

Thoughts and Comments from Patients – 2024

Overcoming the odds

- *Having just celebrated the 20th anniversary of my SCT, I've taken the opportunity to reflect on the dim prognosis I faced and the trials I and my family endured that brought us to the place where I can fill out this questionnaire. Without getting into any melodrama, I can only conclude that, "Anything you're around to complain about, WASN'T THAT BAD!" When I was originally diagnosed in 2003, my doctor told me "maybe" 1 patient in 10 with my underlying issues survives treatment and that I needed to "get my affairs in order." I complied, rewrote the will, made financial arrangements, etc. Another thing I felt compelled to do is leave personal video messages to each of my three kids (15,12 and 6) commemorating all the anticipated life events (I didn't leave anything out!), up until they had their first child, and then one to my wife (who became my hero!). That proved really hard, as I came to grips with my "pending" mortality and the prospect of leaving my family without a dad and husband. I believed then and believe now that God's will is perfect in my life, even when I think it sucks! Death didn't scare me... dying, a different matter. I asked myself this question though, "If 1 in 10 survive, why can't I be the ONE? It turns out, I am. Allogeneic transplant 2004– now 72 years old.*
- *In 1984, at the age of 26, I had an allogeneic transplant from my brother for relapsed B-cell lymphoma. At the time, my bone marrow was so packed with tumor that I was transfusion dependent and had less than a month to live. Hutch accepted me after I had been turned down by every other transplant center in the country (there were only a few at the time). Immediately after the transplant, I caught pneumonia, was intubated, and remained unconscious on a ventilator for two weeks. After I finally awoke, the Hutch staff threw a little party for me because I was their first patient ever to survive pneumonia and the ventilator. Over the following 9 months the GVHD and platelet dependency faded. By October of 1985 I had returned to playing competitive basketball, healthy and all muscled up, which shocked my teammates who had watched me wither away the year before. Only over time have I come to realize how extraordinarily lucky I was. Over the next 40 years I got married, had two beautiful children from sperm stored prior to the transplant, adopted two more from Russia, started a successful company that worked all over the world, and retired to an idyllic life at age 63. Allogeneic transplant 1984 – now 67 years old.*
- *After lymphoma diagnosis 2008, on one of early visits at SCCA a doctor told me: We may not cure you, but if we can keep you alive for 5 years there will be better treatments available. I went through R-CHOP (relapsed) Autologous transplant (relapsed), first recipient of CAR-T cells (almost cured, relapsed), Allogeneic transplant 2014 – severe GVHD including 111 days in UW hospital, numerous clinical trials. Finally, total remission for last 10 years. Thankful for all the incredible caregivers at SCCA and UW hospital. Allogeneic transplant 2014 – now 69 years old.*
- *Wow 45 years. I'll never forget the day our family doctor told my father my chances for survival are very slim. They stood in the lab looking in a microscope. I was 16. Not a care in the world until the day I looked at my father's eyes, tears coming from his face. I knew something was*

wrong. They found Fred Hutch and two months later I was on a plane to Seattle. It's been an amazing journey. All thanks to my brother/donor, father and the good Lord and FHCC. Without the awesome care, I wouldn't be here. Allogeneic transplant 1979 – now 61 years old.

- *At the time of my transplant in 1985, my CML had moved into an accelerated phase. Only 5 transplants had been done at that stage before me; 4 died right away and the 5th lived 2 years. I think I was given extra radiation to boost my survival chances. Apparently that worked! I am astonished that I will be 72 this summer and am not on any prescriptions. I walk slowly with a walking stick and my muscles are pretty weak, certainly not what they once were. But I am 71 and thankful every day to be here! Thank you to the Hutch for the life you have given me! Allogeneic transplant 1985 – now 71 years old.*

