

## ***Thoughts and Comments from Patients – 2019***

### ***Celebrating the decades***

- *10 years! Wow. A major milestone, I am so blessed. I have lost friends and family to cancer and I really appreciate how fortunate I am. Autologous transplant 2008- now 64 years old.*
- *20 fantastic years! Hard to believe I had my syngeneic (identical twin) transplant that long ago for multiple myeloma. Never thought I'd see my kids graduate high school. Now they are college graduates, married and have children. I have six grandchildren! My husband and I are now retired and living the life. Thank you, Fred Hutch, for giving me all this! Syngeneic transplant 1999- now 65 years old.*
- *I celebrated 30 years post-transplant in January and everyone, including my mother, sister (donor), and myself (!) forgot the anniversary! The ordeals that I faced during that time are but a fading memory and I'm happy to report that I'm as physically fit as guys 10-15 years my junior. I witness this on a daily basis as I commute to work by bike and blow past everyone as I plow up the hills. Life is good, but I've found that daily exercise and breathing have been key to my sound health. Allogeneic transplant 1989- now 42 years old.*
- *On 4 August 2019 it was 30 years since my unrelated BMT in Seattle. Thank you for those 30 years, giving me a gift of life and our 3 daughters, all of this which without the help of doctors & nurse at the FHCRC would have never been born. With my gratitude for your medical care and research. Allogeneic transplant 1989 – now 59 years old.*
- *I am so grateful to be celebrating my 30th anniversary this year - and am so fortunate to be doing so well, both physically and mentally. Always aware that there is an elephant in the room that could impact my life expectancy, but it is really just a shadow in the corner. I am so grateful to Fred Hutch for giving me the past 30 years and also following up with your patients thru the LTFU program. Wish I could find a local Dr. that was as engaged in follow up care! Thank you!! Allogeneic transplant 1989 - now 56 years old.*

### ***Life is different after transplantation***

- *I have spent a lot of time wondering if I have been a “good” cancer survivor, like, am I grateful enough? Am I doing enough? Am I honoring those who didn't survive with the way I live my life? But I recently realized this: I really did live my life to the fullest before I had leukemia. I savored all the moments and chased all the passions! That made me realize that after my transplant, I put a lot of limitations on myself on myself, and spent a lot of time – 7 years, mourning the time I “lost” to AML. My work since then has been re capture that zest for life, and the confidence that*

*I could live it! I know you “can’t go home again,” but I am finally focused on recovering my passion, my purpose, my excitement for life. Sure, it’s not the exact same life, but I’m the same ME again (or at least, I’m getting there). Allogeneic transplant 2010- now 43 years old.*

- *I used to be able to run with great endurance and I cannot do that now. But I also do not push myself as I did before, in part because I can hurt myself more easily. But the largest difference is my eyesight, which deteriorated (or was damaged) so I find it hard to bike, ski, or hike scree or rocky ridges. I feel very lucky with the health, strength, -and life- the transplant allowed, but this, of eyesight, I do feel. In many ways I feel more energized than before the transplant- certainly more confident. Perhaps the close encounter with mortality has made me realize that insecurity is just a waste of valuable time. This is too long and detailed for the ‘comment’ sheet, but I wished to express how, despite the vision loss, this life the transplant has given me is more full, exciting- and infused with love- that I ever could have imagined. Few days do not pass that I do not laugh in sheer gratitude. Allogeneic transplant 2015- now 65 years old.*
- *I think I’m normal. I have good and not so good days. I’ve always been positive, upbeat. I’ve always been organized. Always been a little emotional, and I’m kind of lazy. I don’t think 25 years later that my cancer and transplant still affect my life. Changed it yes. But a bad car crash could do that too. I think you should ask how often we think about our treatment days. Sometimes I forgot to think of myself as a cancer survivor. I have moved on with my life. When I think of those days... I remember the staff, the people I met. How blessed I am God spared me... then I go on with my life. Allogeneic transplant 1993- now 40 years old.*
- *I am blessed to be alive. At first, (for 5 years after the transplant) I was discouraged and depressed that I had to let go of my job. As I got further out I gradually began to accept my limitation and am very content with my life today. Thank you. Allogeneic transplant 2005- now 70 years old.*
- *Being 32 years post-transplant is a blessing and a curse. I’m blessed to still be here and have had a daughter. However, I find that many times my issues/difficulties simply have no answer, no treatment, no comfort. I’m told I’m “uncharted territory.” Yay for me! Allogeneic transplant 1986- now 35 years old.*
- *I constantly live in fear. I worry all the time about how much longer I have to live and what will end up killing me. It makes me sad, upset, “crazy”, anxious, lose sleep, short fused... you have it. I am currently healthy, but constantly have that horrible sense of wonder. Allogeneic transplant 1988- now 37 years old.*
- *I moved to the edge of a city park and I enjoy seeing wildlife every day. So far, we have seen deer, quail, squirrels, rabbits, fox, pheasant, turkeys, and doves in our back yard. Life is good. Can’t do what I used to do but I still love being alive. Thank you again for all my bonus years. Allogeneic transplant 2004- now 76 years old.*

