Thoughts and Comments from Patients – 2016

Transplanted 30+ years ago (1986 and before)

- There are no words to express having 30 extra years of life except thank you from the bottom of my heart. Allogeneic transplant 1986 – now 51 years old.

- Since it has been 32 years, I don’t feel like a lot of these questions apply. Actually I don’t see any real benefit. For instance, to ask about my mental or emotional health in the past 4 weeks after 32 years out doesn’t seem relative. It could be sad or depressed because my pet died or I could be anxious because I am caring for an elderly parent. I could feel tired because I am training for a serious athletic event or I could work only part-time because I am able to financially. And as I age, so many issues could just be age related which could apply to anyone my age. Allogeneic transplant 1984 – now 53 years old.

- I just celebrated the 34th anniversary of my BMT. The world has changed quite a bit in those 34 years and I’m grateful to have experienced all of it. I’m slowly turning into an old man and I couldn’t be happier. My health is good, my two kids are growing up, my wife and I are happy – what more can a person ask for? Here’s to another year! Allogeneic transplant 1982 – now 49 years old.

- 37 yrs. post-transplant & still counting!! I was a young 31 yr. old wife & mother of two children ages 6 & 3. My daughter was going to be starting 1st grade in Sept. (My transplant was in July). I remember talking to my sister-in-law, scared to death crying to her that I didn’t know if I would live long enough to see my little one make it through first grade. We just celebrated my granddaughter’s 21st birthday, my little girl’s daughter. Talk about blessed – thanks you for all these wonderful years. Allogeneic transplant 1979– now 68 years old.

- 37 year anniversary!! I’m very grateful for the chance to wake up every day. In 1979 my doctor told me my chances were almost zero. And my best shot was to go to Seattle to get treatment from FHCRC, still today I thank God and the people of FHCRC. And of course my brother + his sacrifice for my life. Allogeneic transplant 1979 – now 53 years old.

- It has now been 39 years post-transplant and am still doing great. Thanks to all at FHCRC. Back then they didn’t know much about what was going on with me ‘Aplastic Anemia’ and they still may not know much, I don’t know. I do know that I am thankful and grateful to be here. Allogeneic transplant 1977 – now 45 years old.

- I’m not sure if any of my aches and pains have to do with the transplant or just aging. But thanks to you I have had 43 years of life and looking forward to more. Allogeneic transplant 1972 – now 74 years old.
**Thoughts about the reunion**

- I had a wonderful time at the reunion this summer. The staff at Fred Hutch were all very friendly and interested. I still celebrate every birthday and my allogeneic donor sends me a card since I met her in 2013. Allogeneic transplant 2003 – now 66 years old.

- I attended my first BMT reunion last year. The reunion was awesome. It was nice to see other BMT survivors that were several years longer than my 22nd year post BMT. Allogeneic transplant 1993 – now 59 years old.

- I loved the reunion in July! Thank you! I don’t love that I get bombarded w/ solicitations for donations. I will give when I can, please stop wasting $ on printing & mailing. Allogeneic transplant 1996 – now 49 years old.

- Going to my first 5 year post stem cell transplant survival reunion last year with my wife gave me new spirit. I am healthy, but just felt lost and failing. After meeting so many amazing post-transplant survivors, first it frightened and depressed me that I could have died, and then it inspired me to apply for and get a new job at a hospital to improve primary health care. At 67 years, instead of preparing to retire. I’ve reinvented myself and I will also be a grandfather for the first time! Autologous transplant 2008 – now 66 years old.

**Sex, intimacy and fertility**

- After I was discharged from transplant in 2009, there was little if any discussion of the effects of the treatments and GVHD on my sexual heath and their effects physically and psychologically. It would have been helpful to have more information at that time so that I could cope with the sexual/gynecology side effects better and not have struggled so much trying to cope on my own. Allogeneic transplant 2009 – now 67 years old.

