# Thoughts and Comments from Patients – 2022

# Kids doing well

- 5 years post transplant!! [My child] is doing amazing. He just finished a season of soccer and is in the 2<sup>nd</sup> grade. Thank you for everything, he is doing great! Allogeneic transplant 2016 now 9 years old.
- [My child] is happy and healthy. She is thriving in first grade. She is scoring at grade level in all areas. She is a bouncy and active six-year-old. She takes gymnastics class and loves to dance. We are so thankful for her health! Allogeneic transplant 2019 now 6 years old.
- [Patient] just celebrated his 10 year birthday since transplant. He is living a very fulfilled and happy life. We are so grateful for Fred Hutch. Allogeneic transplant 2012 now 28 years old.

### The toll of transplant

- I magically thought in my head that my child would have no more problems after going through treatment, the transplant. It has been 5 years and [she is] still experiencing issues that are now affecting her socially. Covid did not help. Trying to find mental health counselor to help anxiety. I'm grateful she survived, but still lots to deal with. Allogeneic transplant 2017 now 15 years old.
- Damn hand and abdominal cramps. Allogeneic transplant 2013 now 63 years.
- I had my transplant in 1999 for CML at the age of 51. At that time I just wanted to live long enough to see my daughters get married and have children. They have both married wonderful men and I have five grandchildren from 13 to 18 years old. I feel incredibly blessed. At present my biggest concern is my declining brain. It is becoming increasingly difficult for me to keep track of the characters in novels, follow conversations, remember people's names, and sometimes I am talking and forget words. To be honest, my chemo brain really scares me. Allogeneic transplant 1999 now 74 years old.
- As I have gotten older and wiser I realize how lucky I am to have had this opportunity, and really this cure that many before did not have the chance to get. However, it is hard sometimes to not be frustrated with what the treatments and the disease have left me with. I look at others my age and sometimes have some jealousy and feel that through the years my body has become broken. It is hard to not get down on myself and I constantly have to remind myself of the battle and fight I had to go through to even be here today. I feel as I get into my 40's, I am more forgiving to myself, but still feel a sense of burden or weight, of the frustrations I feel when I see the ease and security that others have. Allogeneic transplant 2008 now 40 years old.

# Dental problems

- All my teeth are almost gone. My teeth are very thin and they had to pull most of them out due to cracking. I only have 14 left. Allogeneic transplant 2012 now 44 years old.
- In March I visited my dentist and found out that I need extensive dental work due to the impact of the chemotherapy. I had teeth pulled and numerous crowns. My out-of-pocket expense was 15,000 dollars. Autologous transplant 2018 now 75 years old.

- Wondering if my ongoing problem with my teeth is due to the leukemia (transplant) I had. Allogeneic transplant 2004 now 58 years old.
- I have had many more dental problems since the transplant. Autologous transplant 2018 now 79 years old.
- I seem to be suffering from old age, which I never thought I'd have to. After no dental caries for 46 years, in the past 7 years I've had a bunch of cavities, and two of them filled in February 2022 blossomed into root canals within a week. Allogeneic transplant 2004 now 53 years old.

# Graft-vs-host disease

- After 13 years, GVHD <u>finally</u> seems to be resolving. It has caused huge damage to my body. Steroids saved my life more than once, but caused more damage that has made life difficult. I sincerely hope that today's patients do not have to suffer from GVHD. Allogeneic transplant 2009 now 76 years old.
- I can hardly believe that my AML/transplant happened 17 years ago. It seems so recent to me. My life goes on, growing into "old age" as gracefully as possible. My only souvenir from my SCCA days is severe bronchiolitis obliterans. It limits my body but not my mind & I try to work around the limitations it puts on me. I won't be running any marathons or playing in the US open anytime soon, but with my ever-present portable oxygen concentrator I can travel, shop, dine out & live my best life. Allogeneic transplant 2005 now 74 years old.
- The chronic GVHD is wearing me down. It's taking over my life. Allogeneic transplant 2014 now 65 years old.
- I feel like I can never completely relax, but instead I'm waiting for the next health issue. I will have a GVHD episode, it will get dealt with, then after feeling good for a while, something else crops up. I cannot assume the repercussions of the transplant have all shown up yet. Allogeneic transplant 2014 now 69 years old.

