Thoughts and Comments from Patients—2012

The Best of Times....

- When I was diagnosed at age 63, I “closed the door” to my teaching career of 38 years. I totally enjoyed a 9-year retirement! Now, I am teaching first graders. I have 6 very special students! I never dreamed I would be doing this at age 72!! Autologous transplant 2004 – now 72 years old

- Life is fabulous – last year for my 20th anniversary, my husband & I bicycled 70 miles around Lake Tahoe. Wahoo! Quite a ride! This year we adopted a baby girl. Hooray! We are very happy, life is wonderful...planning to stick around a long while!! Allogeneic transplant 1990 – now 47 years old

- Twelve years! How amazing that is. For the first time I hit the stage that I read on the survey from comments from others. I would go days, even weeks, without thinking about the transplant. Yes, I even would forget I ever got one. How cool is that! I finally reached that light at the end of the long tunnel. Allogeneic transplant 2000 – now 41 years old

- ...I have also trained a colt and am able to ride him all the time and I love loping through the hills! Allogeneic transplant 1996 – now 38 years old

- I was an electrician (construction). We are currently building a hydro dam/fish ladder complex. I am often 30-40 feet up on the rebar mats installing conduit in a fairly hostile outdoor environment. The forty year-old carpenters can’t believe I am soon to be 61 yrs. old. They hope they are in my shape when they are my age. Allogeneic transplant 1992 – now 60 years old

- P.S. I have traveled to North India & Kenya to provide health care & direct medical missions. In N. India, we packed into villages on the Nepali border. I was in the middle of the pack. I traveled to Paris & London & spoke at the International NP conference. What a year. I am blessed. Autologous transplant 1994 – now 55 years old

- Thanks for everything. Another great year. Who would have thought I’d make it to 50 yrs. old! I’ll celebrate it while on a mission trip in Nicaragua. Completed an Ironman race last year and am training for a Half-Ironman in August and then will trek the TMB trail in France, Italy & Switzerland. Life is good! Allogeneic transplant 1984 – now 49 years old

- My oncologist said “remission” for the 1st time in January, 3 yrs. post-transplant (autologous). Autologous transplant 2009 – now 64 years old

The “New Normal”....

- ...I’m not exactly sure what normal is right now, but I live each day as it comes. I know my issues are not life threatening, so, I do consider myself pretty healthy – healthy enough to take a month’s trip to Italy this May for our 50th wedding anniversary. I am grateful for my life. Allogeneic transplant 2005 – now 70 years old

- ...Day by day, it’s a different scenario. Sometime(s) I can wake up feeling good, sometimes I am totally fatigued - nausea, leg pain, general malaise @ times. Allogeneic transplant 2010 - now 53 years old

- Leg pain and dry eyes – that’s the way it is these days, but it is ok. I enjoy life and I thank God every day for another day with my wife, daughter and my horses. Autologous transplant 2002 – now 55 years old

