Thoughts and Comments from Patients – 2015

Five to Fifteen years (2000-2010)


- I’m thriving as a junior in college. I have few problems except for trouble processing and focusing, which are well attended due to proper medication. There is a time when you can forget about cancer on a daily basis. I even have to remind myself I had it sometimes. Autologous transplant 2000 – now 20 years old.

- This has been a hard year. My oncologist who diagnosed me in 2002 retired. He was my friend as well as a trusted health professional. I feel abandoned kind of. Isn’t that silly! My bones and joints are painful all the time and I just don’t feel good. After shoulder, knee, hip replacement & hip revision, 3 sinus surgeries, I’m tired. Allogeneic transplant 2003 – now 58 years old.

- The main struggle I am experiencing is memory difficulties, particularly when trying to find “that word” during conversations. I just can’t count on being able to find the word which makes me less likely to want to engage in conversation. Allogeneic transplant 2003 – now 54 years old.

- Life is OK. Miss the old me but that life – been 11 yrs. and the cancer is what I call, “sleeping.” But the damage is ongoing. I go to the gym 5 days a week. Did the Mud Run last Oct. and will be going to the Warriors Dash in July. Tired of people telling me what I can’t do. I found doing spin class 4 days a week is great stress release. Still fight depression and sometimes wonder why I get out of bed. Have a new puppy, so there’s one reason. One day at a time. P.S. Started getting tattoos. Awesome! Autologous transplant 2004 – now 62 years old.

- I am currently 11 years out. In some ways I feel grateful to still be here. On the other hand I never imagined my life to be that way it is. I see friends, who are also transplant patients, so much worse than myself. I also know a few friends that are on the complete opposite end of the spectrum-back to work, living ‘normal’ lives. Allogeneic transplant 2004 – now 41 years old.

- Thank you to all others who fill out the questionnaire + share their stories + experiences post-transplant. At 10 yrs. Post-transplant, I finally feel pre-leukemia self. Amazed to still be here and deeply grateful for each and every day. Allogeneic transplant 2005 – now 47 years old.

- 10-year post-transplant celebration so far has looked very different from 5-year post-transplant. At 5 years, it was like I had finished my first ultra-marathon. At 10 years, it was very anti-climactic. In fact I don’t even remember what I did on my transplant birthday, and it was only 6 weeks ago. I know I didn’t have 3 parties in 3 towns like I did at 5. I still have “crash days.” Those are the days that fatigue catches up to me and kind of sabotages my plans for the day. I’ve learned to accept those days and I don’t get so down about them like I used to. I’ve also learned to recognize when I have overdone things, or am overdoing things, to minimize the frequency of the “crash days” or know why I am having one. Allogeneic transplant 2005 – now 40 years old.
• Reading the comments from last year, it’s interesting how wide the variations are in people’s both physical experience and emotional experience with GVHD. While it’s apparent those are common occurrences across the population, each individual’s experience is individual to them; and it appears there is no good way to predict what any individual will experience. Allogeneic transplant 2009 – now 68 years old.

• As you know, I’ll be sixty nine in September and a few days ago someone thought I was ~fifty. Ya’ can’t beat that. I just had my 6th birthday! Autologous transplant 2009 – now 68 years old.

• After my transplant, I was told I had a 70% chance of my disease recurring in the 1st year. I beat the odds & am now just days short of my 5 year anniversary! My physical & emotional health is good. Unlike many of my friends who have never been personally affected with cancer, I celebrate each coming birthday fully & have a stronger appreciation for each year. I am loving life! I especially love that I have the opportunity to watch my children grow. My girls are now all teenagers, growing into young women. I can see how the challenges we faced 5 years ago has impacted the strength & compassion they possess. Autologous transplant 2010 – now 43 years old.

Moving On

• I was wondering how my peers handle the inevitable anxiety/depression/search for meaning after transplant and transitioning to a new “normal.” However, I wish the emotional piece was a bit more of a systemic part of the transition away from SCCA’s 6th floor ...I would also love resources/connections on how I can volunteer and give back to others and share my experiences and skills with SCCA patients and families. I would also love to collaborate with LTFU on developing helpful transitional resources to patients and families that are not in place yet. Autologous transplant 2015 – now 46 years old.