# Healthcare providers make a difference

- Three years out and I've been doing pretty well. Life has been better and better after the post mental and physical healing of the cord-blood transplant! I always look forward to seeing my healthcare providers to show them that our hard work paid off. I would not have recovered this smoothly without their emotional support. I've always felt seen & heard while I was conscious and unconscious. Allogeneic transplant 2019 now 22 years old.
- When I first went to SCCA in need of a stem cell transplant I was somewhat fearful and uncertain of the future. Now when I go back for follow up care it is to see old friends and express gratitude for outstanding care and concern. Allogeneic transplant 2017 now 70 years old.
- I just want to say "Thank you" to all the doctors, nurses and general staff at University of Washington and SCCA. You have been an incredible amount of comfort to both me and my wife and I could not be more appreciative of the care, compassion and patience that we have received. You saved my life! Words cannot express my thanks. Allogeneic transplant 2017 now 60 years old.
- My experience at the SCCA and UW medical center was excellent. I feel like I received top notch care. Talking to other cancer patients that have been treated at other cancer center it would seem that the Fred hutch

organization and its affiliates are the best in the cancer business. Also the LTFU program is super impressive and amazing. Allogeneic transplant 2020 – now 29 years old.

- I have not once felt any of my caregivers "dropping the ball" in any way. SCCA / UW runs a pretty tight ship and I am a beneficiary. Thank you all. Allogeneic transplant 2018 now 67 years old.
- I don't wish anyone the pleasure of having the need for your assistance. But, if they do, there is no better, more professional group of people that you will meet at SCCA. Thank you so much for everything you did for me and my family. Allogeneic transplant 2020 now 74 years old.
- I am so grateful to have celebrated my fifth "birthday" in August-thanks to the fabulous care I received at SCCA and UW Medical Center. Five years ago was a scary time but the compassion and competence shown by the staff, nurses and doctors went a long way toward easing my fears. My transplant gave me the most precious gift I can imagine time. I have been blessed to see my son get married, the birth of my grandson and countless other milestones in the lives of my dear family and friends. I only wish my donor could know how many lives he changed that day. Allogeneic transplant 2017 now 62 years old.

# Loss of those around us

- I still have a hard time with grief over the loss of our sweet 9 and ½ year-old daughter to BMT in 1990. In spite of her years on chemo and intrathecal methotrexate, she was tested and found to have a genius level IQ. You never get over the loss of a child and I often wonder why I should have survived and she didn't. Allogeneic transplant 2016 now 75 years old.
- By now, many of my wonderful doctors and nurses who treated me at the Hutch have either retired or will soon be doing so. Each of my medical providers at the Hutch created a great top notch medical center and gave me life. To each of them, a very BIG thank you. I am forever grateful. Allogeneic transplant 1996—now 60 years old.
- I wish there was more help provided to deal with the fear of relapse. Also in dealing with "survivor guilt". I made friends with two transplant patients during my time at SCCA/Fred Hutch & kept in touch with them. Sadly, one died a year ago. The second one has recently relapsed. This affects me <u>a lot</u>. Autologous transplant 2018 now 62 years old.
- Thank you for extending my life for nearly three decades. My donor passed away in Sept 2021. As I waited next to her bed listening as the heart beat slowed, I bid her a farewell with a prayer, a kiss and a thank you. Allogeneic transplant 1993 now 78 years old.
- Only a week until my 15-year birthday and I am so thankful to all my friends who stepped in to help my husband as caretakers. I'm especially thankful to my donor the man who saved my life. We traveled across the country twice to meet and visit him. It was like meeting the brother I never knew I had an experience I recommend to everyone. I'm so glad we made a return visit, because he lost his battle with cancer not long after, at the young age of 53. It doesn't seem fair, but I will continue to make the most of the gift he gave me and hold him in a special place in my heart. Allogeneic transplant 2007 now 66 years old.
- I'm currently dealing with the after effects of my wife's passing last month. She had a stroke and then a heart attack. She was five years older than I am and also my best friend. It definitely took the wind out of my sails and right now I'm having a hard time focusing on anything. Autologous transplant 1996 now 82 years old.