Transplanted as children

- *I've been healthy and able to do a lot more activities that I couldn't before. Life is great right now. Allogeneic transplant 2016 – now 22 years old.*
- *Thank you for all your work. [My child] is doing well post-transplant. She has struggled socially at school after re-entry following a long 6 year battle with leukemia. With support of family she is taking on the challenges and continues to be a bright light in our lives. Allogeneic transplant – now 15 years old.*
- *We're deeply grateful for the care [our child] received at SCCA and SCH. [His] 2nd BMT has afforded him a durable remission from multiply relapsed AML. Sadly, the treatments required for his remission -- IT chemo that caused severe methotrexate-induced leukoencephalopathy, and TBI -- have resulted in sustained cognitive impairments that have a significant impact on his daily life, his ability to participate in school, his ability to make social connections with his same-aged peers. We have been told to expect that he will likely always need support throughout his life. Allogeneic transplant 2019– now 7 years old.*
- *Thank you so much for the outstanding care our son received five years ago! He is thriving now! Allogeneic transplant 2019– now 8 years old.*
- *This is a picture of me and my granddaughter now 7, only 2 years younger than I was when I had my transplant. Allogeneic transplant 1975– now 59 years old.*
- *My transplant was in 1974 - 50 years ago, and like most of the responders I am very grateful that I got a second chance on life. At this point the patient recovery questionnaire that comes every year is probably the only thing that does bring back some of the memories of my transplant experience. So, after 50 years with no health problems to speak of I think I will sign off as I don't think I have much more to add to the questionnaire (unless it is to see who has survived the longest post transplant). Best of luck to all of the BMT transplanted patients. Allogeneic transplant 1974 – now 64 years old.*

- *We are so grateful to all of the people at Fred Hutch and Seattle Children's Hospital for saving our son's life. [Our son] is now five years post transplant and is looking forward to graduation from high school in the spring. He loves going to the gym almost every day to lift weights and also enjoys cooking. His health is very important to him and we are so thankful to everyone who worked so hard to give him a second chance at life. Thank you! Allogeneic transplant 2019 – now 17 years old.*

Pain

- *I have had 2 failed back surgeries and now am on chronic pain meds. I am alive but now there is a price to pay for what it took to save me. Allogeneic transplant 2004– now 36 years old.*
- *We appreciated all staff and treatments. However, [my daughter] ended her treatment with an additional severe, lifelong illness. Pain medication addiction. She spent her life on these meds, in and out of treatment centers, and passed away on methadone...Although we prolonged her life, it was a lifelong battle with pain med addiction that made her life very difficult. Autologous transplant 1997 – passed away 2023.*
- *I work a full-time job that is very physical. I go home exhausted and in pain every day. I don't have the time or energy to follow up with the appointments and exams I know are necessary. I am falling behind on my GYN, mammo, and other follow up because I am just too exhausted from working and dealing with pain all day. Allogeneic transplant 1990 – now 56 years old.*
- *I'm happy that my life has been saved with the transplant, however sometimes I don't feel that I'm really living anymore. I'm always in pain and tired, I used to be so full of energy. Now I struggle to clean one room in my home. Allogeneic transplant 2021 – now 56 years old.*

Comments about LTFU

- *The LTFU is a wonderful resource for patients and has been very important in keeping me alive for 27 years now, especially by providing expert advice to physicians treating my GVHD, infections and pneumonias. Allogeneic transplant 1997– now 77 years old.*
- *I am completely satisfied with and immensely grateful for my treatment at Fred Hutch. There are a few things that I'm confused about and concerned with, however. While most of my interactions with the doctors and staff were positive, there were some that left me perplexed. From last minute comments from my transplant doctor about whether I actually needed a transplant, to mis-, or no communication between transplant and oncology and LTFU and oncology. Also, things I was originally told were changed. For example, originally I was told the objective of my treatment was cure. Later I was told "cured" was not a term ever used, and "long term remission" after five years was hoped for. Originally I was told I would return to LTFU once a year for life. Then, at my last appointment at LTFU (3 yr 7mo post transplant) I was told I didn't need to return. It seems once I was doing well, with little GVHD, "they" were no longer interested in me. Finally, I was never given any words of encouragement about my future, but rather told those leukemia*

cells can hide and return at any time. Although true, not exactly the only thing I wish had been conveyed.. Allogeneic transplant 2020– now 66 years old.

- *Whenever I have had a question or a problem, your LTFU team has had a quick, helpful response. And any time I have seen a provider at SCCA/Fred Hutch, it is obvious that they have read my chart before seeing me, which is something that doesn't always happen at other facilities.* Allogeneic transplant 2019 – now 61 years old.

Long recovery but worth it

- *I had a very long and hard recovery from AUSCT including 60 days in the hospital and months of reduced activity once home from our 5 full months in Seattle. At 18 months post-transplant, I was finally ready to say I was glad I did it. Now, each day brings gratitude for time I might not have had. I am thankful to Fred Hutch for expert care, and to God who sustained me through the dark times.* Autologous transplant 2021 – now 76 years old.
- *One year after the transplant, I'm not sure I would have done it again. Now I am 8 years post transplant and I would do it again in a heart beat. I feel great, no evidence of disease and I have hope for the future.* Allogeneic transplant 2015 – now 44 years old.

