

# ***Thoughts and Comments from Patients – 2018***

## ***Some Thoughts from People More Than 25 Years Since Transplant***

- *I am so incredibly grateful to still be alive 28 years after the bone marrow transplant that saved my life. As I grow older, I find that I accept my limitations and post-effects somewhat more gracefully- honestly the antidepressants I'm on might help with that. (lol) But overall life is good! Thank you FHCRC!! Autologous transplant 1990- now 44 years old.*
- *I am glad to be part of a LTFU study that may provide insights to other survivors. It is a fitting way to acknowledge 28 years of survival and to say thank you to the group that made it possible. Allogeneic transplant 1990- now 77 years old.*
- *I am very appreciative of the care I received at Fred Hutch. I was unsure if I was going to be able to graduate high school back in 1990 and here it is 2018 putting me 18 years past medical school with a healthy nine year old daughter. Thank you for the work you did then your continued commitment to patients and allowing them a future of their choosing. Allogeneic transplant 1990- now 44 years old.*
- *Thank you for your ongoing interest in my health and well-being. I am blessed to have has a sibling match and to have gone to Fred Hutch for my transplant 29 years ago. I lead an active and productive life. I ski, paddle board, weightlift, mountain bike and ride a Harley for pleasure. I went back to school after my transplant and obtained my master's degree in nursing anesthesia and work full time in that field. Thanks for the second chance! Allogeneic transplant 1989- now 59 years old.*
- *My apologies for not diligently completing this survey every year. In four days will be the 30<sup>th</sup> anniversary of my BMT. I am now 60 years old, have retired from working and have 5 grandsons. I cherish every day of life given to me by having a BMT at FHCRC. My donor (my aunt) passed away two years ago. I am eternally grateful to her for the gift of life that she gave me. Allogeneic transplant 1987- now 59 years old.*
- *I have no idea, cannot imagine what my life would have been like absent leukemia. I would have never chosen the experience of course. But after 34 years I'm confident the transplant provided me a perspective on life I would have not had. Don't waste opportunities. Do what you dream. Go now don't wait. Do work which rewards with not only a paycheck but instills pride. Allogeneic transplant 1984- now 58 years old.*
- *36 years! Growing older and loving every minute of it. Every wrinkle, missing hair follicle, and brain fart. Hardly a day goes by when I don't reflect on those days in Seattle in 1982 and thank God for every person who helped me heal. Thank you Hutch for helping me live life I almost didn't. Allogeneic transplant 1982- now 51 years old.*
- *So thankful to be celebrating 37 years post-transplant! Certainly, there have been more health challenges through the years- too many to list! But I work hard to live a life that promotes good health in body and mind and spirit! Daily exercises, clean eating, positivity, volunteering and lots of laughter sure help in keeping in me moving forward along with being surrounded by those whom I love. Thank you for all goodness that is found at Fred Hutch. Allogeneic transplant 1981- now 53 years old.*

## ***Donor Interactions***

- *Before coming to the Hutch I prayed to be able to raise my girls. The oldest got married last September and the youngest is getting married this September. My donor attended the first wedding and is planning on attending the second. Allogeneic transplant 1998- now 52 years old.*

- *Thanks to my donor whom I don't know but keep in my heart. Allogeneic transplant 2011- now 71 years old.*
- *Is there any chance to still contact my donor? Allogeneic transplant 2011- now 74 years old.*
- *I was wondering how I find out who my transplant donor was. I've asked but not received any info. I would love to thank them for saving my life. Thank you. Allogeneic transplant 2010- now 42 years old.*

[Give us a call at 206-667-4415 or email: [LTFU@seattlecca.org](mailto:LTFU@seattlecca.org) with donor questions]

### ***More than One Transplant***

- *Thank you for the miracles you all performed for me over the 32 years... including two transplants and my miracle son, Matt, who is now 22 years old. Allogeneic transplant 1996- now 55 years old*
- *This is my second transplant at SCCA. I am very lucky to feel close to normal and healthy after this transplant. SCCA is amazing! I am thankful for all of the staff at SCCA and their commitment to helping people heal. Allogeneic transplant 2017- now 35 years old.*