- My donor (one of my brothers) died this past autumn just short of his 92nd birthday. I used to joke with him, "[Donor], I don't care how long you live, just as long as it is at least one day past me!" He was very special to me. Allogeneic transplant 1991 now 77 years old.
- My beloved sister, who was my bone marrow donor, died of cancer in 2018. Allogeneic transplant 1984 now 62 years old.
- For the past ten years, my myeloma has somewhat been on the 'back burner'. However, [this year] my M-spike increased a little more, possibly indicating further progression of my disease. The prospect of entering a new phase of treatment is unsettling to me. My husband, who was with me during the transplant and has been my main support, passed away two months ago. So, I will be 'going it alone' as they say. I have other family members, but it is not the same. Autologous transplant 2012 now 74 years old.

# The value of research

- Thankful for SCCA & FRED HUTCH for extensive research for BMT & previous patients who've made it possible for new life to continue!! Allogeneic transplant 2019 now 55 years old.
- Another healthy year has passed and my appreciation and gratitude for being accepted into the research program never waivers. I was categorized as salvage therapy with virtually no hope of survival, however here I am. To say I am grateful is an understatement, I was 32 at the time of transplant and am now 35 years post transplant. How can someone thank you appropriately for giving them a life? I don't know, I can only hope my time at Hutch aided in the research to help the many patients that followed. Autologous 1987 now 67 years old.
- I am very grateful for the now 16 years of reasonably good health that I enjoy... Thanks to the forward thinking and cutting-edge research from Fred Hutch and the coordinated teamwork of the SCCA. Thank you so much. My family thanks you too. Allogeneic transplant 2006 now 80 years old.
- There is no way I can express my gratitude for the people that have helped me, for the patients that came before and even the animals that procedures may have been tested on. Allogeneic transplant 2020 now 56 years old.
- I've been filling out this survey for 26 years and have never gained any useful information from it. Shouldn't this help the people filling it out??? Autologous transplant 1995 now 39 years old.
- What value do you think these surveys really are? I find them very inconvenient and hard to actually answer them correctly, and so what about everyone else that find them like that too? Hope you get something of value off them, but so many answers are so subjective I imagine I would answer them differently if had to answer them again. Autologous transplant 2018 now 73 years old.
- *I am a proud participant of the LTFU questionnaire. To be able to share my history in order to help others in the future is the least I can do.* Allogeneic transplant 2004 now 39 years old.
- I am very thankful to all the staff at Seattle Cancer Care Alliance. I am currently living a fulfilling life: scuba diving, working as a school psychologist, and doing all activities I did prior to my treatments. My hope is Fred Hutch will continue research for a treatment in case my cancer comes back or in order to cure this type of cancer. I will continue to take on my cancer with all my strength! Allogeneic transplant 2018 now 61 years old.

• And I am so grateful that Fred Hutch and the SCCA work so hard in researching for the treatment and recovery of other patients. Thank you!! Allogeneic transplant 2019 – now 34 years old.