Mental health

- *I began taking an antidepressant in late April 2024. Since then my hobbies of reading, sewing and exercise hold more interest and I hope to lose weight and exercise more. I talked with my close friends and my sisters before beginning treatment. It has been about 5 weeks, but I feel better and am more active. A support group (family/friends) is so important to my well-being and recovery. Being able to voice my concerns to my doctor, family and friends is a skill being a transplant patient at “the Hutch” taught me I am grateful for that. Keep up the good work.* Allogeneic transplant 1987 – now 69 years old.
- *I am still experiencing PTSD symptoms from cancer treatment and being sick for so long, despite being 15 years out of transplant. I didn't realize until recently how traumatic it was to have cancer in my 20's and that I lost my sense of self then, and now have only begun to do extensive deep diving into self discovery to find myself. I'm struggling significantly mentally as well as physically from being fatigued easily.* Autologous transplant 2009 – now 44 years old.
- *I think my biggest concern in my current stage of life is my mental health. The anxiety I experience surrounding any health issues is immense, ie., "is the small ache/pain I'm feeling, cancer?".* Allogeneic transplant 2008 – now 28 years old.

Having children

- *I am so happy to tell you I had kids. I was told after my treatment that I would not have kids. How exciting.* Allogeneic transplant 2004 – now 25 years old.

- *I struggle most after having children with the worry and concern of future health problems or issues. I do not want to be a burden to them, or not be there for them as they grow up. Allogeneic transplant 1989 – now 42 years old.*
- *Feeling good at 41 years old. I'm currently pregnant with my second child – both spontaneous pregnancies without a donor egg or sperm or IVF. 28 years since my treatment at FHCRC! Aplastic Anemia treatment 1996 – now 41 years old*
- *My uterus was stressed from radiation and would only expand to 5 ½ months. I delivered my baby girl vaginally. She lived one hour. Allogeneic transplant 1988 – now 47 years old.*

Positive feelings after transplant have faded

- *I find this annual survey a little stressful and depressing, both as a reminder of where I've been and the need to catalog everything that's wrong me in the past year. Interestingly, I used to find it uplifting as a "look how far I've come." This May was my 20 year transplant anniversary. Allogeneic transplant 2004 – now 55 years old.*
- *For a while I was feeling very grateful. Last year I passed the mark where the majority of people diagnosed the year I was with multiple myeloma (2016) have died. I felt lucky to be alive, and I feel the stem cell transplant is definitely part of the reason. However, lately I'm pretty depressed and lonely, and I do feel like my diagnosis leads to a feeling of isolation from other people who don't understand what it's like. So my mental health is up and down, and I'm not sure why. Autologous transplant 2017 – now 64 years old.*
- *I wish I was able to maintain the positive perspective on life that I had during treatment. Unfortunately it feels easy to slip into old, negative patterns of thought and action. The fact that my diagnosis and treatment in a way feel a lifetime ago makes it easier to do so. Thank you so much for all that you did to give me another 22 years. I never, ever thought I would see 50 years old at that time. Allogeneic transplant 2002 – now 50 years old.*

Over 80 years old

- *I'm 86 years old now so am having some difficulty with balance, weakness, and forgetfulness that my bone marrow transplant has allowed me. Thank you for your treatment. Autologous transplant 1991 – now 86 years old.*
- *In connection to my reference to fatigue, I was told I may (or will) have to endure chronic fatigue the rest of my life. I do suffer from chronic fatigue and doctors tell me there is no solution. Autologous transplant 2005 – now 90 years old.*
- *Most of my symptoms are due to old age. I'm 92 years old. I'm losing my vision and hearing. I tire easily and sometimes get short of breath or get dizzy. Allogeneic transplant 2000– now 92 years old.*