• The first three years after treatment were difficult. There were fatigue and pain issues, seemingly random other health issues as well as the inability to take part in the physical activities that I have always enjoyed. At least three years post-treatment the pain, fatigue, and health issues pretty much went away. I now feel healthy and ‘normal’ again and am once again enjoying running, hiking, swimming, etc. Thanks. Autologous transplant 2010 – now 66 years old.

• I just celebrated my 36 yr. post-transplant. This past November I had a recurrence of Breast Cancer after going thru a bilateral mastectomy 4 years earlier along with chemotherapy. I finished up my treatment a couple of months ago. My point of writing this is to let people know to not give up even though we have these setbacks. I’m back to feeling good now, my energy level is good (I’m 67 years old so I’ve slowed down a little) but I’m trying to have a positive attitude and looking forward to the future. I’m going to keep on fighting till I can’t anymore. Allogeneic transplant 1979 – now 67 years old.

• Thank you for giving me a second chance. I have a 4 year old daughter and I feel like I am finally the mom I was always meant to be. I was so scared pre-transplant, but I would never take a second back. I have grown so much. MS tried to ruin me…it didn’t happen. I feel blessed and beyond. Autologous transplant 2014 – now 29 years old.

• Life is normal for our son & our family. We love it! Thank you! (He started 3rd grade yesterday) Allogeneic transplant 2011 – now 8 years old.
Commitment to better health

- I am doing well after nearly 4 ½ years post-transplant. I work hard at improving my health and am disciplined about my diet (virtually vegan) and exercise. I don’t focus on what is normal for my age but want to be better today than I was yesterday. I have a full life with work and kids starting out on their own. Many challenges, struggles, hassles and frustrations – but I’ll take them all. I feel good and expect to be doing better when I fill this out next year. Autologous transplant 2010 – now 55 years old.

- I’m overweight, but since I started testing my blood sugar & watching my carbs, I lost 45 lbs. and I’m in better health and have better energy. I’m still disability retired from the perm bone damage from the multiple myeloma. It’s great to be in remission for 10 years, thanks to my transplant and I’m still taking the thalidomide. Thanks. Autologous transplant 2004 – now 59 years old.

- The multiple myeloma actually prompted positive changes in my life. I’m no longer a martyr. I don’t enter into relationships that are co-dependent. I left my husband who always took me for granted, and a wilderness lifestyle that would have made treatment difficult and would have made a healthy lifestyle less likely. I moved from a homestead off the road system in Alaska to spend time with my daughter in Texas. Autologous transplant 2011 – now 71 years old.

- I have become a devotee of yoga, and I am convinced that my practice has given me my life back. Yoga has helped to heal my body, but more so my mind. From being a very active young woman, I was bedridden for two years. I had a hard time walking. I fell often. I hurt everywhere, and I couldn’t do much because I had to urinate constantly (and it hurt like a mother!). I was depressed and dispirited. Not to say that everything is perfect now, I still have my issues. But I am definitely living a more full and happy life. Physically, I am really really good. I look better and feel better than I ever have. I can run, jump, dance, and play. It’s a treat! Allogeneic transplant 2007 – now 38 years old.

- Recovery is a long process. There are days where I feel great and others where I am exhausted. The transition back to work is taking longer than I hoped, but my health is more important so I will keep it slow. Allogeneic transplant 2014 – now 42 years old.

- With the new hip, I have decided to celebrate my 20th anniversary by walking another ½ marathon through the TNT program for the LLS. And, I have set my goal high $10,245. If I make my goal, I will shave all my hair off! I was bald once, why not do it again for such a good cause!! Allogeneic transplant 1995 – now 52 years old.

- I’m doing great, but chemo and radiation have caused me problems, so now I’m just a lot of spare parts: cataracts, hips, immune system, and a kidney, but last Saturday for Relay for Life, I walked 285 minutes covered 11.7 miles and took 27,600 steps. Allogeneic transplant 1989 – now 63 years old.