[The Seattle Cancer Care Alliance (SCCA) was formed in 2001 as an alliance between Fred Hutchinson, the University of Washington, and Seattle Children's Hospital]

### ***Children Growing Up***

- *Several days after I returned home from Seattle, my youngest daughter was born. There were days when I wondered whether or not I would even be alive to see her. Not only was I blessed with the joy of watching her grow up and to be a part of her life over the past 21 years, this week I look forward to the privilege of attending her wedding. My eternal gratitude to the Creator, my donor and everyone at Fred Hutch. Allogeneic transplant 1997- now 60 years old.*
- *Another great year (other than sore and artificial joints!). My son graduated H. School (was 18 mo. old at my diagnoses) and I will watch my baby, whom I was pregnant with at diagnosis (in '00), graduate this year! Allogeneic transplant 2002- now 53 years old.*
- *Thank you for all you have done to save my life! My only wish was to be able to be around to raise my children. My youngest just graduated from high school. She was two when I had my transplant. Allogeneic transplant 2002- now 45 years old.*

### ***Brain Fog***

- *I am sure I have something to say but can't think of it at the moment. Allogeneic transplant 2006- now 75 years old.*
- *Please ask cognitive function questions- memory, focus, concentration. Allogeneic transplant 1992- now 48 years old.*
- *"Chemo brain" impact- I've had significant memory /focus/word finding/sequencing/sustained attention problems post-transplant 3 years ago. Moderately affects my daily functioning (driving, in conversations, work projects and planning directions) and I'm only 48 years old. Autologous transplant 2015- now 48 years old.*
- *I find after transplant, (and/or chemo) my thought process seems "fuzzy." This includes a dramatic loss of concentration, where my focus of attention wanders across various processes... causing me to attempt many projects... but accomplish none. I am also experiencing chronic fatigue; which may not be the result of transplant... but instead OMD. (Old Man Disease.) Autologous transplant 2002- now 65 years old.*

## ***Inspiration to Others***

- *I would REALLY love to submit a picture for the wall of survivors- as it is SO important to me as a patient while doing my laps, and found MUCH inspiration to keep going thru seeing them. How do I do this? Autologous transplant 1992- now 53 years old.*

[You can send pictures to 8NE Nursing Station, c/o Sandra Olson, University of Washington Hospital, 1959 NE Pacific Street, Seattle, WA 98195]

## ***When Transplant Works Really Well***

- *I am 15 years out from my transplant and the last two years have been better than ever. I truly feel myself again. I am 67 now, so I am not as fit as I was when I was 52, but I feel great and I am as active as I would like. Allogeneic transplant 2002- now 67 years old.*
- *After having the autologous stem cell transplant in 2010, that actually saved my life from MS symptoms that would have eventually left me bed ridden with full time caregiver or death by now. I will forever be thankful for the opportunity this transplant has afforded me. My cognitive abilities returned, I can walk, talk, read, I do not have the pain I once lived with and have been able to do things I would have never been able to do before. I still have fatigue and because my immune system is not the greatest, I have never been able to return to my athletic self, although I still am able to work out to the best of my ability. I cannot work but I do volunteer. With all the things that have gone wrong with my body since the transplant I would still do this again in a heartbeat. I think about how bad it was before the transplant and am so happy I was given this second chance in life. Autologous transplant 2010- now 60 years old.*

## ***When Transplant Doesn't Go Well***

- *If I really knew how much suffering, pain, PTSD that I would have to go thru the BMT, I would have never done it. I would never do another again or anything like it, the risks outweigh the benefits. Allogeneic transplant 2003- now 61 years old.*