- *At age 84, I am still living independently! I love working in my yard. During the long, wintry months, I developed a liking for mosaic wooden puzzles. Wordle is a fun challenge with family and friends. I am grateful for each new day! Thank you so much, Hutch, for encouraging me to get a transplant way back in 2003! Autologous transplant 2004 – now 84 years old.*
- *A big, heart-felt thank you to all the medical personnel who participated in my care in 2006. Living in Seattle for 6 months and being in and out of the UW hospital for a total of 78 days was a difficult time. My husband never left my side and together we survived the ordeal. Two years ago my oncologist told me not to come back anymore. I am now 80 years old and so blessed to be completely healthy. Allogeneic transplant 2006 – now 80 years old.*
- *I had a wonderful 90th birthday in August 2024! It was peaceful, like I didn't have a care in the world! Had lunch out with family. Autologous transplant 2006 – now 90 years old.*

Words of encouragement to others facing transplant

- *Thank you for giving me back my life! I am 14 years post cancer treatment. Life is good. Keep going forward! Don't look back, you're not going in that direction! Allogeneic transplant 2010 – now 62 years old.*
- *I have been diagnosed with two different types of AML, undergone two bone marrow transplants, months of hospital stays, nine surgeries. I wish the best for all of those in the midst of their journey and for those hopefully on the other end. Allogeneic transplant 2016 – now 38 years old.*

Appearance is important

- *I'm nearly 7 years out and I finally feel like I have the ability to fully live life again. My body actually moves like I need it to. The thing I struggle with the most is that my appearance has changed since the transplant. Every area where I had severe GVHD has now been replaced with dark spots or what appears to be vitiligo. I feel like a look healthy, but I get stares and looks from people that can really affect my self esteem. If only they knew what my body had been through... Allogeneic transplant 2017 – now 38 years old.*
- *I'm surprised that you do not address body image issues. I experience much distress because of general deconditioning post-transplant along with having issues with my post-transplant hair and the psychological effects of looking in the mirror and seeing someone looking back who appears 20 years older. Autologous transplant 2023 – now 58 years old.*

Unexpected benefits of transplant

- *Very thankful for Fred Hutch. I am in remission presently. Interestingly, I had psoriatic arthritis for 14 years, pretty severe pain in my joints and overall fatigue. With the transplant, my arthritis*

is in remission and I no longer need medication to treat it and my psoriasis has also gotten better. Not totally gone, but much improved. Autologous transplant 2021 – now 60 years old.

- *I believe it's unfortunate it has taken circumstances such as this to help me recognize the wonder and enchantment this life brings us all. I sometimes ponder how much more I could have enjoyed my life had I been enlightened earlier. Allogeneic transplant 1991 – now 56 years old.*
- *As I am now celebrating 40 years since my transplant, I am taking some time to reflect what it has meant to me beyond the opportunity to live longer than I would have without it. For me, the BMT was the beginning of a quest to live a better and healthier life. Immediately after recovery, I became a top student in high school and got into Yale. I also quickly gave up eating beef (considered even in the mid-1980's to be an unhealthy meat) and got me started working out regularly and improving my diet. The quest has led me to reach the highest of my discipline. In many ways, overcoming illness at a young age has been a blessing in my life. I remain on a quest to live the longest, healthiest happiest life possible and owe it all to the great work of Fred Hutch! Thank you! Allogeneic transplant 1984 – now 55 years old.*
- *Thank you for the precious gift of life that Fred Hutch gave to me 35 years ago at age 30. My cancer and treatment changed my life and I am thankful to be the person I am as a result. In the darkest moments of my treatment, I found gratitude, living in the moment, and physical activity to be the path forward. I have continued to embrace these skills throughout my life. Allogeneic transplant 1989 – now 65 years old.*
- *Thank you for twenty years. I've seen the little boys become men and gained a daughter-in-law whom I adore. I've grown to middle age with the man who has been there for it all. I would never have chosen this path God picked but I wouldn't trade it for anything in the world. This experience allowed me to face my mortality early and live what's left with no fear. Autologous transplant 2004 – now 54 years old.*

Brain fog

- *Brain fog is real. My motivation is way down. I get very tired by the afternoon and pretty much end up lazing around in the evenings which is a real bummer. Autologous transplant 2019– now 56 years old.*
- *I currently work full time, but find that I struggle to remain coherent where I was fully cognizant in my field prior to the transplant. I do feel a "hole" or loss of function in memory 'pick-up', response time, & overall processing. I find what used to be simple "chore" tasks to be very hard/taxing on my system & it is overly hard to exercise or do yard work or tasks around my home. I find it harder to concentrate on tasks at work and keep things in order. I totally find myself distracted easily by anything else, having no patience for long tasks. I get anxiety because now with all my troubles I feel like everything that takes too much time, or is overly taxing or lengthy, is wasting the time I "have left" here. Allogeneic transplant 2001 – now 43 years old.*