- *The new normal. Before and after treatment I always envisioned returning to the life I had known. It took a couple of years and some fairly serious depression to accept I could not return to the profession I loved. The transition to staying home and keeping active was hard on my family also. Now five years post-transplant we have settled into the new normal and are mostly content. Allogeneic transplant 2014- now 64 years old.*

### ***Things that helped me***

- *Pulmonary rehab prepared me for hip replacement surgery. The absence of pain and the ability to now walk without a walker or other assistance has been tremendously uplifting to my spirit and attitude. Allogeneic transplant 2005- now 72 years old.*
- *I am curious what Fred Hutch suggestions for CBD/marijuana might be. I found it extremely helpful to wean me off of the pain and depression/anxiety medications I had been taking starting after I got out the hospital. I think it was almost miraculous. Autologous transplant 2004- now 60 years old.*
- *Started physical therapy after falling twice. Physical therapy seems to help, getting legs more strength. Autologous transplant 2018- now 60 years old.*
- *I was fortunate to be included in a University of Washington student study on PTSD that allowed me access to free mental health counseling for about 8 weeks, free of charge. I had no idea that when I left SCCA I was suffering PTSD symptoms and would not have gotten help otherwise. This was invaluable to my recovery once I returned home. Allogeneic transplant 2007 - now 63 years old.*
- *I have thought that physical therapy for muscle endurance and cardio should have been part of the transplant recovery process. 20-30 treatments with a physical trainer could have helped recovery of fast twitch muscle movements, agility, muscle strength and muscle endurance, that was lost through transplant process. Allogeneic transplant 2004 - now 66 years old.*
- *It would be helpful to emphasize the importance of focusing on emotional, spiritual and mental health thru alternative methods such as massage, acupuncture, restorology, meditation, etc. and leave the medical care to the medical staff. The two approaches are together extremely powerful, and the not traditional medicine is the one the patient has the most control over. It's empowering. Autologous transplant 2018- now 61 years old.*
- *It appears that my fatigue score is 33, somewhat lower than former stem cell transplant recipients.... Thank you for citing several websites where I can find additional information about fatigue and how to manage it. I will review the sites and may have questions that will prompt a phone call to the number included in your letter. Autologous transplant 2014- now 76 years old.*

- *Feeling very grateful for the good state of health I am currently in. Through the 38 years post transplant, there have been many health challenges, some extreme, some just really hard to get through. However, I have found that daily exercise, healthy eating, good rest, work, volunteering, positivity, laughter and sharing time with those I love has greatly enhanced my overall health and keeps me moving forward. I am grateful and feel honored to be so deeply connected to all that is Fred Hutch. Thank you. Allogeneic transplant 1981 - now 54 years old.*
- *Compliments to the SCCA website. It is very high quality, easy to use, filled with education and to the point facts which answer your questions with no grey areas. I use its for truthful and concise answers to my questions. Autologous transplant 2016- now 63 years old.*

### ***Thoughts about the annual survey***

- *I would love it if you asked people the proudest thing they have done in the past year. I look forward to this questionnaire. There was a long period that I did not, I hated getting it, I hated the reminder. In two years, it'll be fifteen years since my transplant! Allogeneic transplant 2006- now 32 years old.*
- *What is happening with this information? How is it continuing to be used in your research and what information would be even more effective in future research? I would like to help but don't know how. Allogeneic transplant 1995- now 36 years old.*
- *Still doing fine at my 45th anniversary of BMT and very grateful to God for my health. I have decided to continue to fill out this same questionnaire for another 5 years - but at 50 years post transplant - I think I will retire from the Fred Hutchinson follow-up research. Allogeneic transplant 1974 - now 59 years old.*
- *After years of filling these out I wonder if other people feel the same as I do after transplant or are better or worse. As I age I am starting to wonder if my health ailments are related to the years of treatment or are normal for my age. Diabetes at age 30 and my BMI sure doesn't seem normal, and after research I see that the long-term prednisone may be to blame. But wondering if other people are as tired as I am, or pull muscles as easily as I do. It is what it is, its my life and I'm living it and mostly happy, but wonder what I would feel like today if I had been cancer free all my life. Allogeneic transplant 2004 – now 30 years old.*
- *The LTFU/patient relationship through my lens is one sided. I provide feedback for your research, but nothing is given back in return. Links to new research, tips for survivors with bronchiectasis, etc., would be appreciated. Allogeneic transplant 1984- now 52 years old.*