- My sex life is destroyed. I have erectile dysfunction. Viagra doesn’t work and I have to use injections. I’m only 47 years old. I’m very sad. Allogeneic transplant 2013 – now 47 years old.

- In terms of romantic relationships, I don’t really have any hope. I feel like ‘damaged goods.’ I can’t have children on my own and thought about other options (i.e. adoption). My peers are having children and their parents are becoming grandparents, but that’s something I know my parents would be good at, but I can’t give them. Without their care and support, I wouldn’t be here. I am glad you have included a caregiver supplement. Thanks for all the good work you do. Allogeneic transplant 2010 – now 35 years old.
• It’s interesting what becomes less and more concerning as time passes. And it’s interesting what still lingers: grief over infertility. I’ve found the grief and pain are still there in the quiet, pensive moments. Perhaps not as intense, but still deep. Hair grows back, I get a new job – not like I had planned, but it’s a job I like; muscle strength returns; even a ‘new normal’ returns; we become reestablished in a community, our marriage looks different but is stronger….many things have returned, changed or become new and life has gone on except for fertility. We opted not to proceed with reproductive technology for personal reasons. Adoption will be the means we use to start a family. However we will never know natural, medically unassisted fertility—aside from a miracle. And that still makes me sad 11 years out – not to a depressed state – but it’s a sad fact that comes with survival. I wonder how I will be looking at this issue when I’m beyond the typical child-bearing years. Will it be easier? Harder? Same? Allogeneic transplant 2005 – now 41 years old.

Celebrations

• Kayaked Lake Union in front of FHCRC over Labor Day, 2015, waved ‘hi’ – did you see me? Allogeneic transplant 1997 – now 53 years old.


• Arriving at this anniversary brings a smile to my face. I have now lived 25 years before BMT and 25 years after. I am looking forward to my next 25 and beyond!! Allogeneic transplant 1990 – now 51 years old.

• I am now married for two years and am pregnant with my first child after the very first try with my sister’s donor egg! Amazing! Allogeneic transplant 2004 – now 30 years old.

• I am still a competitive ice skater at 69. Skated adult nationals and placed 1st in partnered pre-bronze ice dance. (Apr 2016) Partner is 30 yrs. my junior. Autologous transplant 2011 – now 69 years old.

• My son celebrated his five year ‘transplantiversary’ and started 4th grade last week. Life is good! Allogeneic transplant 2011 – now 9 years old.

Survivorship care

• Even for those of us like myself fortunate to have had continuous insurance, the greatest difficulty in medical care post-BMT has been finding a primary care provider who is
reasonably knowledgeable and willing to work with BMT survivors to manage chronic health concerns and coordinate care. While it’s positive that the ACA has ended the ban on coverage exclusions for pre-existing conditions and lifetime maximum coverage caps, much more needs to be done to promote access for all of us to affordable, high quality, and comprehensive care. Syngeneic transplant 1998 – now 65 years old.

- This treatment and recovery are such a roller coaster ride. 2 years post-transplant I’m still on meds, still trying to deal with the side effects, just wanting to get on with my life, feel better and get off the rest of the meds. Sometimes it seems like issues are dismissed. It would seem that for some of the issues they are referred to as items that just happen, maybe because you are older now, that they aren’t associated with the transplant and possible complications because it’s better for ‘statistics’ to show fewer issues. As a patient this is how it seems, ‘oh no this isn’t transplant related, it's just the new you...’ well the new me is a direct result of my transplant, don’t diminish how impacting these items are or that they are associated with this horrific journey. I have no doubt that this process has resulted in PTSD. Coming back to the SCCA causes me extreme anxiety, as I’m sure it does many people. Some days you question if it is all worth it, the ongoing problems, the fear of the future and additional complications. But some days, the amazing ones, life is so splendid and I wouldn’t change a thing since this is all part of who I am now. Allogeneic transplant 2014 – now 41 years old.