- I’m grateful every day for the life-saving treatment that I received at SCCA. When my health is good – I feel amazing. When I have little bumps in the road, I become anxious, stressed, and easily feel overwhelmed. No matter how I am feeling, healthy or not, I’m so very thankful. It’s easy to forget how far I’ve come. Allogeneic transplant 2006 – now 39 years old
• ...I’m grateful for the questionnaire. It affords me the chance for appraisal and reflection. Six years out, GVHD continues to be a challenge, but, I’ve finally had to acknowledge that it may not disappear any time soon and I’d better “get on with it.”...I can do many things – but slowly. Allogeneic transplant 2006 – now 65 years old
• The most important advice I could ever give to someone dealing with life after transplant is: waste no time wishing you could get back exactly to where you were before transplant. Your life will instantly become more fulfilling and enjoyable the moment you stop being, say 70%, of what you used to be and becoming 100% of what you are now! Allogeneic transplant 2005 – now 52 years old
• I do what I need to do. I take time to do what I want to do (every day). Even though I have serious concerns, I do NOT stress out over any of them. (At least try not to). Fatigue and the effects of premature aging will NOT stop me from thoroughly enjoying the good times that are also part of every day. Never thought I’d reach 60!! Given 2 mos. to live @ 35. Autologous transplant 1991 – now 60 years old
• I’m so grateful each year when I fill-out this questionnaire when I realize again what a wonderful gift of life I’ve been given. I have had minor consequences – cataracts & avascular necrosis with 1 knee replaced – but, overall great health. Allogeneic transplant 1991 – now 58 years old
• The biggest challenge continues to be fatigue and depression as a result of the fatigue. Also, the impact of knowing the multiple myeloma will return, again and again, until it no longer responds to treatment. Coming to terms with this reality and learning to live with a semblance of grace is my focus. Gratitude helps. My current state of remission is more precious knowing it will not last. I’m thankful for maintenance chemotherapy that is giving me more time. Autologous transplant 2010 – now 58 years old
• I think about my disease and treatment every day. I use it as an opportunity for gratitude. I’m so very thankful to be with my husband and our boys. When I was diagnosed, the boys were 3 yrs. and three months. This year I’m getting them ready to enter high school and middle school. I would never have picked this “new normal” but have learned so much...I wouldn’t trade it either. Autologous transplant 2004 – now 42 years old
• My “new 4th birthday” was 2 days ago, and honestly, I forgot about it. Now that says something about how my life has returned to normal! My new normal though isn’t quite the same. I can’t quite tell if my fatigue and poorer eyesight is due to my transplant or if I’m just getting older. My optometrist assures me it’s my age! I do have to remind my family and my employer that my fatigue does occasionally impact my life, but, because I’m now fine in every other way, they forget. But I’ll take my “new normal” a thousand times over for a trade-off with leukemia. Autologous transplant 2008 – now 45 years old
• I only wish I could have known what I was in for with long-term effects of the transplant. If I could have known at least the range of possible effects, I would have been better prepared for not being able to participate fully in music as I did before diagnosis & treatment; and having to cut my work hours to the point where I had to give up the professional position for which I worked so hard to attain. Nonetheless, I’m glad to be alive – thankful to God and all human participants that made my survival possible. Autologous transplant 2010 – now 59 years old
• I’m grateful for the 3 years the transplant has given me. However, life is hard. Lot of pain-severe fatigue. Meds. alone make me ill, but the pain is excruciating if I don’t take (them). Allogeneic transplant 2008 – now 67 years old
• After 2 years of treatment and recovery, I just want my life back. I’m REALLY looking forward to normalcy, even though I will need to alter my life to a new kind of “normalcy.” Since I don’t work, I’m doing as much as I can w/my kids: schoolwork, rehearsals, sports practices, dinner together. Just getting outside and kicking or throwing a ball is vital. It might not be there tomorrow. Allogeneic transplant 2012 – now 47 years old
The Worst of Times: Definitely not the “New Normal”….

- I have absolutely no libido. I am not in a relationship, nor have I been since my transplant. I have bladder and urethral pains since my transplant which, combined with me being post-menopausal (at 35), makes it hard for me to feel sexual. I worry that I am never going to have sex again! Is this common at my age? And, is there anything that can help me? If my transplant saved my life, but left me alone forever, was it worth it? This has become the focus of my anxiety and depressed thoughts. Allogeneic transplant – now 35 years old

- I had a double mastectomy for breast cancer. I am 30 years post-BMT. We found the cancer when I went to have a routine mammogram. Allogeneic transplant 1982 – now 49 years old

- …I want my life back, but, have less of a desire for things and want to help others more. I can live with less, but my wife can’t, which led to separation and divorce. Now I am living alone and lonely, trying to figure out where to be and what to do. The only thing keeping me going is my faith in God, knowing He is in control. Autologous transplant 2007 – now 59 years old

- …it was discovered I had a mixed chimerism and my old cells had a JAK2 mutation for polycythemia vera. My donor cells have been dropping so I will have a DLI (donor lymphocyte infusion) in a couple of weeks. It seems unreal that this is all happening to me 13 years after my BMT. I thought I was cured many years ago. Allogeneic transplant 1999 – now 55 years old

- By having the transplant, relationship with my ex-wife has changed and we got divorced eventually. The event was too big for me and its effects on my emotional problems. I wonder if other patients have same problems with (their) families. Allogeneic transplant 2000 – now 45 years old

Ups and Downs….

- …I know the trade-off for being cancer-free could mean permanent lung impairment to the extent of needing supplemental O2 for the rest of my life, which, only being 26, is a bit daunting to think about. Yet I noticed something as I went through treatment, and as I’m still kind of in treatment, really. Life goes on, with or without you. And that includes all the wonderful, amazingly good things too. If I’d pulled into myself and wallowed in my misery, I’d have missed out on getting to know and be changed by one of the most wonderful people I’ve ever met. So, even on the hard days, I try to keep looking outwards, because you never know what life might throw at you, which includes lots of good things, as well as the hard things. Allogeneic transplant 2011 – now 26 years old

- It is difficult to answer “how is your health generally?” I work, travel, cook, enjoy life much as I always have. But I have this terrible disease (MDS) that is going to claim the next 6-12 months (or, forever), and I got that disease due to my lymphoma treatment. I am still optimistic, and I still feel lucky, but facts are making that a little harder… Autologous transplant 2010 – now 57 years old