- I had my stem cell transplant for refractory anemia in 2003 at the age of 65. I had very little immune system and was taking blood transfusions every 3 weeks. I am now walking 8 miles each day, seven days each week. The only medication that I am on is BP meds. I have had 12 good years. Life is good thanks to the doctors, nurses, and staff at the SCCA. Allogeneic transplant 2003 – now 77 years old.
• I am concerned and working on making my legs work better. I want to be able to walk the golf course. Allogeneic transplant 2014 – now 75 years old.

Fear of future health problems

• I am so thankful to be in remission but I still get serious worries about a reoccurrence of myeloma. I have chronic pain in my back from deteriorating discs, frustrating neuropathy in my feet which tires my walking – I have some memory problems. Not as sharp as I used to be – “chemobrain”. I suffer from depression & overtired. Can’t do what I used to – yard work, etc. I don’t mean to complain because I have had 4 more years with my grandchildren & family – feel very fortunate. Autologous transplant 2010 – now 69 years old.

• I’m constantly on the lookout for my next illness: I’m so worried my AML treatment is going to cause a secondary cancer that I worry over every ache, pain, bump, etc., but I don’t want to worry my family so I end up sneaking around to see the doctor, or if I have a pain or symptom I end up ‘sucking it up’ so I don’t worry them. It’s a bit overwhelming and stressful! Autologous transplant 1994 – now 38 years old.

• As I age, I worry more and more about all the collateral damage I may have suffered due to the gallons of chemo and scads of radiation. I feel fine, and I am planning for a long and delightful retirement, but I worry… Autologous transplant 1999 – now 58 years old.

• As I age, I wonder if, and if so, when, the consequences of the cure (radiation, chemo) will catch up with me. Filling out this survey always freaks me out a bit as it brings it all back into the forefront of consciousness. My general reaction is to live fully, have fun, and do good deeds. I figure I will hang around longer if I am feeling good about myself and having fun. Allogeneic transplant 1989 – now 64 years old.

Post-traumatic growth

• I am grateful for FHCRC and the life-saving treatment I received. I am 9 years post-transplant though they have been very challenging years. They have been good years full of growth that I doubt would have happened but for AML and transplant. I am a better person in 2014 than I was in 2005. Allogeneic transplant 2005 – now 60 years old.

• Even if I had known up front that I would have to live with the side effects of the BMT that I have experienced I would have still done it. I really do miss the ability to work at my home life and recreational projects as I did before the AML and BMT. I have learned to better understand myself and how to work at these issues smarter and not so reactionary. FHCRC was first class and the experiences I had there and since the BMT have made me more convinced that I can accomplish a lot more in life. Allogeneic transplant 2005 – now 65 years old.

• Thank you for my life. It has been 25 years! Every day I wake up thankful for another day. After the transplant, I completed high school, graduated college, medical school, emergency medicine residency, fellowship and working as an emergency medicine physician. I have a beautiful healthy 6 year old. During college I relapsed and went on alpha interferon which gave me another 4 years before relapsing in medical school and going on gleevec. Since that time I have been cancer free for
13 years. CML has made me thankful and grateful for every day of my life and time with my daughter. CML has made me a better person, father, husband, friend and physician. Allogeneic transplant 1990 – now 42 years old.

Fatigue and Depression

- My depression in the last 2 years has been fueled by the death of 3 friends due to cancer and 1 dear friend whose daughter (age 36) is battling pancreatic cancer. Cancer is a demon and I hate it. Allogeneic transplant 2006 – now 55 years old.

- I’m alone, I’m older feeling than I should, I have little desire to do anything or interact with people, my teeth are a wretched mess and I earn so little I can’t swing dentures. There’s no love in my life and damn few friends and to top it off I’m wracked with pain. So…Yay? Autologous transplant 2003 – now 56 years old.

- I am extremely tired all the time. My husband (who BTW is an athlete) says it is because I am not active enough. (How can I be “active enough” when I am so tired all the time?) I also have sleep issues (CPAP, sleeplessness, etc.) + wonder if that has anything to do with my fatigue. It is a point of contention between me & my husband & it has affected the quality of my life. I would sure appreciate your help with this issue. By the way, my husband does numerous marathons, century bike rides & iron man triathlons. How am I supposed to keep up with that!? It is affecting my marriage since my husband thinks I look perfectly capable, it makes me feel so bad! Syngeneic transplant 1978 – now 52 years old.