### Dealing with my disease or maintenance therapy

- As you know by now my MDS has returned after 20+ years of being "cured". Fortunately medical science has progressed to the point where my life expectancy is now in a number of years rather than months. After 20 years any additional years are welcome. I finally got my free season ski pass and I do plan on hitting the slopes although the easier ones. No more "steeps". I plan on gravity doing most of the work. We still travel frequently and have active social lives. Who knows how many years I have? I plan on taking advantage of every one! Allogeneic transplant 1997 now 79 years old.
- In 2012 I relapsed and I returned to the Hutch for a lymphocyte infusion. There have been no problems since 2012. Allogeneic transplant 1998 now 70 years old.
- [Patient] has been living with Ewing Sarcoma Cancer for 6 years now. The stem cell transplant did not provide any time off from the cancer. It returned immediately after his hospital stay was completed. By May/June 2021 he knew it was back. He had surgery August 2021 for tumor on right side. The cancer returned by Sept/Oct 2021. He continues to receive palliative chemo treatments every 12-18 days. When chemo ceases to work he will enroll in hospice at home. This cancer has been very aggressive. He never really had a chance. But he fights hard. Autologous transplant 2020 now 32 years old [died March 2022].
- I relapsed 10-years post transplant and then started on Gleevec which I have now stopped (10 years ago) and remain in full remission. Allogeneic transplant 1993 now 73 years old.

### People 30+ years out

- Thanks again for life! Because of your treatment I have had 31 extra years of life. I'm now 84! Autologous transplant 1991 now 84 years old.
- I celebrated my 31<sup>st</sup> BMT anniversary. WOW. I'm so lucky to be here after having cancer 3 times. I'm so lucky to have family that supports me. I currently have a job working in early childhood education. I'm healthy and happy. Allogeneic transplant 1991 now 35 years old.
- It would be nice to have a Facebook page for survivors that have been treated from your facilities. Allogeneic transplant 1989 now 42 years old.
- My husband and I trekked the Inca trail to Machu Picchu, Peru. That was a most incredible, gorgeous hike to the iconic ruins of the Incas. Then we trekked to Rainbow Mountain in Peru. Just unbelievable colors on a picture perfect day. Hike ended at 16,520 ft. I am so grateful to my brother for his unconditional gift, the incredible medical staff at the Hutch and the grace of God for 38 cancer free years with good health and countless adventures like this one. Allogeneic transplant 1984 now 59 years old.
- I continue to be so fortunate and appreciative in just living life for the past 37 since my transplant. Surviving cancer taught me to safeguard and take care of my health, and I feel I have been doing my part. Thanks so much for making possible 37 years and counting of a happy and fulfilling life! Allogeneic transplant 1984 now 52 years old.

- I am now 75 years old. Since I wasn't supposed to make it to 40, I am still extremely happy to be alive. Allogeneic transplant 1984 now 75 years old.
- 40 years! Feels pretty good to say it but it's still hard to believe. As a 15 year-old going through a transplant in the summer of 1982, I remember having the thoughts that if I survived I would consider myself lucky if I lived into my 50's. I turned 55 a few months back I know that every day that I spend with my family and living my life, is a gift. Thank you Fred Hutch...Here's to 40 more years. Allogeneic transplant 1982 now 55 years old.
- This is a big one...40 years! Humbled. Grateful. Tearful. I've lived more in those 40 years than most do in 100. I've done all I wanted to do. Grew up, went to college, had 4 wonderful children and raised them to adulthood. I have a rewarding career as a nurse on an oncology unit. I can do all the things I physically have in my heart to do. I've climbed mountains and fell in rivers. I am at peace and my family is at peace. I've had more than was promised in 1981. Here is to the next 40 years! They are just icing on the cake! Thank you for the chance at life. I took it! Allogeneic transplant 1981 now 51 years old.
- How long are the oldest LTFU out? How many of them? This is my 41 years out! I had Covid in November of 2020. Was in hospital for 17 days. Survived that and leukemia. Allogeneic transplant 1981 now 72 years old.
- WOW! 45 years since my bone marrow transplant. Each anniversary I reflect. How fortunate we are to have such amazing Drs and scientists keeping us healthy. The least I can do is spend a few minutes each year to fill out this questionnaire in hopes of helping them help others. Thank you to all the amazing Drs and nurses from 45 years ago, I think of them always. Allogeneic transplant 1977 now 54 years old.
- My apologies for neglecting to complete the questionnaire in 2021. It was a difficult year for me. In spite of the daily aches and pains I experience, I am still grateful to be able to grow old. Thank-you for an additional 45 years! Allogeneic transplant 1977 now 57 years old.
- I came to you when I was nine years old. My oldest grandchild will be nine this year. Thank you for my life. Allogeneic transplant 1975 now 56 years old.