- The major issues this far out from my ’98 transplant for CML remain fatigue & depression, scars on the left ventricle of my heart (cardiomyopathy), and chronic pain in my left foot and ankle from unresolved scleroderma (GVHD). Still, despite my battle scars, I remain forever grateful to the Fred Hutch staff for saving my life. Today I am a full-time high school English teacher and the proud mother of two college students. Allogeneic transplant 1998 – now 49 years old

- My life has totally changed after my transplant. I have to push myself to do the things I have to do and have nothing left for the things I would like to do. My mind is a sieve, my memory comes and goes and my attention span is non-existent. My body seems to be my enemy. Would I trade the last 8 years of my life, if I could? Never! I have learned more about my Lord, mankind and myself that I would not trade for anything. Allogeneic transplant 2004 – now 63 years old

- Suddenly, for no apparent reason, at the beginning of last month (November), I finally feel like I’ve gotten my energy back. Normal things like cooking and cleaning no longer take all my energy. I’m weaving and dying
again after 3 years of doing none. I feel like I’ve finally recovered.  Autologous transplant 2009 – now 65 years old

**Worries....**

- I’m grateful for the gift of life my sister gave me with her stem cells, but I’m finding it more and more difficult to maintain the “joie de vivre” I had which helped take me through the difficult recovery and GVHD problems. I feel like maybe I am becoming a burden on my two children. Health problems and now financial problems make it very hard to remain positive.  Allogeneic transplant 2001 – now 68 years old

- I continue to take Revlimid as maintenance therapy under a trial at FHCRC. I hope that one day it will be unnecessary to take this (or any other drug), but, the fear of a relapse makes that seem a remote possibility. Finding health insurance was difficult during a spell of self-employment – having this very costly drug provided, lessened my anxiety about obtaining it.  Allogeneic transplant 2008 – now 32 years old

- I’m in remission. Terrified it will come back. I know there is no magic wand/or crystal ball that will tell the future, so, I worry...  Autologous transplant 2011 – now 61 years old

- The fear of the return of CML has diminished tremendously after 8 years, but ... still there always hangin’ out and when I’m a little low with emotions or in a little pain, sometimes it does have a tendency to return.  Allogeneic transplant 2004 – now 48 years old

- I’m concerned about my anger level.  Autologous transplant 2004 – now 43 years old

**Getting Older....**

- I’m working construction 40-50 hrs./week. Mostly, the BMT doesn’t affect me directly, but I feel the radiation has aged me quite a lot...  Allogeneic transplant 1985 – now 58 years old

- Like most children, when I was small, I advertised my age, including the extra months (e.g., 5-1/2!). At 30 and 40, I hoped people wouldn’t ask. After my transplant in 2008, I once again enjoy advertising my age – and I’m thrilled to say I’m 52 years and 11 months!  Thank you!  Autologous transplant 2008 – now 52 years old

- My energy level is less than before transplant ... 5 yrs. (ago) .... However, since I’m now 80 yrs. old, I think that is part of aging – though the 6 mos. spent at SCCA for my allogeneic transplant (mini) was difficult both physically & emotionally. I’m amazed & grateful to have had my 80th birthday.  Allogeneic transplant 2007 – now 80 years old

- I’ve developed a lot of small medical issues and am losing my ability to keep rolling with the punches. My vision is failing and it’s scaring me. It seems I have the body of a 65 year-old at 41.  Autologous transplant 2004 – now 41 years old

- ...I may complain sometimes but I do realize that I am a lot better off than some of the other survivors. The aging process is my biggest opponent, but my wife always reminds me that “Old age is not for sissies!”  Allogeneic transplant 1983 - now 68 years old

- Although it doesn’t interfere with my daily life, I do wonder about the effects of my treatment and how it will affect my life span. That being said, I live down the street from the movie theater where 12 people were killed and 59 others injured. It has once again reminded me that there are no guarantees in life, cancer or no cancer.  Allogeneic Pediatric transplant 1993 – now 36 years old

- Had my 3 mos. checkup a month ago with my oncologist & now it’s 6 months span and he said some of the most beautiful words I’ve heard – “I think you’ve beat it.”  Wow!!! I’m 83.  Autologous transplant 2007 – now 83 years old

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Exercise!!!!....