- Are there any specific drugs/supplements that are especially beneficial to help with fatigue or other symptoms? Allogeneic transplant 2009 – now 69 years old.

- My transplant cured my myelofibrosis, but has left me with our significant side effects, such as chronic fatigue, adrenal insufficiency, and spine issues. The fatigue is often overwhelming, yet I find little sympathy or solution from doctors, who only urge me to exercise, exercise, exercise, which proves virtually impossible. This causes major frustration!!! I wish you could live in my skin for a week... Allogeneic transplant – now 65 years old.

- I’m so fatigued, I feel like I’m wasting my life by sleeping and napping all the time... and by all the time I mean when I’m not working 40 hours/week + 10 hours commuting. I have no time to do what I want to do, what I need to do, or hang out with my kids. Very sad and a huge cause of guilt and stress. Autologous transplant 2009 – now 35 years old.

- One thing I am having a hard time with is the limited resources on just how hard to push to improve physically. I am a physical therapist and even I am having difficulty knowing how hard to push – how high is okay for my HR to get? The fatigue is a constant challenge and figuring out how much I can do for exercise and still function the rest of the day without a long long rest break changes weekly. I am sure this is different for everyone, but so much of our physical well-being depends on the ability to move, building strength and endurance is so important, I just want to be back to moving easily (like not feeling 80 getting out of bed) and hiking and running. Autologous transplant 2015 – now 32 years old.
I worry that I’m pushing myself too hard by continuing to work full time. I’m exhausted M-F and push myself to be social on the weekends. At 62 am I over doing it? Autologous transplant 1996 – now 62 years old.

Need 9-10 hours of sleep or can’t function. Autologous transplant 1991 – now 66 years old.

I have lost a job and fallen out of a graduate program because of the effects of the treatment. It’s very depressing to be considered a failure because of conditions that I cannot control. I wish there was a way to get coping mechanisms to affect these weaknesses. Allogeneic transplant 2000 – now 25 years old.

Unfortunately, I can’t sleep at night. That fact then leads to fatigue and depression. Vicious circle. I am now unable to work because of severe fatigue. Now applying for disability. Allogeneic transplant 2005 – now 52 years old.

Prednisone side effects

I wish I had known about the importance of exercise. While on prednisone I was very obese, and did no exercise. Allogeneic transplant 2011 – now 62 years old.

My bad history with prednisone drove me to attempt to get through the GVHD once it started without taking that horrible stuff again. Big mistake. My mouth dried completely up. My heart, liver, lungs, lungs and skin were all involved. The rash all over my body caused a widespread loss of pigment and my hair for good. I lost all my molars and my gums started to rot. But the worst was the impact on my gut which caused wasting and more pain than I could handle. I had to take Prednisone again to survive, so I took it by the ton for a year. At first it made the gut pain so incredibly worse but I kept it up anyway. Then, miraculously. Over the next couple of years my gut and almost everything else resolved including Osteonecrosis of the hips. I still have the bad hearing and vision, albino look, lack of teeth, some mouth GVHD, osteoporosis, and maybe a little brain fog. But the gut pain is mostly gone, I have regained to normal weight and energy, and life is good. My ten year anniversary just passed without me even remembering it on that day. During those ten years a lot has happened. I got to watch my kids grow up and be part of their lives and I love my wife more than ever. There is a lot of good life ahead that I wouldn’t be around to enjoy without the BMT and wonderful care I received at the SCCA and Fred Hutch. Put me down in the “feel good, grateful to be alive, and many things to be thankful for” categories in the questionnaire responses. You do awesome work that has saved my life and many others. Thank you. Allogeneic transplant 2004 – now 62 years old.

Prednisone is eating my body – reassess whether the cure is worse than the disease. Weight loss/muscle loss. Allogeneic transplant 2007 – now 68 years old.