# Help with recovery

- I feel like there needs to be a focus on care after transplant. We should have to meet with a counselor and a physical therapist to help us adjust to our "new normal". Specifically with an exercise training program that is safe to follow to keep your body and mind in shape. Allogeneic transplant 2019 now 44 years old.
- I feel that SCCA has done a great job with the cancer treatment. But once they feel that they have got the cancer somewhat under control they stop with any help with pain or anxiety or depression help!!! That you become a number and they kick you to the curb. Allogeneic transplant 2021 now 67 years old.
- Anxiety related to watching and waiting with labs. Not enough info available about supplements. Too healthy for attention so sometimes feel like I'm walking this alone. Autologous transplant 2017 now 66 years old.
- My husband and I decided that we needed to "get healthier" by going on Weight Watchers and going to the gym. I am walking a mile on the tread mill three times a week and I have lost about 40 lbs since my highest weight and we continue to lose very slowly. I feel so much better. Autologous transplant 2011 now 75 years old.

- Peer support (either 1:1 or group) for leukemia patients receiving chemo and transplant patients after they get past day 90. My experience was so isolating, even with great support from family and friends. It would have been particularly helpful to have peer support when active treatment was over and I was trying to reenter "normal" life. I would be interested in a volunteer peer counselor role should that become a possibility. Allogeneic transplant 2014 now 53 years old.
- I know I am unusual in that my transplant was for a rare disease and not a cancer. I wonder if the survey is meant for me since it feels very related to cancers. Reading the round up of quotes from other survivors every year is a bit alienating because one, I was a baby when I had my transplant and don't remember it. And two, I didn't have cancer that also means I only had chemo and no radiation. I guess I just feel really lost as to what I should be following up on health wise at this point. This year was the first year I had a new doctor that seemed to know what I was talking about when I mentioned I was born with SCID, not seem confused, and believed me when I said I have a healthy functioning immune system now. I was lucky to stumble on this doctor, but even then, I generally feel lost when it comes to my health and what may or may not be transplant related. Allogeneic transplant 1993 now 29 years old.
- As I am getting older, I see that there are not many transition hospitals/places for cancer survivors in their late teens/early adult years. It seems that once we are through with our initial treatments, we are forgotten about. What about the long-term effects that the treatments have caused? I am still dealing with problems that are caused by radiation and chemotherapy. An example is leg length discrepancy and joint problems. Autologous transplant 2000 now 23 years old.
- I feel like a unicorn and that we don't understand/do enough for the young adult population. I have rebuilt my body into a more athletic/stronger version of itself... yet had to do all of the research on how I rebuilt myself by myself. I feel that we stop at just surviving, when thriving is the key to surviving, as what I have done has given me the best chance of true, high-quality survivorship. Please learn from me. Autologous transplant 2020 now 32 years old.
- The main frustration is going to doctors that are not necessarily educated in care after bone marrow transplants and I know that is not possible to have everywhere but I felt lost about a lot of my symptoms and I just read comments that others have the same issues...but no guide or answers to help them. I am all for helping others...always but I also thought filing out these questionnaires might lead to recommendations or referrals to resources that could help. I understand that everyone person is different and unique in their case. Allogeneic transplant 1999 now 46 years old.

#### Some more COVID comments

- This has been a very tough year. Unsurprisingly. While a source of great anxiety, the pandemic has ironically permitted me to thrive in certain ways. Perhaps it is the introvert in me, but spending most of my time by myself or with my nuclear family seems to remove a lot of social anxiety and stress. Allogeneic transplant 1997 now 58 years old.
- Yesterday was my double birthday (I'm 66 and 24 years post BMT). Having had the transplant on my 42 birthday seemed like a good omen at the time. Now it makes my "special day" so much more significant and deserving of celebration! Also, after 24 years of filling out my questionnaire, this is the first time I'm not complaining about something. Yes, I had complications & cascading health issues along the way, but it is now just my new normal.