- Life for me is pretty much back to normal: walk 3 miles or more each day; lift weights 20 mins. each day; golf 18 holes, 6 days/week; do all housework and yard work @ my home. Autologous transplant 2011 – now 60 years old

- I can row M, W, F at 5am – 7 am with my masters’ women’s team the last 14 years – I only missed the year I was treated for the AML (leukemia) I developed from the treatment of lymphoma. My husband & I were out hiking & backpacking 5 weeks last summer & fall. Autologous transplant 2007 – now 67 years old

- 15 years and counting, Paul Simon has it right – AN AGE OF MIRACLES & WONDER. I’ve been diligent & committed to exercise the past year. Recommend it to all. Skiing with abandon now. Still can’t quite believe it... Allogeneic transplant 1997 – now 67 years old

- My physical issues are “self-inflicted.” Exercise, softball (4x/week in summer), and golf have taken a toll on the knees & shoulders. But my wife claimed this exercise was the reason I sailed through the transplant 10 years ago. I guess I can’t sit still for long. Stay active - find something to get you UP & MOVING! Thanks again for all you have done. Allogeneic transplant 2002 – now 61 years old

- I’m still going strong and feel pretty darn good. Still have a problem accepting that I’m 67. I exercise with people 30-40 years younger than myself and can easily keep up with them. Have lots of energy – though I retired 2 years ago, I’m looking to go back to work a few days/week to help stay active. Love to volunteer. Have more vigor than my donor. Allogeneic transplant 1985 – now 67 years old

Some Expressions of Gratitude, among Many....

- ...I am most thankful to God, but also to all of you guys who give of yourselves to all of us who need you. You have never failed to answer the phone, answer any question we might have had or show such sweet compassion the times I have relapsed. Allogeneic transplant 1992 – now 65 years old

- With the physical, as well as financial fear, emotionally it can knock the snot out of everyone involved. Anjelica Tsoumas (social worker) was there with us thru it all. The compassion and care that I received didn’t stop there. My caregivers were extended the same compassion as I was. The talents, skills and professionalism of everyone I encountered were not only informative, but also comforting. Bless you all and thank you. Autologous transplant 2012 – now 51 years old

- INCREDIBLE – SPEECHLESS – WOW – THANK YOU! Years 7-10 were fraught with more emotional/mental “pain” or was it just that I turned 40? Who knows! All I know is that as I approach 10 yrs., I am giddy with happiness---I can’t help but want to scream & shout with joy as we plan laser tag party #5 for my son’s 14th birthday next week. WOW!!!!!!! OMG to the max! Allogeneic transplant 2002 – now 44 years old

- ...I was told by my physician --- that I should have my transplant (even though unrelated & incompletely matched) if I wanted to see my daughter grow up. Tough, but appropriate & very timely advice. THANK YOU!! Allogeneic transplant 1991 – now 56 years old

- I’m thankful you still care about me. It’s nice to know you’re not one of those places that just treat you and then send you on your way like fixing a car. Allogeneic transplant 1989 – now 65 years old

- The entire time I spent at FHCRC I felt I was in very capable, knowledgeable hands. My wife & I have tried to describe our experience to others & I can tell by the blank look in their eyes that they don’t really believe us. In short, we were pampered. Your collective efforts are nothing short (of) miraculous. Thank you all so much for caring the way you do. We really felt loved. Allogeneic transplant 2012 – now 60 years old

- I have just completed a very productive and fulfilling year. I am thankful for the excellent care I received at SCCA, but, honestly don’t dwell on my illness, transplant, or the relatively minor side effects of CGVHD. I
am a practicing oncologist and recognize how blessed (lucky) I am. Sometimes, that is difficult to think about when my patients are not responding to treatment, etc.  Allogeneic transplant 2008 – now 58 years old

• ...You saved my life 17 years ago...I’m 74 years-old now and in many respects, I feel like I’m 40 again. My grandchildren thank you/my children thank you/my wife of 57 years thanks you and I certainly, with all my heart, thank all of you.  Allogeneic transplant 1995 – now 74 years old

• I have been blessed with 26 years following 2 transplants, a miracle son ---, and wonderful doctors, nurses full of knowledge and care here in --- area, at the SCCA and Fred Hutch. Thank you all for this miracle of life!!  Allogeneic transplant 1996 – now 49 years old

• Today is my 24th anniversary (post-transplant). Every year this questionnaire reminds me that I actually had a bone marrow transplant. Otherwise, I am too busy working & enjoying life. This gives me an opportunity to take a deep breath & give thanks to those who took care of me. I plan to retire this fall at the age of 60. Life is great. 35 yrs. pre-transplant, 24 years post-transplant. I look forward to the day these numbers match. Then we’ll see what happens beyond that. THANKS AGAIN!  Allogeneic transplant 1988 – now 59 years old

• Please accept my sincere thanks to all your folks – I could not be here to snivel about minor stuff if they had not had the patience or professionalism to care for a major pain like me – Thank you.  Autologous transplant 2006 – now 60 years old

Memory and Fatigue Problems and Coping Strategies....