Second cancers

- *Unfortunately, I did develop a secondary cancer after decades of relatively good health following successful treatment for CML accelerated phase. Likely cause was the radiation during the BMT that saved my life. I am working very hard to regain my health. Allogeneic transplant 1996– now 63 years old.*
- *My fear of a secondary malignancy is much greater than a recurrence of my original Dx -ALL / CML. Allogeneic transplant 2006 – now 60 years old.*
- *I have nothing but high praise for everyone who is involved in Fred Hutch and LTFU. I have always felt as though they all truly cared whether or not I was doing all right, and made me feel as though I could make it through the original illness....If it wasn't for the long term follow up my lung cancer would not have been caught at such an early stage. I am grateful. Allogeneic transplant 2018 – now 76 years old.*
- *42 years! After my diagnosis of both prostate and liver cancers last year, and the treatments to deal with them, I'm more vigilant than ever to make sure that I know exactly what's happening in my body. It was the biggest wake up call since the days of my BMT and another reminder that we can never let our guard down when it comes to our health. I'm happy to say, as of writing, I'm liver and prostate cancer free. But I'm also sad to say that I know that I'll die someday of some kind of cancer, but it won't be today. Every day is a gift, so thank you to all of the doctors and nurses for giving me over 42 years of presents. Allogeneic transplant 1982 – now 57 years old.*
- *I've had thyroid cancer and multiple skin cancers since my transplant and wonder what else might pop up over the rest of my life. But I'm also 39 years post transplant after being treated at the age of 15 so the life I was given is all more than worth it! Thanks Hutch and Seattle Childrens! Allogeneic transplant 1985 – now 54 years old.*

30+ years since transplant

- *30 years! As they say it goes by very fast. Thanks to my transplant and the exceptional care I received at Fred Hutch I celebrated my 50th turn around the sun this year. My initial survival rate was extremely low and GVHD and PTSD post transplant were extremely challenging but so very worth it. I'm ever-grateful for the years and true quality of life I've enjoyed since. I'm in good health with a wonderful family and community of friends. I look forward to this time of year to give extra thanks for this gift of life. Allogeneic transplant 1993– now 50 years old.*
- *I'm another year older. At one point in time I wasn't sure that I would live past 30, now thanks to the medical treatment I received at FHCRC I am still very much alive and 66 years old. Allogeneic transplant 1987– now 66 years old.*
- *I was diagnosed with multiple myeloma in 1987 and it was in 95% of my marrow. After initial treatment to keep me alive, I went to Fred Hutch and had an Allogeneic transplant with my brother's marrow in 1988. My experience at Fred Hutch was amazing. My brother (and donor) was asked to stay six months and his company was able to transfer him to Seattle. I guess it was*

all meant to be! I am 36 years post-transplant and I might have been the first multiple myeloma cure for Fred Hutch! I am now 71 and healthy. Allogeneic transplant 1988 – now 71 years old.