- And, while I hope Covid-19 goes away soon, this past 2+ years of limited social interaction has been the healthiest 2 years I've had. Allogeneic transplant 1998 now 66 years old.
- Has been a struggle emotionally working as a (premature baby) nurse post transplant, and having coworkers/family/friends deny the seriousness of covid and refuse vaccinations. I worry a lot about immunocompromised people and the pandemic, and have anger at people who refuse the vaccine. Autologous transplant 2016 now 50 years old.
- Some of my answers might be skewed due to addition of long covid (had it in Jan 2020 before they knew what it was). At the risk of sounding dramatic, I have never had anything like it. That is why I called LTFU to push my doctor into action. It was quite scary and has left a permanent mark. Hope they find out more and how to make long covid go away. Allogeneic transplant 2009 now 62 years old.

## Had more than one transplant

- Having survived two stem cell transplants I'm living proof that a near complete recovery is possible! I am very active with running, pickleball, biking, hiking and golf. I still have concerns about life expectancy but after 6 years these thoughts don't consume me anymore. Allogeneic transplant 2016 now 55 years old.
- It has been 13 years since my auto/allo transplants. I am now 63 years old, have lost 80 pounds and go hiking with my husband a couple weekends a month. I work out on my elliptical and rowing machine almost daily. I feel better than I have in years and am very grateful as they were only giving me a 5 year survival timeline before my transplant. Allogeneic transplant 2009 now 63 years old.
- As a two-time BMT survivor, now 27 years post 2nd transplant and almost 40 years old, I can say I am finally getting into the best health and shape of my life. Having battled leukemia for much of my childhood, and metabolic syndrome for all these years post transplant (overweight, diabetes, hyperlipidemia and high cholesterol), I am proud to say I've finally made exercise a priority in my daily routine and it has truly changed my life and my outlook! There really is hope for those who are convinced they'll never be in good shape again. It takes baby steps and dedication, but it can happen! Allogeneic transplant 1995 now 38 years old.
- I've been tired lately but it has nothing to do with my health. I got a puppy! Word of advice: NEVER get a puppy when you are in your 60s! Thank you all <u>so</u> much for any work/research you are doing regarding Covid 19. For those of us who suffered through a transplant & had to experience isolation (LAF room) it's sad that we have to go through this again. I wore a mask for a year after my 2 transplants & when I see the backlash from people who don't believe in masks I want to scream. I was 18 when I got sick. I'm 61 now. My mask worked! Allogeneic transplant 1979 now 61 years old.
- 21 years post Auto-mini Allo for myeloma. Thank you Hutch! Allogeneic transplant 2001 now 69 years old.

# **Fatigue**

- My problems with fatigue continue to get worse. I sleep (am in bed) about 12 hours a day. I have an ongoing to do list that I make little progress with. I can rise to an occasion but pay a price with days of doing less than normal. It significantly interferes with my life. My one wish for my health now is to have more energy to get more done and to be able to spend time with friends. Allogeneic transplant 1999 now 71 years old
- Life is relatively good yet I am so tired of always being physically tired. I'm tired because I don't exercise much but I don't exercise much because I am so darned tired. Can't seem to break that cycle. I'm 10 years post stem cell

transplant for AML with FLT3 gene. I feel very blessed. Just wish I had more energy. Allogeneic transplant 2012 – now 70 years old.

• I feel very much like I'm near the end. I have no more energy or strength, and I'm in pain constantly. But I've lived 23 years post transplant and for that I'm very grateful. Allogeneic transplant 1999 – now 59 years old.