• I deal with fatigue on many days, so I am excited that you are doing a study on fatigue & depression. Thank you for watching over us even many years later.  Allogeneic transplant 1977 – now 55 years old

• My memory is terrible! I forget appts., even though I write them on a calendar. (I forget to look at the calendar?) (The Problem of) Recall of facts, names, information seems to have accelerated since treatment. I know age is a factor, but this seems excessive.  Autologous transplant 2009 – now 70 years old

• 1) depression/anxiety; 2) attention problems; 3) recurrent prostatitis (not current); 4) sexual dysfunction. The survey has helped me knowing that other people have attention/memory issues after transplant that last a long time – or never resolve fully.  Allogeneic transplant 1997 – now 57 years old

• ...I am still improving my quality of life, and the last year was good. Less trouble with cognitive functions, brain exhaustion. Still dealing with unpredictable fatigue, just glad to be here for my children. Thank you!  Autologous transplant 2008 – now 55 years old

• What helps me get motivated? My pet (dog) gets credit for a lot of my recovery! She’s been by my side since day one. Yes, I truly believe animals, music and art can help in sickness or feelings of depression.  Autologous transplant 2009 – now 50 years old

• When I’m fatigued, it’s hard to know if exercising is a good idea or not – because of the fear of getting more fatigued.  Allogeneic transplant 2012 – now 54 years old

Finance and Insurance Problems....

• ...My major problem since then is that I spend my time worrying about finances instead of exercising and taking proper care of myself.  Autologous transplant 2005 – now 65 years old

• One of the significant stresses has been dealing with the finance/accounting process. Several times I have received bills for amounts over $10,000 without any advance warning.  Allogeneic transplant 2012 – now 61 years old

• Probably my biggest stress factor is financial. We are living in very reduced circumstances and it requires some creative shuffling by the end of each month to meet our bare essential needs. I can’t afford vision or
dental insurance/care. All of my family (sisters, children, nieces/nephews) live more than 200 miles away. Finances dictate I only get to see them maybe once a year. That tends to depress me a lot. Autologous transplant 2008 – now 55 years old

Other Problems....

- I had no idea steroids would do as much damage as they have. Losing muscle was easy, getting it back is difficult. Allogeneic transplant 2012 – now 52 years old
- As I live on a farm with horses, gardening, etc., I am restricted at this time from my usual activities: i.e. cleaning stalls, feeding hay, weeding in garden & flowerbeds, mowing the yard, etc. for one year from date of my transplant. This is maddening to me, as I love to do all of the above, however, I am refraining as I do not want to cause another health issue – but am counting the months. I have been told I can prune bushes, brush & ride my horses, etc. I prefer to focus on what I can do rather than what I can’t do. Autologous transplant 2012 – now 64 years old
- I am not happy with the person I have become since my treatments (physically, mentally or emotionally). Because of having to depend so much on my husband during my transplants & treatments, I find it difficult now to be as independent as I would like to be. Allogeneic transplant 2010 - now 65 years old
- My teeth are a royal mess, I’m uninsured, my credit is less than stellar. Help. Autologous transplant 2003 – now 52 years old
- BMT saved my life – however, it seems to leave a legacy of stress, confusion, and increased depression for this patient. Allogeneic transplant 2005 – now 38 years old
- Sometimes I feel totally alone. My husband is very quiet and doesn’t talk very much. I seem to continue to have some little problem after another and I know he has to be tired of me telling him about “my problems.” Six years is a long time of me, me, me. I try to hide my loneliness and depression and to put on a good face for everyone. My husband sees more of that than anyone, yet I don’t let him know the extent of these issues. Autologous transplant 2007 – now 65 years old
- …Since BMT, have been shaving head bald as hair never did grow in full. Allogeneic transplant 1999 – now 47 years old
- …I’m still interested in determining if the treatments are causing my current issues with ED. My urologist says that treatment may have caused damage to the blood vessels in my penis causing difficulty in maintaining an erection. It’s a serious concern as a youngish single male. We are still seeking solutions. I have tried Cialis with some success and just recently started on testosterone treatment. I am wondering if these occurrences are common after treatment. Allogeneic transplant 2006 – now 37 years old

Pediatrics....