My main reason for filling this out is in hopes it can help with other patients in the future. Too much prednisone for too long has ruined my life – caused AVN and after both hips & one knee replaced I walk (not well) with a cane. Allogeneic transplant 2010 – now 64 years old.

Have a ton of problems because of Pred. I would be pretty good otherwise. The Pred. gave me diabetes. Made my leg muscles too weak to stand up. Made red discolorations all over my forearms, because the skin is thin. Also gives me depression. Allogeneic transplant 2014 – now 58 years old.
Need better information

- I would advise finding a way to convey information about the transplant incoming workup & schedule more prior to arrival to initial conference. Those first 2 weeks were extremely overwhelming & I had a mental breakdown for the first time since my initial diagnosis. Also I feel prior to transplant (at the time it is first discussed by referring physician) it should be explained how long of an overall process this is (treatment & recovery). I was told transplant would be 3 months in Seattle but was unaware of the 1-2 year recovery process until my initial conference. I thought I would be 100% once released from Seattle. Autologous transplant 2014 – now 41 years old.

- Wish I had been better informed in advance of increased likelihood of chronic GVHD problems in a female to male unrelated donor transplant. Allogeneic transplant 2013 – now 69 years old.

- I never see comments regarding folks that have had 2 transplants. I have had 2 allogeneic transplants in 1997 and 2007. It would be very interesting to know how these people are doing in every aspect – I am interested in the future effects of 2 rounds of myeloablative chemotherapy. Allogeneic transplant 2007 – now 63 years old.

- I don’t mind filling out this questionnaire, but it leaves me feeling lonely. After I’ve gone to the trouble to take stock of so many of my health concerns & over all condition, it is terribly unsatisfying to not have any feedback on them. It would be nice if I got at least a recommendation of a website or support group for my problems. Allogeneic transplant 1998 – now 59 years old.

- I feel that I was not fully aware of the commitment that having a bone marrow/stem cell transplant would entail. Following chemotherapy I felt better than I had for years and would have been happy to live with the risk of coming out of remission for a better quality of life based in what I know now. Quality of life needs to be more of a factor in the decision process especially in cases where survival rates approach above certain levels and good donor matches become a factor. Please take this as an analysis not a criticism, again I have greatest respect for the Hutch and would be my first recommendation to any in need of treatment. Allogeneic transplant 2011 – now 66 years old.

- I would like a better understanding of when I can stop taking some of these meds. I feel like I wasn’t told all of the long term effects on my health. I don’t know whether I would have had the transplant if I had known. Allogeneic transplant 2015 – now 52 years old.

- Knowing what I know now, no one would elect to be treated, nor should they. I have never known pain, misery, loss or hopelessness such as this and I was in the Marines twice. I’ve been to war – a picnic compared to your ‘treatment.’ But I will say you all are incredibly professional and well intentional and for that I am grateful. The road to hell is apparently paved with such intentions. Autologous transplant 2010 – now 42 years old.

- I was not aware of this BMT cardiac risk effect. I think that the Hutch needs to be much more proactive in communicating post BMT medical risk factors – especially when they are life threatening. Stepped up cardiac monitoring for post BMT patients can fairly easily monitor and manage these risks. Allogeneic transplant 1996 – now 60 years old.
Chronic GVHD

- It has been difficult to deal with chronic GVHD. Many providers are not familiar and are not good at managing/identifying the symptoms. Also hard to relate to people my own age. Many are married and having children. I feel much older than my peers and have more health issues. Allogeneic transplant 2010 – now 34 years old.

- I have been completing this questionnaire for 9 years. In the beginning I was totally joyful to have survived AML. Then the GVHD set in, and for many years now, it has been an ongoing battle with this disease. It’s a “wearing down” disease. People, doctors, don’t seem to fully get it. Several times I presented options to my oncologist before she suggested them. My health issues are permanent, unlike the AML that went totally away. Keeping positive and motivated and finding joy in life is now the battle; and it is in many ways harder than the fight to be cured of AML. Allogeneic transplant 2006 – now 64 years old.

- When GVHD keeps a very active person at home & isolated. What are ways to deal with it? Contacting friends, family, phone calls, exercising, hobbies (knit, read, paint, cook)? Allogeneic transplant 2012 – now 66 years old.