- Physicians need to provide more information regarding nutrition post-transplant. They should not just settle for their lack of education in this regard and rationalize this deficiency by saying to see a nutritionist when asked basic questions. Allogeneic transplant 1998 – now 67 years old.

**Happy to be alive but I lost so much**

- I am on disability and cannot work my previous job. I could do menial work, but I used to launch the Delta II & IV rockets at Cape Canaveral. I’ve found my desire to work & my inability to work in great conflict resulting in depression and frustration. Allogeneic transplant 1997 – now 63 years old.

- The ongoing experience of treatment and insurance has been extremely difficult. I did not think I would live long enough to need retirement. I am now quite worried about my finances. Being out of the job market for 10 years has left me far behind my peers and I am having a hard time getting the experience that employers feel I should have by my age (mid 40’s). It is a good problem to have, but still a problem. Allogeneic transplant 2004 – now 42 years old.

- I still appreciate the fact the I’m a survivor but I wish I knew that I would still be here...I wouldn’t have sold my business thinking I would not be here and would have still had a
source of income and a business that been in the family for over 50 years. Allogeneic transplant 2007 – now 72 years old.

- I would love some chemo brain relief. I feel as if my body recovered better than my brain/mind. I had cancer, cancer treatment, and three brain surgeries in the midst of my treatment, so I feel I am affected to a greater extent, with no solution. I feel like I aged and have a screw loose! I keep being told this is my new normal...I hate to accept this. Allogeneic transplant 2015 – now 44 years old.

- Would like to know how patients are after treatment. I expected more of ‘old life’ after my bone marrow transplant. I’m 6 years out. I use oxygen 24/7 and suffer compression fractures and loss of muscle from Prednisone. My biggest concern after pain would be constant fatigue. The daily exhaustion that keeps me at home and isolated. If anyone knows how to find friends/social life I’d like to know. Allogeneic transplant 2010 – now 58 years old.

- Physical exam-wise, I am extremely healthy. However I am damaged – fatigue, waking nerve injury, pain, tremors, lightheadedness, and lack of pulmonary function... Allogeneic transplant 2010 – now 60 years old.

- After two years I am still getting stronger and learning how to deal with the up’s and down’s of having chronic GVHD. I cherish the times when I have more energy and the symptoms are diminished so activities are more easily accomplished. My biggest surprise wasn’t the physical challenges and treatments, which I expected. The mental aspects of losing my career, the impact on my relationship with my wife and kids, and my (few remaining) friends is a much larger issue than I could have imagined. It’s almost like I’ve started a whole new life. Allogeneic transplant 2014 – now 61 years old.

- Having my transplant saved my life but also changed my life significantly. It changed relationships as well. I find myself often disconnected to people because I have to weigh all decisions I make when it involves being exposed to groups of people, so even when trying to involve myself in volunteer activities. I have that thought in the back of my mind. Often people don’t understand that when I get sick I’m out of the count – it takes a while to get well + feel good. I sometimes feel disconnected because people really don’t understand. But I do feel lucky to be alive! Allogeneic transplant 2007 – now 60 years old.

**The mental, emotional and financial burden of transplant**

- My depression has had a significant negative effect on my life following transplant. In retrospect, if my doctors had warned me ahead of time that it was a possible after-effect, explained symptoms to look out for, and made it clear that there it is a medical condition and nothing to be ashamed of, my life would have been significantly better. Now that I’m on
antidepressants my life is much better, but I can't help thinking of the times at the end of high school and in college and later in my career as a teacher when I would have really benefited from those meds - they might have spared me some heart break and pain and possibly even my career as a teacher (I no longer teach). I am hugely grateful to my doctors and nurses and FHCRC for the extra 26 years of my life that I've had so far, and things are good now, I just regret not treating my depression sooner! Thank you! Autologous transplant 1990 – now 42 years old.

- Although my life has not returned to what it was before cancer, I am glad to be alive. Cancer has spurred me to return to school for a career that will make a difference in my community. I’m doing well in school (I go online) and hope by the time I graduate my PTSD will be well controlled enough to permit me to be successful working again. Autologous transplant 2008 – now 45 years old.