## ***Total body irradiation***

- *I am currently out from my BMT 27 years. I would like to know what the long-term effects have been for those who had TBI as part of their treatment. Allogeneic transplant 1992- now 65 years old.*
- *I would be interested in finding out how many others who had the same dose of TBI that I had have also come down with horrific secondary cancers. Allogeneic transplant 1991- now 40 years old.*
- *I was unable to carry a baby to full term due to uterine scarring from radiation - lost my little girl at 5 1/2 months. Allogeneic transplant 1988 - now 42 years old.*
- *Since my transplant I've had 3 joints replaced- 2 hips and 1 shoulder (second shoulder scheduled 1/22/2019). Per my ortho surgeon in Seattle total body radiation melts/destroys cartilage. You should let patients know that is a possibility- it wouldn't have changed my course of treatment as I am thriving and almost bionic. Allogeneic transplant 2011- now 57 years old.*
- *Is joint pain and overall weakness over time a symptom of my BMT and total body irradiation or just a process of aging. I turned 60 in 2018 but feel more like 70. Getting moving in the morning is a process. My friends of the same age don't seem to be aging like I am. Even my 77-year-old mom gets around better than I do, I am not sedentary but do struggle with muscle weakness. Autologous transplant 1992- now 60 years old.*
- *I have had numerous basal and squamous cell cancers. I have Irish skin and spent my life often outside without sunblock in those days. I wonder about the effect of total body radiation here. Allogeneic transplant 1997- now 72 years old.*

## ***Autologous patients***

- *So many of those whose comments/thoughts are from "Allo" patients, not "Auto" patients. I'm curious as to why that is. Autologous transplant 2016- now 75 years old.*
- *It has been 2 years and I feel great! Autologous transplant 2016- now 17 years old.*
- *The issue I still deal with is fatigue. I am always tired. Autologous transplant 2009- now 48 years old.*
- *Because I had my SCT for Scleroderma, some of the questions don't really apply to my situation. I have answered them to the best ability. Autologous transplant 1998- now 44 years old.*
- *Been in remission for 7 years. Sometimes I have courage. Sometimes I am afraid. Cancer is mostly in the background. Autologous transplant 2012- now 67 years old.*

- *In May of 2000 I was lucky enough to be in a small group of about 25 patients who had autologous stem cell transplants for MS. They couldn't reverse what previously happened, but the hope was to stop the progression. After a small decline, I am happy to report that my MRI scans have showed no active lesions in my brain. I am forever grateful to Fred Hutch for my fascinating 3 weeks in quarantine at the Hutch. I was 48 when I went in and now I am 66. Autologous transplant 2000- now 66 years old.*
- *Endless gratitude to all who ministered to me. Can't help but be endlessly grateful to all who didn't survive as their deaths must surely have informed today's care methods. Age 62- and 3-years post stem cell transplant for mantle cell L. Year 1- don't feel tip top but grateful to be on the planet. Year 2- Gosh, feeling better and still grateful. Year 3- Feel great! And tremendously grateful! The delicious gratefulness will never stop. I push myself to as active as I can be and seem to sustain greater muscle soreness and fatigue than my contemporaries. Can walk 3-4 miles with hills and am very proud. There are gifts that come with cancer. One being an exquisite awareness of the fragility of life. Helps one live more intentionally. Autologous transplant 2016- now 62 years old.*
- *I can never express my thanks and gratitude to all of you past and present at the FHCRC/Seattle Alliance for giving me back my life. FHCRC had accepted me as Salvage Therapy with a "10-20% chance of surviving the first two weeks of therapy" (High dose Ara-C). It was a gift I can never repay. If there is anything I can ever do for you I am at your disposal, ready, willing and waiting. Autologous transplant 1987- now 64 years old.*

### ***Better preparation needed***

- *Would like to see a support group for transplant recipients to attend before, during and after treatment that prepares us for physical, emotional changes. I don't feel like this was addressed at all and I had a hard time adjusting before, during, and after transplant. Allogeneic transplant 2014- now 42 years old.*
- *It might be helpful for patients to have access to a financial counselor who could help with budgeting issues. It might be helpful to provide some guidance for those patients who have completed treatment but cannot return to their former life. Allogeneic transplant 2012- now 66 years old.*
- *Neither my local oncologist or my primary care is particularly pro-active when it comes to long term follow-up care such as monitoring GVHD or scheduling test and immunizations. Consequently, I have to be assertive in managing my own health care. I think this is a common problem for individuals who have undergone allogeneic PBSCT and it would be easy for some individuals to receive subpar follow-up care as a result. It would be great if staff from SCCA would phone individuals yearly to discuss medical issues and see if survivors are on track with*

