; and six weeks of radiation (five days a week) to my entire brain and spinal column. I am taking hormone replacements for some pituitary malfunctions, and those are expected to be permanent.

Non-medical side: I have had a really hard time with the physical side effects—the vomiting, the fatigue, the pain, the pills, having no appetite. All of these combined have taken their toll on my emotions as well as my body. Some of the hardest parts have been being unable to help out around the house with the smallest things; I feel so useless sometimes. I still have times that I cry for the smallest reason.

**WHAT IS YOUR CURRENT MEDICAL STATUS?** Treatment is over for now; I am waiting for my follow-up MRI which will hopefully show cancer free! I am still experiencing severe radiation-induced fatigue and my appetite is still a disaster.

**HOW IS LIFE DIFFERENT FOR YOU NOW POST-DIAGNOSIS?** Life is different in a lot of ways. Physically, I have had a really hard time not being able to help out with housework, yard work, etc. I have been an emotional wreck for most of the last six months, and going out in public is tough too. I have been away from the real world for so long I find it hard to take sometimes.

**WHAT WAS THE TOUGHEST PART OF YOUR CHALLENGE?** I was unprepared for the emotional roller coaster of the whole thing. The smallest things can send my mood into huge ups and downs the likes of which I have never experienced before.

**WHAT WAS THE BEST PART OF YOUR CHALLENGE?** I would say the new perspective I have on life; I literally take time to enjoy every small thing, like when food actually tastes good, or when the snow stops. (If the snow stops.)

**WHAT REALLY MOTIVATED YOU TO KEEP GOING WHILE YOU WERE SICK?** My wife had her first positive pregnancy test the day I was diagnosed, so we have had that to look forward to the entire time I was in treatment. Truly a miracle baby!

**WHAT LESSONS OR MESSAGES HAVE YOU TAKEN AWAY FROM YOUR EXPERIENCE?** I have learned to call or visit the doctor with health concerns, and to stay away from the Internet for diagnoses, and not spend too much time speculating about medical stuff. That is what doctors are for, and my team has my complete confidence.

**WHAT ARE YOUR THOUGHTS AND FEELINGS ABOUT YOUR ILLNESS NOW? HOW HAVE THEY CHANGED SINCE BEFORE YOUR DIAGNOSIS?** Cancer isn't picky, and it will affect all of us in some way or another. I used to think that my decent diet and lifestyle gave me a good chance to not get cancer, but now I know otherwise. I have a hard time reading some of the articles in lifestyle magazines talking about cancer prevention; I guess I am a little bitter because for some of us, it's just bad luck.

**WHAT ARE SOME (IF THERE ARE ANY YOU KNOW OF) PREVENTATIVE MEASURES THAT PEOPLE CAN TAKE TO LOWER THEIR RISK OF HAVING AN EXPERIENCE LIKE YOURS?** Absolutely none, and that is one of the scary things about it.

**HOW ARE YOU CONNECTED WITH YOUNG ADULT CANCER CANADA?** I have been to a couple of Localife events here in Calgary, and I am going to Retreat Yourself West. The group was recommended by my brain tumour counselor.

## SURVIVOR PROFILES CONTINUED

### ROBIN HARRY

**WHAT WAS/IS YOUR DIAGNOSIS?** Non-Hodgkin's Lymphoma (diffuse large B-cell, primary mediastinal), Stage II.

**WHAT SCHOOL DID YOU ATTEND?** University of Toronto (2005 graduating class)

**WHAT IS YOUR CAREER GOAL?** I have a great job right now, but I would like to go back to school to be a physician's assistant.

**WHAT IS YOUR OCCUPATION?** Psychometrist & Research Assistant (Behavioural Neurology)

**HOW DID YOU FIND OUT YOU WERE SICK? WHAT LED TO YOUR DIAGNOSIS?**

In May 2011, I had some chest pain that I thought was just inflammation from an injury I had from the gym. It was the day of my choir's big concert and I had to sing, so I thought it was that with some anxiety. I popped some Advil and went on with the show. A week later, I was at rehearsal on a Friday night, and the pain started again. But this time it was severe; it radiated from my chest all the way up my neck to my chin and over to my right shoulder. I couldn't sing—I could barely breathe without being in pain. I didn't go to the emergency room and still kept taking Advil (I'm that stubborn), but the pain stayed all weekend.

That Monday I went to see my doctor. He ordered an ECG and X-ray stat, and from the ECG I was diagnosed immediately with acute pericarditis. I was sent home with Advil to rest, and the pain subsided. I saw my doc a week later and he said I was fine, but God bless him, something made him look at my X-ray again that night. He called me back the next day and told me there was a mass in my chest, and he laid out the possibilities. A CT scan, bone marrow biopsy, and mediastinoscopy under general anesthetic followed in the next month, and I was formally diagnosed with Diffuse Large B-cell Lymphoma at the end of June.

**WHAT YEAR WAS IT? WHAT WAS YOUR AGE AT THE TIME?** 2011. I was 28 when the symptoms and tests started, and was officially diagnosed a few days after I turned 29.