## ***Against the Odds***

- *I am so thankful for another good year of life. Fred Hutch, SCCA. You hit a home run in your care for me. I was near death after a 14 year slide into chronic disease. You saved my life. You found my donor, and used her stem cells to heal me. Somehow, after so much pain, struggle, and years of decline, you turned it all around. Two hard years of GVHD had to be endured, but it's been all uphill after that. Thank you so much. Please share this with all these other good people at Fred Hutch, SCCA. Allogeneic transplant 2004- now 65 years old.*
- *I was told I had a very low chance of surviving my stem cell transplant. I still had cancerous cells in my cerebral spinal fluid even after several rounds of spinal radiation. Thank you to my doctors for allowing me to proceed with the transplant even when hopes were low. 4 years cancer free and no GVHD. I have been blessed! Allogeneic transplant 2013- now 43 years old.*
- *When I was initially diagnosed with amyloidosis, you were reluctant to do stem cell transplant, because one of your previous patients had died. I am still here 9 years later. The odds of me surviving my transplant weren't great, but I am so glad I did it. Just don't give up on anyone. Given a choice between slim and none, I will take slim every time! These last 9 years have been a gift. Thank you. Autologous transplant 2008- now 63 years old.*

- *I am incredibly grateful for SCCA, Evergreen Hospital, and UW for keeping me alive. I was 26 weeks pregnant when I was diagnosed with Primary B-cell Lymphoma, and 6 months later they found a tumor in my brain. I am now 2 years post-transplant! And my baby will be 3 in February! Thank you for everything! Autologous transplant 2015- now 29 years old.*
- *When I presented, in Feb. 1998, I was told I wouldn't last more than 2 weeks because I had two types of leukemia in the blast phase. Because of all your efforts, on April 15, 2018, I'm celebrating 20 years post-transplant. Allogeneic transplant 1998- now 65 years old.*
- *It's been almost 8 years since a doctor in Germany told me I had leukemia, and over 7 since a really amazing young woman from Oklahoma City gave me my second chance with a stem cell transplant. I know some of you weren't sure if it would work because nobody with a history of not one but two Rhizopus infections had ever survived HSCT, but I will be grateful to you forever for taking a chance on me and helping me be the first. Allogeneic transplant 2011- now 28 years old.*
- *I am 13 years post- transplant and will be retiring this year from my CPA career. I had a very difficult transplant- whatever could go wrong, went wrong. My family was told twice that I would not make it. I survived and am doing extremely well today. I have so much to be thankful for. Allogeneic transplant 2005- now 62 years old.*
- *I was told that I still had malignant cell activity in my spinal fluid right before my transplant and that there was a very low chance that I would survive. Thank you for proceeding with the transplant despite the poor prognosis. You have saved my life! I feel that I have had a full and complete recovery. THANK YOU!!! Allogeneic transplant 2013- now 44 years old.*
- *The autologous transplant I underwent five years ago for treatment of relapsed lymphoma was by far the most difficult thing I ever did. I suffered from PTSD for many months after the transplant. Unfortunately, I relapsed 9 months later and returned to SCCA for additional treatment. I was one of the first to participate in the CAR T-cell trial (no. 6) and unfortunately that also failed. My immune system destroyed the cells within a month. The SCCA doctors then suggested an allogeneic transplant, but were concerned about the outcome since my bone marrow and immune system were severely impacted due to all the chemotherapy I had undergone. The doctors gave me about a 20 percent chance to survive the treatment with manageable GVHD. I decided against the second transplant because of the potential poor outcome. Since the lymphoma was localized on my upper left side, I decided to undergo radiation treatment. I'm glad to report I've been in remission since May 2014. Autologous transplant 2012- now 64 years old.*