*the LTFU guidelines. I really appreciate that I can call LTFU and ask questions regarding my health care. Allogeneic transplant 2013- now 56 years old.*

- *With the constant fatigue and body pain, I feel I aged 10 years from my actual age. This was unacceptable to my husband and we split up. Has this happened to other survivors? What are the statistics on staying together? Maybe you need to offer marriage counseling on accepting the “new normal” after the stem cell transplant. This is something I wasn’t prepared for. Autologous transplant 2011- now 64 years old.*

### ***Things doctors should not say***

- *I'm 37, but my hematologist tells me that my body's inner workings are that of a person who is 57 and it's depressing. Allogeneic transplant 1986 - now 37 years old.*
- *Tell people just after transplant what you feel like today is not necessarily what you will feel like in a year. "Things can be way better, the same or worse" instead say, "you will feel like a completely different person". Allogeneic transplant 2018 - now 49 years old.*
- *When I went for an initial consultation at UW the Oncology doc showed me a magazine cover with one of his patients on it, a marathon runner who he said had relapsed 3 times, but he was still going strong, his success story. Seeing it at the time was inspirational, thinking about it now I find it overwhelming and discouraging, to have to deal with all this multiple times? I applaud her, but we can't all be that person and in the back of my mind I think that her amazing health didn't protect her from relapse. What do we all have to look forward to? Today is a rough day but there will be better, that's what I tell myself. Allogeneic transplant 2014- now 44 years old.*

### ***Feeling energetic***

- *Feel great, running my first marathon next month. Allogeneic transplant 1990- now 54 years old.*
- *I feel great, am working full time, joined a gym and am exercising more this year. I keep in contact with many friends from high school and feel my health is at least on par with all of them. Stress is mainly ordinary work/life stress with deadlines and a 20-year-old daughter in college with a boyfriend. Allogeneic transplant 2001- now 54 years old.*
- *Very happy to still receive the questionnaire, 27 years after treatment. I feel full of life and energy, now I have patients of my own (orthopedic surgeon), and never forget what it's like to be a patient. Allogeneic transplant 1992- now 37 years old.*

## ***Feeling exhausted***

- *It has been almost 19 years since my diagnosis. What a journey... there have been many interesting and even wonderful experiences, but also a lot of loss of self. I can no longer sing, I can't lift anything over 5-10 lbs. I prefer a caregiver with me when I go anywhere because I have developed, from experience, a fear of finding myself too exhausted and ill to get home. My world has become smaller and smaller. I have no energy for friends or family. I feel like the air in my life balloon is leaking out slowly. It seems that every few weeks I experience another loss of autonomy. Managing the multiple of health issues I have is exhausting. Allogeneic transplant 2001- now 64 years old.*
- *Since I was tapering off the Prednisone last summer and until now I have gotten progressively weaker and weaker. I have almost zero stamina and can't seem to lose an ounce of weight even with a good diet. I've been unable to exercise and on days I don't work I accomplish very little and everything I do takes effort. My fear is that I'm one virus away from being done completely in because I just can't seem to bounce back. I've always been a highly active person. Allogeneic transplant 2015- now 53 years old.*
- *As the day goes on, and I get tired, cognitive skills do deteriorate. I never make financial or other major decisions after 8 pm. Allogeneic transplant 1991- now 74 years old.*
- *I would like to get my energy back. Sometimes I need to stop or slow down what I am doing. I would like to start working out, exercise, but do not feel up to it, or afraid I might pass out. Autologous transplant 2016- now 57 years old.*

## ***Weight gain***

- *I gained A TON of weight during this process. When I tried to discuss this with doctors, I felt accused and shamed and not listened to or taken seriously. I am concerned that weight stigma is biasing medical professionals against adequate treatment and I frankly need help with a reasonable exercise program. For example, one doctor told me to walk 20k steps every day after transplant which is irresponsible advice for a post-transplant patient. Autologous transplant 2017 – now 51 years old.*

## ***Poor Lung Function***

- *Every year I asked about any updated research re: dealing with lung damage due to GVHD. If I could be contacted re: any changes. I obviously have adapted to what I refer to as “the new norm” as it pertains to dealing with the depleted lung function over the years, I've never let it*