- Last week marked the sixth anniversary of my transplant. This is a bittersweet event every year. My transplant experience was pretty horrific, and stopping to ponder it makes me both angry and sad. But I am also thrilled that I am here to write this because of the procedure and the care I received. In the past year I even had the privilege of talking with my (unrelated) donor. My health is remarkably good, with diminished lung capacity my only significant chronic issue post-transplant. I have endured mild instances of skin and joint issues which may be GVHD-related, or simply may be part of approaching my 60th birthday. Similarly, I have noted some cognitive changes (call it ‘random access memory’) in recent years, but again, is the treatment – or – age-related? The anger I felt through the transplant process and recovery has faded for the most part. As time passes and I have had more friends and acquaintances fall victim to cancer and other serious illness, the more I appreciate how blessed I am. Thank you. Allogeneic transplant 2010 – now 59 years old.

- I have new pains, but haven’t seen the doctor yet for it and don’t know if it is related. Sometimes I feel like a hypochondriac because of feelings like this. Depression sometimes comes too often. I still cannot handle a lot of situations since the transplant. I don’t like to drive far anymore or go to various functions due to anxiety. These are weird feelings. I actually feel like I don’t want to do the questionnaire because I feel like I am not contributing anything. Allogeneic transplant 2007 – now 65 years old.

- At this point in time my stress and anxiety is overwhelming. My brain seems to be getting worse – confusion, anxiety. My dexterity in my hands, fingers, body is worsening. Allogeneic transplant 1994 – now 61 years old.

- I believe a greater focus of health post treatment should be on anxiety, financial strain. There are areas that are currently underserved in the cancer community. They are also 2 of the top 5 stresses I encounter personally and with the hundreds of patients, survivors and caregivers I speak with every day. Autologous transplant 2007 – now 40 years old.
• I need $50,000 in dental work that my insurance will not cover – all my teeth have either fallen out or are decayed. I am working full time but wonder about my life expectancy. Allogeneic transplant 2003 – now 62 years old.

• One thing I wish my care team would have done better at is, evaluating, treating, and validating my emotions. So often I felt my depression was written off as part of my disease. But it almost killed me. Mental health should be just as important as physical health. Autologous transplant 2015 – now 27 years old.

• As a 19 year-old, I am just now beginning to develop an adult life. I struggle daily with anxiety and depression, as well as PTSD. We are also looking into the possibility that I might suffer from a ‘soft bipolar disorder.” The mental effects can be just as bad as and even more severe than the physical at times. Autologous transplant 2000 – now 19 years old.

• I still have PTSD/anxiety problems occasionally, usually around anniversary of diagnosis & BMT. Allogeneic transplant 1994 – now 45 years old.

• I still have PTSD when I have to go out of town. I usually have to take anti-anxiety medication, if I am not going with family, and even then I can get very overwhelmed. I know it sounds crazy, but it messes with me. Allogeneic transplant 2006– now 60 years old.

• At 21 years post-transplant, my wife still refuses to accept that my short term memory issues (which are by no means severe) have anything to do with my BMT. She is always concerned that they are indicators that “my mind is going,” and actually gets angry with me when I have no recollection of a recent discussion, times and locations of kids’ soccer games, etc. What can I do?? Allogeneic transplant 1995 – now 56 years old.

**Thankful**

• It’s hard to believe I’ve enjoyed 22 years of health and happiness post-transplant. I’ve officially lived longer than I had prior to being diagnosed. It wasn’t and isn’t always easy, but it’s so worth it. There are moments when I’m overwhelmed with gratitude of life – whether it’s a special memory I’ve created with family, a good belly laugh or simply enjoying a beautiful sunrise. It’s pretty much always a good day in my book, even when everything goes sideways. What a gift! Allogeneic transplant 1993 – now 42 years old.