- (Our son) returned to school for the 1st time in 2-1/2 years...and is doing well socially & academically. He played on his soccer team and baseball team and basketball team since his transplant ...and continues to get faster & stronger every day. Allogeneic Pediatric transplant 2011 – now 11 years old
- It’s been 2-1/2 yrs. since my son ... had his transplant for JRA. He continues to surprise us. Going from completely immobile to participating in sports at the public school he is now able to attend. He is pain-free and enjoying life. I am so grateful for this chance of life (he) has been given. Autologous Pediatric transplant 2009 - now 13 years old
- (Our son) is excited to start kindergarten this week! He will celebrate his one-year “transplantiversary” on -- at Bullwinkle’s Family Fun Center. Thank you, SCCA!! Autologous Pediatric transplant 2011 – now 5 years old
• We count every day with (our son) as a blessing. It is painful, however, to see how the long-term effects of the transplant have taken their toll on him. At almost 16 years-old, his younger brother has passed him up in height and weights over 40 lbs. more! His 10-year-old brother weighs the same as him and is almost as tall. He suffers socially w/kids his age, as we all know how tormenting children can be. It’s not fair! And yet he goes through every day w/his head held high! He is a fighter and an inspiration for all our family! Allogeneic Pediatric transplant 2003 – now 15 years old

• I enjoy reading the comments from others. When I got the paper work, I didn’t want to fill it out, but, after reading the comments, I felt compelled to fill it out again. It’s been 33 years and I don’t remember much as I was only 3, but, as a parent of two children of my own, I can just imagine what my parents & others went through. We are thankful for the opportunity we had to venture to Seattle for the transplant, as there was only one other option at the time. The date is celebrated each year with a special dinner, flowers or, since moving away from home, a phone call from not only parents but grandparents, aunts & uncles who all pitched in during the process. Allogeneic Pediatric transplant 1978 – now 36 years old

• Thank you for 31 years. That’s a lifetime to grow up, have a family and fulfill my dreams. I backpacked all summer with my children, covering over 150 miles. I work as an RN in an oncology unit where I am involved with many patients that are possibly going for transplant, and am proud to be an inspiration to them. Recently discovered that I work in the same hospital as (the doctor) who participated in my transplant 31 yrs. ago. Small world. We are now very good friends and see each other often. Allogeneic Pediatric transplant 1981 – now 42 years old

• From patient: At 2 years post-transplant, I feel very healthy. After missing about a year and a half of middle school, I came back for 8th grade and am doing fine in my classes. Overall, I feel good and happy. I am not having any immune suppressants and steroids. Thank you, SCCA and Children’s. Allogeneic Pediatric transplant 2010 – now 14 years old

Children, Grandchildren and Great Grandchildren….

• My first son was conceived with sperm frozen before my transplant in 2001; my second son was a happy surprise, and conceived “naturally” without fertility treatment. Allogeneic transplant 2001 – now 40 years old

• This has been a long trip, but the journey has been worth it. I saw the birth of my 1st great-grandson. I am constantly amazed at the things I can do such as caregiver for my mom who has Alzheimer’s. Allogeneic transplant 2006 – now 67 years old

• Our miracle baby is happy and healthy (we were told we would never have kids, (he) is now 1-1/2 yrs. old!). Allogeneic transplant 2004 – now 36 years old

• I’m very excited to say that I’m pregnant and didn’t really believe it was possible with all my medical issues post & present. A new chapter in my life. Allogeneic Pediatric transplant 1995 – now 34 years old

• Since my transplant at SCCA in 2006, I have gone on to become a father of a beautiful daughter. I also earned an associate’s degree in Information Technology. I can thrive on life instead of dwell on death. I owe you more than I can ever repay. Thank you! Allogeneic transplant 2006 – now 38 years old

• So blessed and thankful for so many reasons, especially the desire to become a mom was fulfilled. In 2008, my husband and I adopted 2 children and very thankful to have the stamina to care for them as they are VERY energetic. Life still has its struggles as I had lost my hearing from my disease pre-transplant, also have limitations from my dual hip replacements. Overall, it is hard to complain as I am here and life is good. Autologous transplant 2004 – now 44 years old
Perspectives from a Distance….

- In reflecting on 11 years of healing and hard work in recovering from an unrelated BMT, these are the truths that help guide me: 1) acknowledge my limitations & accept them; 2) focus on what I can do, not my restrictions; 3) continue to maintain my current health; 4) be grateful for the love & support around me; 5) feed my soul through faith and my trust in God. Allogeneic transplant 2000 – now 49 years old

- I have been retired for a while now. One day, upon reflection, I realized that the most rewarding, challenging and interesting part of my career came after transplant. Allogeneic transplant 1999 – now 64 years old

- I wondered why I survived & so many others didn’t. I felt the burden of survivor’s guilt – believe me! But then in Nov. 2011, I found out that my 34 yr. old son has M.S.---He is a single dad w/3 children, too. Naturally, I was right there – desperate to do anything I could to help him as he tried to digest the terrible news & figure out a way to tell his 3 children (16, 14, 11). He stopped my crazy running around with this comment…”Mom, I don’t need you to DO anything for me. I just really need you to BE HERE for me.” Thank you all for saving my life so that I can BE HERE for my son & my grandchildren. By the way – I no longer suffer from survivor’s guilt. Now I KNOW why I survived. Allogeneic transplant 2001 – now 58 years old