**IN WHICH HOSPITAL ARE YOU BEING TREATED?** I'm being treated in Toronto at Sunnybrook Health Sciences Centre.

**AT WHAT LEVEL OF EDUCATION WERE YOU AT DIAGNOSIS?** I've completed my Honours Bachelor of Science.



Robin Harry, 29, Toronto, ON

## SURVIVOR PROFILES CONTINUED

**WHAT WERE YOUR FIRST THOUGHTS WHEN DIAGNOSED?** My first thought was, ‘How on earth am I going to tell people this?’ I was most nervous about how my friends and family would react when I gave them the news. I hate being the reason people are upset. I was quite calm and not really worried about myself; my medical oncologist was honest and told me the truth about my kind of cancer, but he also laid out the plan, so I felt alright with that.

**HOW DID YOUR FAMILY REACT?** My immediate family took it hard, especially my younger brother with whom I’m closest. They were all upset about it and a bit scared, but with varying degrees of transparency; there were tears, there was anger, there was silence, there were jokes. But I think my remaining positive has kept them reassured and calm after the initial shock.

**HOW DID YOUR FRIENDS REACT? WERE YOU TREATED DIFFERENTLY, OR DID THINGS REMAIN THE SAME?** They were all shocked by the news. My closest friends have been nothing but supportive and sensitive, while still treating me as the same person. I’m so blessed to have them, I’m sure it’s not easy for them. My coworkers have been amazing and have really been looking out for me; they have given me a stuffed Angry Bird for each chemo—I love it! Lots of the others still don’t quite know what to say or how to approach me and get all awkward, but I understand. But a very special few are pretty much MIA. Oh well.

**WHAT DID YOUR TREATMENT CONSIST OF?** My treatment first consists of six R-CHOP chemotherapy sessions, once every three weeks, as an outpatient. The sessions are six to seven hours long. After that, I’ll have 18 days of radiation. Then, we’ll see. I haven’t had any nausea or vomiting. I have fatigue, and my hair fell out in clumps so I’m sporting the bald look these days. My sense of taste is completely warped (it’s worst the week after chemo), and I have hot flashes and night sweats due to the fertility treatment. My temperature regulation is also way off, and I’m constantly dehydrated. I’ve started to feel tingling and numbness in my fingers and toes.

**WHAT IS YOUR CURRENT MEDICAL STATUS?** I’m in treatment, just about halfway through chemo.

**HOW IS LIFE DIFFERENT FOR YOU NOW POST-DIAGNOSIS?** Physically, I get tired much more easily, and always want to eat, though food tastes disgusting. The fatigue takes its toll on whatever social life I had. I’m not able to do as much as I used to. Not to mention I have to avoid crowds because of neutropenia. Emotionally I’m still quite well and I’ve managed to stay positive and upbeat, though I have moments where I think ‘This sucks!’ My faith and trust in God has never wavered, and it gives me peace.

**WHAT IS THE TOUGHEST PART OF YOUR CHALLENGE?** Hmm...it’s hard to pick just one tough part. It’s difficult being limited and restricted. I’ve always been very self-sufficient, so it’s hard not being able to do things I want to do, like go to work after chemo, or hang out with my friends at late hours, or go anywhere with a crowd, avoiding crowded public transit. On a social level, I’m usually in good spirits and I have been handling this well, so the family members who are constantly crying and the trite encouragement from others don’t make sense to me. Trying to reassure others all the time is tiring.

## SURVIVOR PROFILES CONTINUED

**WHAT WAS THE BEST LESSON YOU TOOK AWAY FROM YOUR CHALLENGE?** Facing something like cancer really shows you what stuff relationships are made of, and what they should be made of. I think I've learned a lot about myself and the people that surround me. Oh—that and bald headedness actually works for me (who knew?)!

**WHAT REALLY MOTIVATES YOU TO KEEP GOING?** I just keep thinking that I'm not done with life. There are so many things I want to do, so many places to see. I just tell myself that God's not quite done with me! I'm determined to be a survival story; surely I can encourage someone.

**WHAT ARE YOUR THOUGHTS AND FEELINGS ABOUT YOUR ILLNESS NOW? HOW HAVE THEY CHANGED SINCE BEFORE YOUR DIAGNOSIS?** I think working at a hospital has given me a sense of realism about cancer, both before and after. I haven't really been scared of it. I know what the odds are, and I'm doing what needs to be done to try to beat the odds.

**WHAT ARE SOME (IF THERE ARE ANY YOU KNOW OF) PREVENTATIVE MEASURES THAT PEOPLE CAN TAKE TO LOWER THEIR RISK OF HAVING AN EXPERIENCE LIKE YOURS?** Oh my goodness, stop smoking and going to tanning salons! Cancer is not easy road, folks! It really pains me to see people putting themselves at risk for cancer when so many people are struggling to live through it.

**DID YOU ATTEND ANY SUPPORT GROUPS DURING YOUR CHALLENGE?** Nope.

**IF YOU DID NOT ATTEND A SUPPORT GROUP, WHY?** I haven't felt the need for one yet, and when I do need to talk or vent, my friends are my support group. They've been fantastic. I have also been keeping a blog that I find very cathartic ([lymphomalowdown.blogspot.com](http://lymphomalowdown.blogspot.com)). However, I did attend a Look Good Feel Better seminar, and it was really great being around other people who understand the experience. It's so much more relaxed when another cancer patient asks you, 'So, what kind of cancer do you have?' It's almost a feeling of camaraderie!

**HOW ARE YOU CONNECTED WITH YOUNG ADULT CANCER CANADA?** I was just looking online to find people who had experiences similar to mine. There weren't many people at my treatment site that looked my age, and the one young adult that I knew with cancer passed away years ago. I happened upon this site by chance!

THANK YOU



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