• Thank you for all you wonderful folks do at the Hutch. We continue to maintain very important friendships with the awesome nurses and RD who provided me with care 15 years ago. I am proud to be a Fred Hutch Alum of sorts. Allogeneic transplant 2000 – now 49 years old.
As I write this, I just passed my ten year anniversary since an allogeneic stem cell transplant. I have chronic GVHD, mostly my severe dry eyes which require scleral lenses. My skin and joints have also been affected by GVHD. Over time, it seems all my body fat has disappeared. I am fat-free! Most women would love that; but it's not the most attractive look. I always say this is the price I pay for survival. Ten years ago, I had two options, my local hospital would not do a stem cell transplant on a patient in relapse, so in a few months, I would have died. The Fred Hutch organization accepted me as a patient; and here I am today. It's pretty amazing and I will be always grateful to the wonderful people who saved me. Allogeneic transplant 2006 – now 65 years old.

I felt my care at FH, UW, and SCCA was exceptional. All staff treated me with dignity and respect. I felt that the brightest minds were generally interested in my well-being and felt fortunate to have been treated there. I feel I have hope! Allogeneic transplant 2015 – now 55 years old.

As I celebrate 25 years, my thoughts go back to that time. I will ever forget as long as I am alive. I now have had the privilege to love my husband, see my sons grow up, and have my 4 grandchildren, with one due in a few weeks. Thank you, and God Bless all those fighting at this very moment. Allogeneic transplant 1991 – now 57 years old.

It is not lost on my how much I owe to the doctors, surgeons, nurses, and other staff members of Children’s and the SCCA. I will be forever grateful for the fact that together, we made impossible odds possible, and that is something I will never take for granted. Allogeneic transplant 2011 – now 26 years old.

Thank you #14 done. Allogeneic transplant 2002 – now 48 years old.

I can hardly believe it has been 6 years since my transplant. This was my first year I forget to ‘celebrate’ my second birthday. I still have GVHD in my mouth, eyes, and vaginal area. But overall I would say I am doing pretty well. Allogeneic transplant 2009 – now 49 years old.

I honestly feel that the trinity of doctors I’ve seen at FH and SCCA have saved my life over the last few years. Dr. Press, Dr. Gopal, and Dr. Maloney have all been 3 of the best doctors I’ve ever been in contact, and I would be sorely disappointed if I ever had to go to another place to be treated. Thanks for saving my life guys. There’s no comment box I can write in that can express my gratitude. Just wanted to make sure that this was out in the universe somewhere, that someone might see it. ;) Appreciate what you all do, and the skills with which you do it. Thanks so much. Autologous transplant 2013 – now 46 years old.

Although I know there are new drugs, some on the horizon, as well as some in clinical trials, we multiple myeloma patients understand that the way the drugs work depends on our bodies’ response; therefore, I know that I am extremely lucky to be able to live my life as I do now. All in all, I am so glad to be alive, learning new things about myself and about others.
As I sit on my screened deck typing this comment, I stop and look around, seeing the green trees and the brilliant sky, listening to the sounds of the birds tweeting and the bugs humming, I understand how precious every day is, and I am thankful. Autologous transplant 2002 – now 61 years old.

- Five years ago I had a BMT to hopefully cure my MDS. I thought a lot of things during that time. I thought I wouldn’t live through it. I thought I’d be a weaker version of myself. I thought I’d never see the islands of Hawaii again. I thought I’d never have a family. It turns out I thought wrong in all my thinking! I have a fiancé and a lovely 9 month old daughter now. I definitely have my down days (physically and emotionally), and exhaustion still happens somewhat easily but everything is mostly good! I love reflecting back on my life with this survey!! Cheers! Allogeneic transplant 2011 – now 33 years old.

- Thank you for making the questionnaire shorter! I’m just doing great, perfect health except about 20lbs. overweight. I just started a weightlifting class + even though I’m by far the oldest in the group I am proud of my growing muscles! 😊 Allogeneic transplant 1995 – now 56 years old.