- It has taken me a long time to let go of the anger I felt at getting AML and that drove me during my treatment. It is only recently that I have come to truly appreciate how blessed I have been. I have come through this experience with my life, my marriage, my career, and my finances intact. During and since my treatment, I have encountered many not nearly so fortunate. Allogeneic transplant 2010 – now 55 years old

- I don’t blame my transplant for every ache & pain. I am alive and living with most of my bucket list I have accomplished. Hated you while at Fred Hutch – grateful for my life & 8 grandchildren – always grateful. Autologous transplant 1999 – now 68 years old

- I LOVE the fact that I never leave behind my transplant experience nor would I want to do so. The period of time involving my transplant taught me many lessons about myself, my family and my faith... Allogeneic transplant 1987 – now 57 years old

- Smooth sailing! Expect many more years of a full and active life shared with my wife, children, and grandchildren. Now view my cancer as a chronic treatable condition comparable to the treatment/management of diabetes, not a terminal condition. Still believe there’s a complete cure just around the corner. Autologous transplant 2008 – now 68 years old

- My goal is not to forget I have had non-Hodgkin’s lymphoma, but remember every day to feel blessed. Autologous transplant 2008 – now 62 years old

- When I was at the UW hospital after transplant, I questioned myself if I would do it again if it comes back. Now that I feel good, I would do it again. Thank you. Autologous transplant 2012 – now 56 years old

- ...I don’t know what surprises me more – that I had cancer twice plus a stem cell transplant or that I’m turning 50! I now feel that every day is a gift. There are worse things in life than leukemia x 2 and a stem cell transplant. Ask any police officer. Allogeneic transplant 2005 – now 49 years old

- I was 49 yrs. old when I started down the cancer road and in June I will be 63+on Medicare...how did that happen? Life is some adventure and the older I get the more appreciation I have of the wonder that life holds. I firmly believe there are no guarantees in this life and I think control is a myth. Autologous transplant 1997 – now 64 years old

- Today I celebrate 26 years post-transplant. My odds for living after the transplant were horrible 26 years ago. I heard all the things that could go wrong and also what I could be living with for the rest of my life. Yes, I did get some of those, but, I’m here and living. For those that don’t know my story, they look at me as
normal and a little silly at times. When I reveal my medical journey, they look at me as a miracle and it gives them a new look at life. That’s about the time I re-look at my life and realize it’s not so bland and that there is a purpose. Thank you, Hutch, for giving me these years! I am making a difference. Allogeneic transplant 1986 – now 46 years old

Compliments, Complaints and Suggestions....

- I appreciate your being there for answers to questions doctors around our area are not familiar with. In particular, GVHD and its many, many different faces. Allogeneic transplant 2003 – now 60 years old
- Transitions between doctors from transplant team & oncology need to be more seamless. I often felt like no one knew what was going on with my care. I had to be (my) own advocate & this was the last thing I needed added to my plate during this already very difficult time. Allogeneic transplant 2011 – now 38 years old
- All in all, still extremely happy to be waking up on the right side of the grass. Anyone & everyone that we run into with cancer, we tell them to run, not walk, to the Hutch. You’re the greatest. Autologous transplant 2006 – now 60 years old
- ...After working in the health care industry for over 35 years, I view the care I received at FHCRC as the best I’ve ever experienced!!! Autologous transplant 1993 – now 59 years old
- I would like to express my appreciation for the care I got. Top of the line care given with respect and caring – from the receptionist on the transplant floor to the nurses, physicians, assistants, Mercedes the appointment magician, to the café workers and cleaning staff! Autologous transplant 2011 – now 57 years old

About the Questionnaire....

- I am glad you added the spiritual/religious questionnaire. My faith plays a large part of my well-being. I appreciate all the support I have. Glad to be able to help when needed, overall I am doing well and I am thankful and blessed. Allogeneic transplant 1999 – now 54 years old
- I look forward to this questionnaire every year. It means I lived another year thanks to you and all you did for me. I love reading all the comments – I am glad you do this. I can’t believe it has been 11 years for me – it was worth the spleen and gallbladder taken out, the cataract, the new hips – all worth it. Thank you. Allogeneic transplant 2001 – now 54 years old
- I really enjoy filling out this questionnaire every year. It gives me an opportunity to reflect on my life and remember how fortunate I have been. I will always live with the physical side-effects of my treatment, but, it is a part of me now and I rarely think about my past illness. Thank you FHCRC. Allogeneic transplant 2004 – now 32 years old
- Thanks for doing these questionnaires. It helps me sit down and review the year and see the ups and downs, the progress, the hang-ups, the struggles, the victories. It always turns out to be a form of therapy for me. Allogeneic transplant 2005 – now 37 years old
- I really enjoy reading the patient comments in the yearly questionnaire. Even after 24 years, I can relate to the issues that patients are dealing with, whether they are 24 years or two years post-transplant. Each of our experiences is unique, but there are common threads that tie each of us together. I took comfort in knowing that I wasn’t alone with many of the issues I dealt with in the beginning. We learn from each other through our experiences. Allogeneic transplant 1988 – now 58 years old

Giving Back....