## ***Eye Chronic Graft-vs.-Host Disease (GVHD)***

- *I am a 12 year stem cell survivor, but long ago I gave up concern about AML; my life today is managing Chronic GVHD. Dry eyes and scleral lenses are my major problem; but I have been fortunate to have the care of excellent doctors who understand GVHD dry eyes. It is a reality that there is no cure for GVHD dry eyes. But I always remain hopeful, especially when I hear about the research on CAR T-cell therapy- and how it is a rapidly emerging form of cancer treatment for blood cancers like leukemia and lymphoma. It will be a great day when stem cell and bone marrow transplant are obsolete. Allogeneic transplant 2006- now 67 years old.*
- *I do have severe Dry Eyes. I am now wearing Scleral contacts which have drastically helped!!! I am 16 years out from my Non-related Allo Transplant and feel wonderful! I continue to thank Fred Hutch, SCCA and all the wonderful doctors and nurses every day for the wonderful care I received and continue to receive. Allogeneic transplant 2002- now 65 years old.*

- *I would like to know if anyone has GVHD issues that really worry them. My dry eyes are a big problem lately with infections, soreness, red itchy and hoping I do not go blind. Seems to be getting worse. Allogeneic transplant 2011- now 51 years old.*
- *I had terrible Graft vs. Host in my eyes, much pain for many years. The only thing that helps is the autologous eye serum. It has been amazing relief and I have tried everything. Allogeneic transplant 2006- now 60 years old.*

### ***How long does chronic GVHD last?***

- *I had no idea GVHD would last this long or be this hard of an ordeal. It's been 12 years from transplant and I am finally starting to taper my meds, only to replace them with a newer regimen. Allogeneic transplant 2005- now 49 years old.*
- *I feel like GVHD will last forever. How long will this last? Allogeneic transplant 2016- now 64 years old.*
- *I was originally told GVHD would last 1-3 years but I just celebrated the 10<sup>th</sup> anniversary of my stem cell transplant and I'm still dealing with it. Allogeneic transplant 2008- now 63 years old.*
- *I feel I am making steady progress in my recovery and energy. Finally getting off Prednisone after 5 years was a big step in improving my energy level and I think I have had fewer illnesses. I feel good and can be more active than the last few years and am grateful for how far I have come. Allogeneic transplant 2012- now 64 years old.*

[Treatment for chronic GVHD lasts 5 years on average, with individuals requiring shorter or longer treatment. Please call us at 206-667-4415 or email: [LTFU@seattlecca.org](mailto:LTFU@seattlecca.org) if you have questions about GVHD.]

### ***Self Improvement***

- *Sober, no smoking. I will tackle sugar next. Allogeneic transplant- now 55 years old.*
- *Overall health has greatly improved- limited alcohol, started aggressive exercise program. Allogeneic transplant 1995- now 69 years old.*
- *My life and general health have been exceptionally great the past 8 years. After my 75<sup>th</sup> birthday I decided to begin a regular fitness program at a local gym. Now, 8 months later, I can truly say that I am stronger, more active, with better energy, than I was- even before the transplant! Autologous transplant 2009- now 76 years old.*

### ***Anxiety***

- *I have occasional anxiety and tend to stress over things at night more than I should or did before transplant. Allogeneic transplant 2012- now 62 years old.*
- *I am glad to see the questions about PTSD, depression, and anxieties are included in the health assessment. I struggled with all 3 for years before realizing these were common among other transplant survivors as well. For a long time I thought it was just me. Allogeneic transplant 2002- now 38 years old.*
- *Been having panic attacks and becoming more anxious lately. Not sure why. Allogeneic transplant 1994- now 31 years old.*

## ***Impact on Work***

- *I feel like my aging is accelerated. I am 59 years old and feel like physically and mentally I am much older. Friends that are 6 to 10 years older have more strength and energy than I do. I have joint pain and stiffness. My memory is getting much worse and is now affecting my work. I have been doing the same job since 1979 and until the last year or so I have been able to learn new technology with no problem. Now I struggle. I feel like I have the brain of a 70-80 year old. Autologous transplant 1992- now 59 years old.*
- *Returning to work has been a challenge- there is so much I can no longer do that I did before. But trying to get disability is next to impossible. I continue to work because I can't afford to be out of work until maybe I can get disability. Autologous transplant 2015- now 61 years old.*
- *Though I am happy with my treatment, two transplants in 3 years impacted my work. I feel like my employability was impacted. I was laid off after 28 years with the company. I never felt like the legal elements of transplant were addressed. For me it was a big issue that I felt all alone on. SCCA tried to address the rest (emotional, nutritional, health). For that I am thankful... but I still feel like a victim in this one regard. Allogeneic transplant 2016- now 51 years old.*