- 24 years later, I still have such fond memories of what could have been the worst few months of my life. Instead, they are filled with nurses who would take their lunch break with me in my hospital room, so my mom could go home to do laundry, and I wouldn’t have to be alone...child life workers and volunteers who gave so much time to make me feel at home (despite being nowhere near my actual house many states away)... and a caring staff who will still answer my questions today. It continues to be a joy to look at the many, many things I have gotten to do, thanks to a wonderful hospital that helped save my life. I am indebted forever...THANK YOU just barely scratches the surface. Allogeneic transplant 1992 – now 37 years old.

- Made it to age 70 – thanks to all! Life is good! We have traveled the world and that’s hard to do if you’re sick or deceased. Autologous transplant 1993 – now 70 years old.

- In all regards, I will always be grateful for the excellent care I received at Fred Hutch. I believe because I was sent there, it saved my life. I continue to get excellent follow-up care here. The time of 6 years has gone fast. Although I live in a ‘new normal’ – tired a lot of the time + some trouble w/A-fib now, eye surgery re: cataracts, and a lot less endurance than I should have at this age – and have a lot of meds to take. Having said that, I am thankful every morning that I wake up! – I can think of people enduring a lot more than I am – and some old friends not here anymore. Allogeneic transplant 2011 – now 69 years old.
“Just keep swimming, just keep swimming….” – Dory, Finding Nemo

- Recovery is taking longer than I expected, but I am learning to be more patient and gentle with myself. At about 1 ½ years post-transplant both I and my wife started transitioning from ‘extended emergency’ mode to ‘long term recovery’ mode, and that has been quite a relief. Even though various issues keep arising, we experience them very differently now. I had my two year ‘birthday’ a couple of weeks ago and that felt like quite a milestone! Allogeneic transplant 2014 – now 47 years old.

- Still working on my goal of being a 25 year survivor – even though they are no longer featured in any publication from you. Must be too many of them! Allogeneic transplant 2000 – now 70 years old.

- There needs to be better support set up for post-transplant patients to get their lives back post treatment. Allogeneic transplant 2014 – now 31 years old.

- Life has certainly changed post-transplant, but ultimately for the better. I do not think every day about my experience anymore and feel gratitude towards every new day that I continue to live on ‘borrowed time’ – my suggestion to those undergoing a transplant – it does get better and confidence does return the more time passes. Allogeneic transplant 2012 – now 46 years old.

- After 11 years, I no longer worry about AML rearing its ugly head. In fact, I completely forgot my SCT anniversary for the 3rd year. Thank you SCCA for helping me get to this point. I am truly grateful for every day of my post-transplant life. Life is truly good except for Bronchiolitis Obliterans which appears destined to be with me for the rest of my life. I am limited as to where I can go (no destinations with much elevation), what I can do (forget skiing + hiking), but I have learned to enjoy what I can do. I am glad I opted to do my transplant. Allogeneic transplant 2005 – now 68 years old.

- After my transplant 19 years ago, I never got much stamina back. If I did any physical activity, I would have to rest every few minutes. I could only work part time for 15 years and was too tired to do anything else. Last year I retired and have been going to the gym several times a week. Now I feel much better most of the time. And can do more than before. I wish I had started doing this years ago. Allogeneic transplant 1997 – now 63 years old.

- Most people think that because you are cured of your disease/disorder you are back to completely normal. They have no concept about the toll that it takes on your body! Allogeneic transplant 2008 – now 66 years old.

- Terminal GVHD, no medications have worked. Trying to get into new clinical trial with new med that shows promise of eradicating my GVHD. Allogeneic transplant 2010 – now 56 years old.
• For me, a key challenge has been, and remains, how to think about hope. On the one hand, patients are told to be positive and plan on good outcomes. On the other, that attitude can obviously lead to disappointment when hopes do not materialize, especially when that happens over and over again. I tend to be optimistic but have been burned often enough now that I makes me hesitant to get my hopes up. This must be hard for providers to balance too, whether they are making the case for transplant or presenting treatment options for chronic GVHD. Allogeneic transplant 2014 – now 63 years old.