#### Thank you LTFU!

- I am so sorry to hear Dr. Flowers is retiring. Let her know she is on my mind often because after transplant she helped me go home with her expert knowledge and made me mentally cope with medical issues. <u>She understood.</u> Allogeneic transplant 2004 now 72 years old.
- A BIG THANK YOU to Mary Flowers for all of her efforts over the years to support transplant patients!!! Allogeneic transplant 2005 now 54 years old.
- Please convey my thanks to everyone in LTFU for always being there. When I was diagnosed with MDS, FHCRC was my first choice, but video conferencing was not available in Oklahoma. Since my BMT 31 years ago, I have fought cancer 3 other times (renal cell in 3 places) and now MDS. I am hopeful my treatment will be at a point I can attend the reunion. Oh, how I have missed that great time of success stories! Allogeneic transplant 1991 now 73 years old.
- Thank you very much for all that you do for us. It is every comforting to know that no matter how long it's been, I can always reach out to LTFU if I have a question or need help and I'll always be greeted by a warm, friendly and helpful person. Allogeneic transplant 1992 now 47 years old.
- I'm very appreciative that I can call LTFU and get answers for my questions. Thank you! Allogeneic transplant 2015 now 67 years old.
- The long term follow up program is unique and it is great to be able to be a part of. As a transplant patient who suffers from chronic GVHD I feel safe knowing that I am being seen by experts that have experience in this condition. Allogeneic transplant 2012 now 50 years old.

### Thank you!

- Thank you for saving my life so I could watch my children grow up. Allogeneic transplant 2000 now 53 years old.
- I [parent of patient] was contacted by Be-The-Match the other day because I may be a match for someone who needs a transplant. I am so excited for the chance to give to someone, just as someone did for [my child].

  Allogeneic transplant 2014 now 11 years old
- Thank you for all y'all have done & continue to do for each of us. I wouldn't be here today without you. I've lived to see my eldest daughter graduate high school & begin college and my youngest daughter is now a freshman in high school. Seemingly normal occurrences to others that are milestones of gratitude for my family. We look forward to many more wonderful milestones TOGETHER because of the care I received there. Allogeneic transplant 2017 now 57 years old.

- My medical teams were unwavering in pursuing cures for my illnesses and I am approaching my tenth year cancer free. Allogeneic transplant 2013 now 67 years old.
- *I am so very grateful every day for the chance to open my eyes, to see my children and to go to work and see my friends. Life is grand!* Autologous transplant 2019 now 72 years old.
- My wife and I welcomed twin boys in August, and we're all adjusting to life as a family of six (!). I started a new job just over a year ago that will provide opportunities to travel to some really interesting places. It would have been tough to imagine this life when I had my allogeneic transplant twelve years ago, but here we are. I can't decide if it feels like the blink of an eye or an eternity--somehow it's both. Our life is wonderfully full. Allogeneic transplant 2010 now 40 years old.
- I am just very grateful for all the care I received at SCCA. When I was diagnosed it was a death sentence, now I just celebrated my 4<sup>th</sup> birthday and live a pretty good life. Thank you for everything. Allogeneic transplant 2018 now 57 years old.
- Every year I read my diary from my experience and it fills my heart with the strength, support and love I was surrounded by during that time. Most people want to forget these types of experiences... not me. I want to always remember what I went through and how I beat my odds. My health in general is very good at almost 49 years old. Allogeneic transplant 1995 now 48 years old.
- In 2015 my doctors said three years of life would be a great expectation. Today I ski, bike, hike and live! Allogeneic transplant 2017 now 65 years old.
- 18 years post transplant, fortunately I am dealing with everything a 56 year old should be dealing with. Allogeneic transplant 2004 now 56 years old.
- This year (knock on wood) has been cancer free. It is so nice to have some healthy "open field" running again. It is such a welcome sense of freedom. My only complaints this year are old man complaints, that most of my old friends are also experiencing. It is hard to imagine how happy plain old age-related physical problems can make me. They remind me, in some weird way, of how lucky and blessed I really am!!! There will be no complaining from me about getting old. Heck I didn't seriously think that I would ever make it to 68. Thank you, Fred Hutch, for making it all possible!!! Allogeneic transplant 1996 now 67 years old.
- This yearly survey reminds me to be grateful for the wonderful treatment I received. I thought I'd "maybe live to be 50. Looking at my 70th next January. Allogeneic transplant 1994 now 69 years old.
- Gratitude is an insufficient word to express how fortunate I am to have received my stem cell transplant at UW and to have gotten such excellent care at Seattle Cancer Care Alliance. I view my life with a more positive outlook knowing I've been granted a second chance at life again and I will live to enjoy the beauty of family, friends and nature for years to come as a result of the scientific miracle of transplant and the dedication of such wonderful providers! Autologous transplant 2020 now 58 years old.
- I owe great thanks to so many anonymous blood donors; heroes that gifted the blood that contributed to my survival. I owe my life to my very generous stem cell donor. I want to pay his gift of life forward, through advocacy and sharing our story. If I could help save another, I'd be proud to be part of this team effort. Allogeneic transplant 2019 now 53 years old.