## ***Muscle Cramps and Neuropathy***

- *The muscle cramps are annoying/ usually when in bed. Allogeneic transplant 2013- now 53 years old.*
- *Leg cramps at night is the reason for some fatigue since transplant. Nothing seems to work consistently. Any suggestions? Autologous transplant 2013- now 50 years old.*
- *Can anything else be done to improve cramping and muscle strength. I fear walking as I fall due to foot drop (if I don't wear braces). Allogeneic transplant 2007- now 65 years old.*
- *One area or topic absent from your survey is neuropathy. That's the one residual problem that bothers me the most, and I wonder how many others have this problem. Autologous transplant 2016- now 67 years old.*

## ***Feeling Disconnected***

- *Where are all the people like me? Although it is nice hearing comments from folks post-transplant for cancers, I still feel disconnected, as those people have a healthy normal life up until their cancer diagnosis. I had to fight with my disease every single day. I never knew what normal was like UNTIL I had my transplant. Having an immune deficiency disease, I feel has a whole different weight to it, as we had to deal with it for our entire lives. It is great to read the positive comments, but I still feel a sense of loneliness. How do I deal with the fears, and the doubts that creep into my mind continuously, because this pain could be the infection that shows the transplant has failed? How do get past the trauma that I dealt with daily for 26 years, and now I am supposed be normal and happy? Allogeneic transplant 2008- now 36 years old.*
- *I find it hard to believe I am alive and that my bone marrow transplant went so well. My biggest concern was not dying, but having serious, chronic GVHD. I consider myself very fortunate. That said, my outlook on life has changed significantly. I know longer take it for granted that I will live a long life like most of my relatives. Between transplant, chemotherapies, and radiation, I assume that my lifespan has been shortened somewhat. I will be surprised if I see my eighties, whereas before I was confident I would. The other change is that while I enjoy life, I feel a kind of detachment I did not have before AML. I don't take unnecessary risks, but I don't have any fear of dying. I feel like I already died and am just enjoying a strange delay in leaving this world. Allogeneic transplant 2016- now 55 years old.*

## ***Getting Back Fatigue Scores***

- *I appreciated seeing my fatigue score and related info!!! Allogeneic transplant 2013- now 57 years old.*
- *It was nice to see after all these years where I rate/rank with all the questions (fatigue score). Keep up the good work!! Allogeneic transplant 1996- now 52 years old.*

## ***Second Cancers***

- *It is frustrating to have a successful BMT that cured me of CML, only to have two occurrences of oral cancer that are most likely linked to the BMT. I feel like I was cured of one cancer only to be set up for another kind of cancer. I am thankful that my BMT was successful, but I was not thinking of how it would open the door for another cancer. Allogeneic transplant 2001- now 52 years old.*
- *It has been a very difficult few years since my triple negative breast cancer diagnosis (which doctors attribute to my TBI during my BMT). After 22 years I felt safe from cancer but to have such severe “side effects” (essentially) from my leukemia was earth shattering. I am beginning to feel a bit better with counseling and medication. I would say I wish I had truly understood the risks this many years down the road, but if I’m honest I’m not sure that is completely true. Regardless, I am truly thankful for 25 years FH has given me and I hope for 50 more. Allogeneic transplant 1993- now 42 years old.*
- *I am forever grateful for the treatment I was given at the Hutch, without it I wouldn’t be here (20 years later!!). I also participated in a stage 2 trial at U.W. after I developed a different breast cancer (triple negative) in the other breast. I’m sure that that experience contributed to my current well-being. Who knew I would one day be grateful to grow OLD! Autologous transplant 1998- now 81 years old.*
- *This year I celebrated the 25<sup>th</sup> anniversary of my BMT. I tipped the scale, I now have loved longer post-transplant than pre-transplant. Thank you for this wonderful milestone. Unfortunately... 5 days later my mammogram revealed an 8mm mass in my left breast. Fortunately, the doctors believe it can be resolved with surgery and radiation. Life is a rollercoaster. Autologous transplant 1992- now 49 years old.*
- *I am 15 years out and recently had a squamous cell carcinoma removed from inside my cheek (which was much more involved than I expected). I just want to alert other survivors that even though I am pretty healthy we still need to remember the side effects that can happen even 15 years later. Allogeneic transplant 2003- now 66 years old.*