Accommodations for the new normal

• Regarding my responses to energy level, fatigue, etc. – this is all very much time of day selected. I generally start to run out of gas around 5pm, or so. I do not make financial or any significant decisions after dinner. Mornings are best. Allogeneic transplant 1991 – now 71 years old.

• 24 years is the gift I was given. The most surprising things to me were not being able to get my muscle strength back. I am fairly active + young at heart, but my body & mind seem to be aging faster than I like. I don’t think most people understand what ½ years of chemo, total body irradiation, and a bone marrow transplant take from the body and some expect more from me than I can give. I want to, I just can’t. I am 57, but feel like physically I am 70. My 75 year old mom has more energy than I do. Autologous transplant 1992 – now 57 years old.

• If I knew how hard the process would be, how much it took from my family I would not go through it. But each day I forget the bad moments (mostly, that is) and have not had a hospitalization for 16 months. Allogeneic transplant 2009 – now 68 years old.

• I just celebrated my third year following stem cell transplant. There are side effects, but I’m alive and doing well. Things could always be better, but things could also be much worse. Thank you! Autologous transplant 2013 – now 49 years old.

• I operate at a much lower level of energy and have had to deal with frequent illness likely due to immune system suppression and/or GVHD. I have learned to schedule my times for when I will have more energy and basically have learned to live with fatigue, illness and GVHD, but overall lead a good and productive life even at a reduced level. Allogeneic transplant 2012 – now 62 years old.

• Everyone’s new level of normal is different post-transplant. A couple of years ago a patient had written recommending we don’t wait to return to our old normal to return to ‘normal’ activities & it truly struck a chord with me. From the moment I read this, I decided to stop waiting & start doing. My increase in activity was the best thing I did for myself and my family. Allogeneic transplant 2013 – now 56 years old.
Survivor guilt

- I wonder if it's normal to have 'survivor guilt'. I have lost 3 people dear to me in the last few years and I often wonder why I am still here and they couldn't be saved. I know there is no answer to that, but the completion of this survey hardly seems like enough to try and assure others will be cured. Allogeneic transplant 2015 – now 56 years old.

- I feel so well & so normal that sometimes it seems impossible to believe my AML ever happened. I also wonder why I was so fortunate and others not and I feel sad for them and also kind of guilty. No one would wish for cancer, but my experience was actually enriching in so many ways...the wonderful people, the knowledge of my body and mind and strength that I gained and many other ways. Allogeneic transplant 2013 – now 64 years old.

- You should ask: Do you feel guilt regarding your recovery/remission while others have been less fortunate? Autologous transplant 2004 – now 47 years old.

Are there any other questions that we should be asking?

- I am typically a rule-follower, but as I have gotten closer to the one year mark, I too have started breaking the rules (cleaning my cat box, carefully with mask and daily for indoor cat, yard work, etc.) and it would be interesting to ask on the survey if people are following the guidelines to the letter of if they are breaking them as well, may help for future recommendations if everyone is breaking certain rules by a certain time frame and there are no repercussions from it. I look very carefully at a guideline and then where I am at and the risk of it before deciding to proceed. Autologous transplant 2015 – now 33 years old.

- The questionnaire is great. One suggestion is more questions for patients who have suffered from post steroid depression and PTSD regarding how long these lasted, how the patient is doing now and if this affected their person relationships with spouse / caregiver and family? Allogeneic transplant 2005 – now 60 years old.

- Questions that address what it is like to face ongoing or repeated medical events, e.g. more tumors after the first one. Many of us are not in a “one and done,” status. Allogeneic transplant 2011 – now 63 years old.

- Are you using any cannabis or related products for medical reasons? (The number of medical uses of cannabis is increasing and various government entities are now discussing them, including the VA!) Allogeneic transplant 2011 – now 56 years old.