- I am 12 years post allo transplant for MDS that progressed to AML. In the time since my transplant my sons have gotten into their careers, gotten married and given us 4 lights-of-my-life grandchildren. I returned to and then retired from a career I enjoyed. My wife and I have traveled extensively and hiked and biked in the US and Europe. None of this would have been possible without my transplant. I am so grateful to the Hutch and everyone who works and has worked there, right back to the original Don Thomas research team. You have given me a second life as fulfilling as the first life. Allogeneic transplant 2010 now 66 years old.
- Life is a good challenge, but not easy! Now as a fragile patient and watching for possible developing metabolic syndrome issues I am lucky I have a relatively good memory, cognitive skills and common sense. My continuing philosophy is "Keep the coffee hot, beer cold, food good and the rubber side down" and ability to reflect on my life accomplishments. Autologous transplant 2002 now 77 years old.
- My health is great. (Insert marching band glorious sounds here!) Thank you to all at Fred Hutch who allowed an amazing future to unfold in spite of a horrible prognosis 23 years ago. Choose hope, people, always choose hope. It has ways of showing up in the most unexpected places keep your eyes and your heart open to experience it. My gratitude to the Hutch team always. Allogeneic transplant 1999 now 64 years old.
- I continue to be a very, very lucky duck!! Thanks to all of the brilliant minds & skillful hands who had at me. 6 years post transplant now. I live deliciously. Thank you. Thank you. Thank you. And those words are immeasurably inadequate. Autologous transplant 2016 now 65 years old.

[Turn over for resources for transplant survivors]

#### 1. Fred Hutch Cancer Center, Blood and Marrow Transplant Frequently Asked Questions

https://cutt.ly/BMT-FAQ

#### 2. Fred Hutch Cancer Center, Information for Patients

https://cutt.ly/BMT-Info-for-patients

#### 3. Resources to read more about fatigue:

- American Cancer Society: <a href="https://cutt.ly/ACS-fatigue">https://cutt.ly/ACS-fatigue</a>
- National Comprehensive Cancer Network (page 41-45): <a href="https://cutt.ly/NCCN-fatigue">https://cutt.ly/NCCN-fatigue</a>
- National Cancer Institute: <a href="https://cutt.ly/NCI-fatigue">https://cutt.ly/NCI-fatigue</a>
- American Society of Clinical Oncology: <a href="https://cutt.ly/ASCO-fatigue">https://cutt.ly/ASCO-fatigue</a>

#### 4. Resources to read more about thinking and concentration:

- American Cancer Society: <a href="https://cutt.ly/ACS-chemo-brain">https://cutt.ly/ACS-chemo-brain</a>
- National Comprehensive Cancer Network: Pages 30-33 <a href="https://cutt.ly/NCCN-survivorship">https://cutt.ly/NCCN-survivorship</a>
- National Cancer Institute: <a href="https://cutt.ly/NCI-memory">https://cutt.ly/NCI-memory</a>
- American Society of Clinical Oncology: https://cutt.ly/ASCO-memory-problems