## ***Out of Suffering***

- *This year marks nine years since my transplant. So much happened in the interim, and I am grateful for renewed health to experience the birth of two nieces and a nephew, holidays and every day with family and friends, new jobs, race-walking adventures and so much more. Even the troubles and tragedies have enriched my days: a diagnosis of melanoma, several broken bones (due to clumsiness, not bone loss from transplant ☺), and the death of my brother and miscarriage of my sister. Perhaps ‘enriched’ isn’t the proper term. These events serve as a reminder to appreciate the joys, and my heart is fuller as a result. ‘Out of suffering have emerged the strongest souls; the most massive characters are seared with scars.’ - Khalil Gibran Allogeneic transplant 2008- now 39 years old.*

## ***Fear of the Disease Coming Back***

- *I constantly worry about the cancer coming back. I know that this is common feeling among cancer patients who have gone through treatment. Having had cancer, the fear of it coming back is always the elephant in the room.* Autologous transplant 2011- now 67 years old.
- *How do patients handle their fears and worries about their cancer returning? 95% chance mine will (and as of July blood test shows it is). How do they plan their lives with knowledge their cancer will probably return, as with multiple myeloma?* Autologous transplant 2012- now 69 years old.
- *Scared of relapse.* Autologous transplant 2013- now 51 years old.
- *I still feel guilty about putting my family through this, I feel troubled- at times- that the mantle cell lymphoma could return. I do some volunteering with the local cancer support group. Upon my first visit there, a doctor actually used the word cure. Thank you.* Autologous transplant 2003- now 65 years old.

## ***Second Chance***

- *I feel like I gain ground by looking at my life as a gift like a second chance to do all the things I had put off and I look at every day as an opportunity.* Allogeneic transplant 2009- now 53 years old.
- *Thank you "Hutch", seventeen years post Auto-mini allo. Not an easy 17 years but I have gone more places, seen amazing things and have enjoyed life more than I did pre cancer. Thank you for keeping me alive. Life is good.* Allogeneic transplant 2001- now 65 years old.
- *I feel blessed at getting a 2<sup>nd</sup> chance and that some don't get.* Autologous transplant 2014- now 61 years old.
- *It's been 7 years now. This survey is a good yearly wake up for me. This is my second life (now one with a 3 year old daughter), and I need to do better for her, my wife, and myself!* Allogeneic transplant 2011- now 35 years old.

## ***Celebrations***

- *I feel very fortunate to have had 11 years cancer-free since my autologous transplant at The Hutch. Each year about this time, around the solstice, we celebrate my survival, my wife's survival of cancer three years before me, and a friend's successful quadruple bypass surgery two years before that. We call it our 'I'm Not Dead Yet' (INDY) dinner. So far, so good. Keep up the good work.* Autologous transplant 2006- now 67 years old.
- *I had a wonderful visit with a fellow Fred Hutch 'alumnus' recently. He also had a bone marrow transplant for CML. His transplant was the day after mine and his hospital room was right next to mine. During our stay in Seattle our families got to know each other and we stay in periodic contact. He and his wife and I had lunch near his home town. We all agreed how grateful we are for everything the Fred Hutch Center did for us and how blessed we feel to be enjoying such a quality of life. I'm sure you hear this type of thing a lot but do always remember there are a lot of very grateful people out there whose lives you helped put back together!* Allogeneic transplant 1997- now 63 years old.