- This is my son’s 9 year transplant anniversary. I am grateful every day for all the moments we have been given but it is hard to see him struggle with simple tasks like tying his shoes because the GVHD has attacked his skin/joints. All he wants to be is a “normal” 6th grader but even after all this time cancer still plays a role in making that not possible. I wish there were more support groups for parents and kids that have gone through this. Sometimes I feel like we are the only ones and it would be nice to talk to other moms who understand. Allogeneic transplant 2015 – now 11 years old.

- This was a challenging year which tested my patience for slow recoveries after 3 upper respiratory bouts. It took 1 ½ - 2 months each time to fully recover due to severe bronchiolitis obliterans. The good news is that I did regain my diminished but stable lung function. I sure hope a viable treatment for lung GVHD can be found someday soon. Allogeneic transplant 2005 – now 67 years old.

- I think when the doctors went over possible outcomes with a SCT, I was so focused on just staying alive that I missed the possibility of the side effects and how long they will stay with you. I had my SCT ten years ago. I still have a severe case of GVHD of the skin. The scleroderma keeps me in a wheelchair all the time. Allogeneic transplant 2005 – now 47 years old.

- How does answering this survey help me? Will someone review this and note possible glaring errors in my treatment? I understand that my answers to this survey may help compile statistics that may help the larger population but it would be good if it could also provide the basis for reaching a successful outcome with the GVHD situation I find myself in. Allogeneic transplant 2006 – now 72 years old.

- I have been astonished at how hesitant even providers seem to be to talk about what my team referred to as “girl parts.” Providers describing my GVHD to other providers would actually not mention that I have vaginal GVHD, and I have almost never been asking about it. For people who
are hesitant to talk about sexual functioning, this silence doesn’t help. Allogeneic transplant 2014 – now 61 years old.

Children

- My husband and I started a family finally in 2014 by way of adoption of two wonderful twin boys born in April and adoption finalized in August. It has been great but the adoption process was stressful and we ran into a lot of negativity surrounding my cancer history. I was turned down by more than one agency as soon as they heard I had a cancer history. Even though my doctor provided the “fitness to parent” statement required by WA State, we were still turned away. Luckily we found an agency willing to work with us who were concerned about current health not past medical history. Unfortunately prior to finding that agency we ran into a lot of discrimination based on medical history. Allogeneic transplant 2002 – now 35 years old.

- When someone gets cancer, they often ask, “Why me?” In my case, I do know why me. Had I not had leukemia and my newlywed wife and I not endured the terrible suffering of treatments and transplant, we would have gone on our merry way and built a family the old-fashioned way. As it is, with the many round of chemo and total body irradiation, we were ‘forced’ into the adoption world and at length received the blessing of two wonderful babies who needed a home. Were it not for the cancer, what might have become of OUR son and daughter? Allogeneic transplant 2002 – now 54 years old.

- On March 18th my wife and I celebrated the birth of our daughter. She is our first child and the light of our lives. My sperm count was low before the transplant and remains low today. We had a 12% chance using my frozen sperm and IVF, but my wife got pregnant on the first try. We are so happy to have our new bundle of joy. Allogeneic transplant 2009 – now 29 years old.

Thanks for asking about (or please ask about)

- Thank you for asking about sexuality issues. Allogeneic transplant 1997 – now 52 years old.

- Questions regarding separation and/or divorce because of disease or treatment. Allogeneic transplant 2014 – now 56 years old.

- You should be asking how the confusing billing system between SCCA, UW, and insurance companies affects the emotional well-being of patients and caregivers. The last thing we need is more confusion and billing conflicts after what we’ve been through. I understand this has nothing to do with this questionnaire, but it’s by far the most emotionally trying part of the process for me. Allogeneic transplant 2015 – now 47 years old.


- More questions on very long term survivors. In the last two years it seems my whole body & psych has fallen apart! Allogeneic transplant 1987 – now 60 years old.
Suggestions

- One thing I would like to add is the food selection. A lot of the food selection was too fancy for lack of a better word. After the chemo and radiation, most patients just want simple food to eat, for example spaghetti with just plain tomato sauce, cheese pizza, french fries, etc. None of that was available at the time of my in-patient stay...Perhaps a menu with blander and simpler options would be better suited for people post-transplant who have sensitive stomachs due to the chemo, radiation, and GVHD of the GI tract. Allogeneic transplant 2015 – now 40 years old.