- *Thank you so much for my transplant 1993! It's been 31 years! I'm so thankful for the life that you gave me – it's been wonderful. I've had a few troubles but all worth it! I just retired from nursing and looking towards another 31 years and growing old – LOL. Allogeneic transplant 1993 – now 57 years old.*
- *Happy and surprised to still be here and doing as well as I am thanks to everyone at FHCC! Thank you all for all you and your research has done for us! I really did not think I would still be here and enjoying every day of my life as I have been able to because of those who came before me as doctors, researchers and patients to contribute to longevity I have gotten to enjoy. I was 34 in 1984 when I had my transplant. I have lived longer since my transplant than my age at transplant! I am sure that those that cared for me in 1984 have long ago retired but so grateful for their excellent care and the dedication to helping me live!! Allogeneic transplant 1984 – now 74 years old.*
- *May 2024 marks 43 years since my transplant at Fred Hutch. As I reflect on this incredible milestone, my heart is filled with immense gratitude. I am thankful for the unwavering support of my family and friends. I am grateful for my doctors at Fred Hutch, the many doctors and medical professionals who continued to provide exceptional care and treatment through the years. Most importantly, I am thankful for the gift of life itself, and for each day I have been able to cherish, grown and experience. Here's to continued health, hope and happiness. Allogeneic transplant 1981 – now 59 years old.*
- *Please continue to send these questionnaires but be aware that I might not find the time or energy to reply for several months. February is a low point in the year for me in terms of workload, depression, anxiety and fatigue. Aplastic Anemia transplant 1983 – now 53 years old.*
- *I recently celebrated my 34 year anniversary of my bone marrow transplant, or my 'rebirthday' as I call it. SO SO very grateful to Fred Hutch Cancer Center for taking care of my all those years ago, and thanks to them I am not only alive but thriving!! Autologous transplant 1990 – now 50 years old.*
- *34 years post transplant. Retired in 2023. Loving retirement. Spending time with husband and grandchildren. Life is Wonderful! Allogeneic transplant 1990 – now 64 years old.*
- *As I near the end of my 70th orbit around the sun and am not always positive in my thoughts and deeds, in my heart and soul I am eternally grateful for each and every day. What a wonderful ride it continues to be! Allogeneic transplant 1972 – now 69 years old.*
- *I had cataract surgery (both eyes) last November. I had a total knee replacement in March. Total recovery from both. I was playing golf 4 weeks after knee surgery (riding in cart). Totally able to walk 18 holes now. So happy to be able to live long enough to get on Medicare and have these problems! Allogeneic transplant 1989 – now 65 years old.*

- *I was 31 years old when my life turned around. I call it the best and worse time in my life. I had a great job, moved into a brand new apartment and one month earlier met the man of my dreams (who is still the love of my life). The day I moved into my apartment I got a call from my doctor telling me I had leukemia. I told my mom that I thought my life was over. It's been 37 years post-transplant. I am 69 years old and still going strong. I think my doctors every day for sending me to Fred Hutch. They gave me my happy ever after. I have a happy healthy life and am truly blessed by their care. Thank you Fred Hutch! Allogeneic transplant 1987 – now 69 years old.*
- *Since my experimental BMT in the autumn of 1983, I have lived 41 wonderful years even though some things would "go wrong" with my body, mind or psyche every so often. My wife and family get 100% gratitude for their unwavering help and support. Thank you to everyone at Fred Hutch for your wisdom, knowledge and vision. You have helped so many live a great life! Allogeneic transplant 1983 – now 76 years old.*

10 years or less since transplant

- *I am very grateful for the wonderful care I have received at SCCA/Fred Hutch. I trusted you with my life and here I still am after 8 years. Allogeneic transplant 2015 – now 75 years old.*
- *I will celebrate the 10th anniversary of my stem cell transplant next week. This feels like a major milestone and I am grateful everyday for my donor, the care I received (and continue to receive) at Fred Hutch, and the life I continue to enjoy with my family. Allogeneic transplant 2013– now 52 years old.*
- *I am currently 2 years in remission post double umbilical cord transplant. I am doing much better with my health and things are very close to back to normal. Allogeneic transplant 2022 – now 46 years old.*
- *I continue to be grateful for the excellent care I (and my husband as my caregiver) received at Fred Hutch. I am now at my 7th anniversary with no long-term effects from the SCT. We are living our lives fully now, when we thought I would have only a few more years to live. I am also grateful for the research Fred Hutch is doing that has contributed to the reality that people with blood cancers now have more treatments available to them than I did all those years ago. Thank you for all you do! Allogeneic transplant 2017 – now 75 years old.*

Anxiety about lab tests

- *Although my myeloma is being managed and it looks like I'm in a good place for the time being my thoughts get consumed with when will this "monster" wake up again. When I get my monthly myeloma labs I still take a deep breath when I look at results on MyChart. It's been a challenge to engage and live with the constant reminder, significant back pain fractured due to this disease. Autologous transplant 2023 – now 70 years old.*

- *I do get a bit of an anxious tummy every month in anticipation of my lab results. Autologous transplant 2022 – now 63 years old.*
- *One big impact with my multiple myeloma is that even though it's been in remission for 7 years, the concern of re-occurrence is always looming over me. I don't worry about it day to day but I'm at a point in my life where I'm having to make big decisions on my future and it really impacts those decisions. I retired earlier than planned, since I didn't know if it would come back. I would like to move to a less populated area, but don't feel like I can in case it comes back. I don't know if I want to get another pet in case it comes back. It feels like I'm in kind of a weird holding pattern on my life waiting for it to come back, even though it might not. I think this wouldn't be as much of an issue if I was older or younger and on an established path. I would just keep on doing what I was doing. Autologous transplant 2017– now 64 years old.*
- *My one year anniversary is approaching so I have some anxiety. I fear relapse. I hope all the testing with LTFU gives me great news! Allogeneic transplant 2023 – now 73 years old.*
- *I am somewhat anxious about disease returning prior to getting yearly lab work. Once CBC comes back normal. I am ok. Allogeneic transplant 2000 – now 65 years old.*
- *Fear and anxiety are real when test time and waiting for lab results. But often forgot between labs. Autologous transplant 2017 – now 68 years old.*