*slow me down. I've proven my pulmonary doc. wrong all the time. Allogeneic transplant 1998- now 52 years old.*

- *Except for my compromised lungs, due to GVHD, life is pretty good 14 years out from my transplant. My goals in 2019 are to exercise more, play more, travel more, and take more time to "smell the roses." Allogeneic transplant 2005- now 71 years old.*
- *I am now transplant + 9 years. I enjoy regular contact with my donor. My health is stable but not excellent. I have permanent loss of lung capacity that limits strenuous activities. I praise God for my recovery, but as I approach retirement, I find myself resenting the years I lost to lymphoma and leukemia. I feel that I missed out on some of my prime years of life. Am retiring at age 63 to try to make up for lost time. Allogeneic transplant 2010- now 62 years old.*
- *My limited lung capacity definitely affects my physical activity. Not able to do a lot of strenuous cardio activity. Hiking and being in the mountains is more of chore than enjoyable because of how hard it is to breathe. It would be lovely if there could be some magical potion for me to take that would heal my lungs of the scar tissue. Allogeneic transplant 1992- now 32 years old.*

### ***Youngest, oldest, longest surviving (of comments selected)***

- *This was good. Keep it up and kick cancers' ass please. I thought it was supposed to happen after a life of living with excitement. Not when you are 18 months old. Parents of autologous transplant 2018- now 3 years old.*
- *Thank you for great care. We have [our son] with us because of your research and loving care. Thank you. Parents of allogeneic transplant 2007- now 12 years old.*
- *I have some joint and muscle pains- attribute that to my old age. But am grateful to be alive and in as good of health as I have. Thank you again for 46 years of life. Allogeneic transplant 1972- now 77 years old.*
- *A lot of this stuff I don't even think about. How can you feel bad when you are told at age 55 you have a year to live and at age 80 you can do most of what you want to do. Every day is a bonus day. Autologous transplant 1996 - now 80 years old.*
- *I have most of my marbles! I'm traveling to Florida, alone, in a few weeks! Life is good! Autologous transplant 2005- now 85 years old.*

## ***Thank you SCCA, Fred Hutch, LTFU, UW, SCH***

- *Thank you for doing what you do at Fred Hutch. Without the treatment I would not be here today with an awesome wife and two great kids. Allogeneic transplant 1991- now 48 years old.*
- *It has been 15 years since my allogeneic stem cell transplant at SCCA. I have way out-lived my prognosis and hopefully living a life that honors the wonderful treatment I received at SCCA. I am forever grateful for the care I received and the wonderful staff at SCCA. I hope there are many more like myself that were treated and are still marching on. Thank you SCCA and LTFU. Allogeneic transplant 2004- now 74 years old.*
- *What an incredible organization. As so many other would agree, I owe my life to Fred Hutch and SCCA- and the doctors who came up with the clinical trial that has extended my life 11 years so far! I am so incredibly blessed. No pains, no hurts and issues. Allogeneic transplant 2008- now 64 years old.*
- *I am so appreciative of the care I received at Fred hutch and the U of W Medical Center. I never in my wildest dreams would have thought I could fill out this survey in the manner I have for the last few years. My biggest concern nowadays is worry, am I a lucky patient that gets to grow old or will this nasty invader prop up its ugly head and disrupt this beautiful life I'm living? Autologous transplant 2010- now 51 years old.*
- *I have been seeing LTFU team every three months for the past two years or so. I suffer from chronic GVHD and am very fortunate to have the LTFU team as a resource. From what I understand, there aren't very many transplant centers that have a LTFU team. Allogeneic transplant 2012- now 47 years old.*
- *Thanks for all the years you have given me!! I was pregnant when I was diagnosed with AML and received my first round of chemo while pregnant. My first and only child was more than 6 weeks early weighing 3 lbs 11 oz. He is now 26 years old and getting married in July 2019. Thank you. Allogeneic transplant 1993- now 52 years old.*
- *I feel like the treatment I received at Fred Hutch has given me 21 additional years of life- most of which has been between good and great. Thank you for not giving up on me when it really mattered. Aplastic Anemia transplant 1998- now 76 years old.*
- *13 years post-transplant. Had my final SCCA- LTFU clinic visit in September. In the past 13 years: Children's HS and college graduations. Children's marriages. Lots of travel. Volunteer with Be the Match. Lots of hunting trips. Lost my dad. Have enjoyed an incredible dog. Well, that's the tip of a very large iceberg of happiness, love, friendship, gratitude, humility, and survivorship! Thanks, SCCA. I love you all. I will miss you and not miss you, if you catch my drift. Allogeneic transplant 2005- now 58 years old.*