- We are so grateful for our daughter’s (now 17) 5 year anniversary. However, we encourage SCCA/FHCRC to aim beyond the goal of “cancer free.” I’d like to see the incursion of nutritional education, complementary medicine and behavioral health support for whole families. When one person in the family has cancer, everyone is profoundly affected. Allogeneic transplant 2010 – now 17 years old.

- Though no one would wish to have multiple myeloma, it is now a part of me and who I am. One booklet provided by a program sponsor, Takeda Oncology Company, was very helpful. It is entitled “Understanding Multiple Myeloma Laboratory Tests.” I wish that I had had such a booklet available when I was first diagnosed – my questions may have been a little more specific and educated. Autologous transplant 2012 – now 67 years old.

- I would like to see it easier to get appts. from LTFU care. There are times my doctor asks me to call & even times when the nurse during my LTFU follow up clinics have asked me to call (given instructions) and request an appt. When I do call – I usually am told, “You just cannot call and make an appointment. It does not work like that!” I understand there is a potential for misuse if this is opened up and you are already so busy. Perhaps a new process or way to determine an appt. is necessary or if we have already seen our doctor? It can get scary + feeling all alone or like your cancer/request is not valid can be very concerning. Allogeneic transplant 2013 – now 55 years old.

- Because neuropathy makes a huge difference in walking, balance, possible pain, I feel it should be discussed more openly, that FH/SCCA should be making a greater effort to deal with this as it influences the quality of my daily life, especially as it flirts with my fingers too. Exercise should be also openly evaluated and if needed, working with a PT EARLY in treatment made mandatory. Autologous transplant 2012 – now 72 years old.

- When in the state of Washington, I take cannabis infused concentrate and use cannabis topical which helps immensely with the pain in my hands, shoulders, knees, and feet. Allogeneic transplant 1998 – now 70 years old.

- Just would appreciate having my med list pre-filled like name and address are each year. Allogeneic transplant 2009 – now 61 years old.

Thankful for the transplant

- This is my 25 year anniversary – allogeneic transplant for acute aplastic anemia. This whole situation still seems so surreal to me. I was (I thought) a healthy 42 year old father of six – the youngest 2 years old, the oldest 19. I went into the hospital for some bruising I developed during
our annual Thanksgiving football game – I was not overly concerned. Three days later I was told I had 3 months to live. None of the Chicago area hospitals would treat me – they bluntly told me that I would not survive the BMT process due to my age. My oncologist told me to contact FHCRC, and the rest is history. Thank you so much for these past 25 wonderful years. My 6 children are all adults now, and I have 10 beautiful grand children to enjoy in my retirement. Thank you FHCRC for not giving up on me! God bless all of you, and all the great hope and life you give to so many.

Allogeneic transplant 1990 – now 67 years old.

- Another year, another questionnaire. So happy and thankful to be able to do this. Life is good, just happy to be here. Just celebrated 29 years! Hope to be at the 2015 reunion. Allogeneic transplant 1985 – now 70 years old.

- I just celebrated 50 years with the most awesome man in the world and so thankful for the years after transplant. I appreciate this questionnaire every year and all the comments from other survivors. Some make me feel so blessed and others make me feel normal and still others I feel so sympathetic & genuine compassion for those that are dealing with so much. Allogeneic transplant 1992 – now 68 years old.

- I want to thank FHCRC for helping me, curing my ALL and saving my life. As a physician with a very full and productive career I feel I have not squandered the opportunity to live a full life of some value to others, especially my family. I especially want to thank the nurse who cared for me and showed me great compassion when I sorely needed it. I don’t remember much detail from those days, but I will never forget a cold night of fever and chills and misery, and being soothed by the angelic voice of a beautiful young red-haired nurse who held my hand and comforted me and helped me to find some rest through a long gloomy night. Thank you all! Allogeneic transplant 1995 – now 57 years old.