Caring for caregivers

- *How the tables can turn. Nearly 20 years ago my husband helped me get through my AML/transplant “adventure”. Now, in his mid 80's, I am his eyes (he can't see very well), ears (hard of hearing), cook, appointment scheduler, driver, etc. Thank you SCCA for providing these added years so I could be here to assist him as he helped me so much so long ago. Allogeneic transplant 2005 – now 76 years old.*
- *My wonderful husband who moved us to Seattle for my BMT in 2007 passed away 6 weeks ago from a very aggressive cancer that had only been diagnosed six months before. I only wish I had been able to find the level of care for him that I had all those years ago at the Fred Hutch. Allogeneic transplant 2007 – now 58 years old.*

Chuckles

- *In the twenty years since my transplant, I have been remarkably symptom-free and trailing virtually no smoke. Allogeneic transplant 2005 – now 65 years old.*
- *I can't sweat, my periods are absent if I don't take birth control, my hair is super thin where I can see my scalp, my hair is growing super slow, I am still tired, I have panic episodes if triggered sometimes, all of my body hair is thin, my knee gives out on me sometimes, my muscles ache from work, I can't go up a ton of stairs without my muscles burning, I have a sweet tooth now, my*

weight is hard to get off, I get mild hot flashes, I also have nasty smelling farts, but other than that I'm good. Allogeneic transplant 2023 – now 20 years old.

Chronic GVHD

- *I look forward to getting the questionnaire every year. It means another year has gone by since my transplant. Thankfully there is no disease recurrence and mild GVHD. However, it seems like the GVHD will just never go away since it has been 14 years. Side effects worse than my mild GVHD. Maybe one day. Thank you for trying to find treatments. Allogeneic transplant 2009 – now 57 years old.*
- *I can't believe I am 14 years post transplant. I am technically a teenager, but I feel more like a senior citizen. Nevertheless, I am very grateful for the care I received SCCA and UW. The long term follow up program is great too. I don't know how many other transplant centers have this amazing program. It is essential to see how patients are doing after transplant, not just 5 or 10 years, but for the rest of their lives. My post transplant journey has not been easy. I have had chronic GvHD which has affected the majority of my organs. Allogeneic transplant 2010– now 43 years old.*
- *I have had Chronic Dry Eyes since transpalnt. My eye Dr recently told me about human serum drops and I have been using them since November 2023 and as long as I use the drops 4 times/day I have no pain!!!!!! They are fabulous!!!! Allogeneic transplant 2002– now 72 years old.*
- *The down side is that I was told my chronic GVHD would last 1-3 years. Tomorrow will be the 16th anniversary of my transplant and I'm dealing with a major flare up. The upside is that when diagnosed they gave me less than 2 years to live and here I am 16 years later enjoying spending time with my beautiful wife of 50 years, doing lots of traveling, and watching 2 incredible grandkids grow up. Allogeneic transplant 2008 – now 69 years old.*
- *I feel very lucky for the past 15 years of very good life and activity following my transplant. The graft-versus-host disease changes to my lungs/broncholoitis obliterans has now progressed to the point where I am getting very close to not being able to do some of the things I enjoy like walking a round of golf or playing pickle ball. I am planning on getting a portable oxygen concentrator to see if it will help extend the time I can continue to enjoy these activities. I am hoping it will allow me to continue aerobic activities at a level that keeps my cardiovascular system in good shape too. I accept that one day I may not be able to do these things. Allogeneic transplant 2009 – now 65 years old.*
- *Two years later I am still in remission but have a very debilitating cGVHD...This was not the retirement that I had contemplated, and I felt a tremendous burden for my spouse of almost 45 years who is my primary caregiver and is an incredibly youthful 66. Suddenly, I had gained 50 pounds, struggled to walk, was confined to my house due to my immunosuppressed state, had a fraction of my customary energy and zest, and spent my time shut up in my den updating wills and other key documents for my wife. Allogeneic transplant 2022 – now 65 years old.*