- I’ve been confronted with some difficult decisions during my adult life and they have contributed to whom I am today. Your questionnaire is timely, seems like I’m often struggling with some life confrontation when it arrives. Just writing to you to inform you of what’s going on with me helps clarify in my mind’s eye that indeed I will do what needs to be done, even with some grace! I will always remember with great appreciation what the Hutch did for me. Would be nice if I could remember names but that isn’t going to happen is the kindness and humor of so many wonderful people. I would think this continues today for all those passing through the doors of the Hutch. Autologous transplant 1997 – now 67 years old.

- My biggest regret is not ever having the chance to meet/thank my French donor. I really wish there was something I could do. Allogeneic transplant 1995 – now 34 years old.

- In 2016, I celebrate my thirtieth anniversary. With endless gratefulness I look back on a difficult period of my life—fighting leukemia. Without my selfless and unconditional helping family and my wife, who was my girlfriend then, always standing by my side I would not be sitting at the computer right now, typing these lines…Today I am 54 years old. I have a wonderful 22 year old daughter, kind friends, a great job, and I am cured for almost 30 years – what great luck! Thank you Fred Hutch! Allogeneic transplant 1986 – now 53 years old.

- Our son did so well after the transplant, until about 1 week before he died. He was healthy, so happy and so beautiful, even up to the moment of his death. His transplant allowed him to graduate from 8th grade, be honored at a Mariner’s game, go to the US Open and fish in Alaska with his
grandfathers. Thank you for those precious months. Autologous transplant 2015 – was 14 years old.

- 27 years post-transplant, my 29 and 32 year old sons are marrying wonderful women and, after my final weeks of radiation that complete 8 months of hellish chemo, hospitalizations, and total mastectomy, I feel lucky to be going on a 3 week 35th wedding anniversary cruise with 28 longtime friends. I’m the luckiest unlucky person I know. Allogeneic transplant 1988 – now 62 years old.

- I feel healthy and still (strangely) think of my time at FHCRC fondly though it all seems part of some distant past. My wife and I are able to travel several months a year and live normal lives. The sons I hoped to see graduate from high school are now 30 and 33 years old respectively. I truly feel lucky. Allogeneic transplant 1998 – now 65 years old.

- Thank you for all you have done for me. I am alive because of your treatment. The care was lovely. I felt you treated me as a precious individual. Autologous transplant 2013 – now 62 years old.

- 41 years – and still getting the same generic congratulation form letter – I am still happy, healthy, and very thankful to God for still being on this earth. I do enjoy reading the comments from past patients but don’t enjoy reading about all the health problems – guilt, maybe? Allogeneic transplant 1974 – now 55 years old.

- I am doing great! I have a good life. I look forward to the future. When the daily grind gets to me. I remember that I only had a 30% chance of survival and it just puts most problems into perspective. Autologous transplant 2008 – now 61 years old.

- I feel fortunate to have survived 16 years. My prognosis was very poor due to very aggressive lymphoma. I told myself only a few extra years would be worth the discomfort of transplant. Allogeneic transplant 1999 – now 63 years old.

- The care I got in Seattle was awesome. 2 years and counting. Hopeful to join the 5, 10, 20, 30, and even 40 years free of cancer. However, it starts with waking up tomorrow and living my life the best way I can. Autologous transplant 2013 – now 48 years old.

- THANK YOU so much for hosting the BMT Survivor Reunion! I had not attended a reunion in 20 years, and learned so much at the reunion this summer regarding my brain, nutrition, and exercise. Dr. Appelbaum’s keynote about Dr. Thomas and 40 years of the Hutch, gave me a ‘big picture’ view of how much has been accomplished in cancer research, great hope for the future, and an appreciation of the contribution of my role as a patient. Spending time with Hutch staff (some of whom remembered me from 26 years ago!) touched me deeply. I left the reunion with renewed gratitude for the fine care I received, for the great health I have today, and with a commitment to share my Hutch experience with others. I highly encourage survivors and caregivers who have not attended a reunion in the last 10 - 15 years to consider attending the next reunion. Allogeneic transplant 1989 – now 48 years old.