Dealing with relapse

- *I have refractory disease and I'm looking at my fourth treatment plan. I feel good and want to travel this summer so I'm hoping treatment will not interrupt that. I'm doing as much as I can to enjoy life while I have the time. Autologous transplant 2019 – now 68 years old.*
- *I stayed disease free until 2020 when I relapsed. It was, of course, devastating to relapse after 12 years but the fact that I had been given that time enabled me to see my both my kids grow up and I will always be grateful for that! In early 2022 I went to Seattle, where my sister lives, to embark on the daunting process of another bone marrow transplant. After 5 months of treatment cumulating in a BMT from an unrelated donor in August, 2022 I am once gain disease free! Allogeneic transplant 2022 – now 66 years old.*

Gratitude

- *Every year when I get the comments section from the Hutch – I treat my reading of it as kind of a respectful solemn deep dive into my old world of bone marrow transplantation. Before I read the comments I have to wait until I am alone, in a peaceful mood, in a quiet place, and that I am ready for a roller coaster of emotion. The tears do flow – tears of triumph, joy, suffering, and deeply buried memories that I don't often think about much anymore after 28 years. What moves me so powerfully is that every one of those comments could be mine – right from my own personal experience. We Hutchers are all comrades on this challenging journey of transplantation. Allogeneic transplant 1996 – now 69 years old.*
- *Cancer comes with many gifts, primarily the gift of gratitude. And the gift of soaking in joyful moments. So very lucky I am to be filling out this survey for the 7th time! That's 8 years since I received the gift of more life through the ministrations of my health team at the Hutch. My continued life I realize, is in part because of those who came before me and did not survive, giving new information for the treatment of our diseases. Autologous transplant 2016 – now 67 years old.*
- *My experience at Fred Hutch over the past year was beyond all expectations I had for the bone marrow transplant. The transplant team of doctors, nurses, PA and techs provided me with ample pre and post procedure information that allowed me to be prepared and experience a very smooth procedure. I was amazed at the level of excellence of the round the clock care at UW as well. Everyone treated me professionally, explained every procedure, answered all of my questions thoroughly and maintained an upbeat attitude with humor that made the days fly by. Allogeneic transplant 2023– now 71 years old.*
- *I was a young man (28) when I was diagnosed with AML. I was lucky to receive a successful allogeneic transplant within 6 months, and I have recovered fully. I am now a middle-aged man (52), happily married with two happy, healthy teenage sons. I work doing a job I like very much. I look up and nod to the 7th floor at the UW Medical Center (where I was treated and spent more than 10 weeks receiving treatment) as I cross the Bridge on my bicycle on my 10 mile ride home.*

I am a lucky person, and I thank Fred Hutch and the wonderful caregivers for giving me the chance to live and love and contribute to society. Allogeneic transplant 2001– now 52 years old.

- *Having my transplant has given me so much respect for life and living in the moment and to never take any time we have in this world for granted. Allogeneic transplant 1990 – now 52 years old.*
- *I try always to be mindful of the sacrifice made by patients in the early days of developing and improving transplant that allowed me to receive mine with such safety and success. The memory of the misery of the time immediately post-transplant and the years of GVHD has mostly melted away. Allogeneic transplant 2010 – now 68 years old.*
- *I'm thankful for every day, week, month, year of life I've had since my transplant. My biggest desire was to see my youngest child graduate from high school in 2003. I watched him graduate from college in 2008! Allogeneic transplant 1997 – now 63 years old.*
- *The best part of receiving this questionnaire is seeing my name with the number of years post-transplant! It is a wonderful reminder of reflection to see the fragility of my health entering in The Hutch to where I am at now! The science, clinical trials and research that is done provides hope and promise of a future. So once again my one word is and will forever be GRATITUDE! Allogeneic transplant 1996 – now 61 years old.*
- *Every year when I get this questionnaire, I rejoice that I have celebrated another year to make memories, love my family, and have new adventures. My son says, "Mom is the only person I know who enjoys getting older". I know what a miracle feels like and it is my life. Thank you for all you have done to give me these additional 15 years. Allogeneic transplant 2009 – now 75 years old.*

2025 Fred Hutch Selected Resources

- 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>