- ...the insight and perspective I have gained from my experience has served me well in my roles of urology nurse and nurse practitioner student. Allogeneic transplant 2004 – now 45 years old
• After 5 years, I am beginning to feel comfortable that we have put the cancer behind us. I was able to ride my bike 120 miles in one day last weekend, raising money for the Leukemia and Lymphoma Society, which I could not have done before the transplant.  Autologous transplant 2007 – now 50 years old

New Medical Careers….

• I graduated nursing school in December 2011 & now work at the hospital I was originally treated at and loved.  I am on the adult oncology and medical floor.  Allogeneic Pediatric transplant 2004 – now 24 years old

• I just celebrated my 20 years of BMT, and here I am, “alive and kicking.”  A few years ago, I became a doctor myself and every time I face a patient, I try to remember how the FHCRC staff treated me, because that way I know I am doing it correctly.  Happy 20th anniversary also to you guys, you are the ones who did the job.  Allogeneic Pediatric transplant 1992 – now 30 years old

• I started my first year as a member of the faculty at Pittsburgh Cancer Institute this past summer (after finishing my hematology/oncology fellowship in June 2011).  Thank you very much for all that you did and continue to do!  Allogeneic Pediatric transplant 1983 – now 32 years old

Donors and Caregivers….

• My mother died from cancer this fall.  She stood next to me, comforted me, loved me, supported me, cared for me during my cancer treatments and BMT nearly 25 years ago.  I was blessed that I could do the same for her in her final months.  Prayer and trusting the Lord’s will got us thru each day and night.  Autologous transplant 1987 – now 52 years old

• I think I have finally gotten over my survivor guilt that had haunted me for the past seven years.  I also have gotten over being defined as a caregiver.  I have often asked in the past 7 years if I am a cancer survivor, since my son could not make decisions for himself.  I’ve had a hard go at redefining myself and letting go of the past, since cancer.  Parent of Allogeneic Pediatric transplant patient 2005 – now 13 years old

• I had no idea what was ahead of me after being diagnosed with leukemia.  There were a few times that I wanted it to end, but I knew I had to remain strong.  I am very lucky to have family and friends that supported me and continue to do so.  I would not have been able to do this without my incredible wife…  Allogeneic transplant 2012 – now 52 years old

• My son is now 6 years post-transplant.  Our “new normal” seems to constantly be changing.  I am thankful that cancer is not our primary area of concern, but it seems like we are constantly dealing with side-effects from chemo and transplant.  Looking back, I wouldn’t have done anything different because it has given me many more years to spend with him, but sometimes I get tired (as the caregiver) dealing with Drs., insurance and scheduling.  Parent of Allogeneic Pediatric patient 2006 – now 8 years old

• I’ve had tremendous support from family and friends – emotional, physical, financial.  The experience has taught me acceptance, patience, relinquishing the need to control what I can’t control, and above all how valued I am by more people than I would have guessed.  So now I understand the meaning of “Living with cancer.”  Allogeneic transplant 2012 – now 60 years old

• (Our daughter) is doing amazingly well!  She is so super-active - doing all the activities she couldn’t do before the transplant.  I can’t believe how perfect her health is now – I never expected it could be so normal after a bone marrow transplant.  We just got in contact with her unrelated donor and are so thankful to her and to God to work his miracle through them both.  Thanks to SCCA for such an unbelievable outcome.  Parent of Allogeneic Pediatric transplant patient 2009 – now 8 years old

• My stem cell donor is German.  I am thirsty for a beer.  Allogeneic transplant 2010 – now 77 years old
Celebrating….

- Each day I wake up, take a nice deep breath, open my eyes to a new and bright day. Allogeneic transplant 1997 – now 55 years old

- Next year will be 5 years post-BMT. I will be entering the Big Climb in Seattle to benefit the Cancer Society, getting a larger survivor tattoo and a long motor cycle ride across the West. Allogeneic transplant 2008 – now 54 years old

- Tomorrow I turn 60 years-old and have been celebrating all month. I remember sitting in a conference room with many doctors, signing a high stack of papers and being told I had a 6% chance of survival or not see my 2 year-old go to kindergarten. That is not a choice! …I’m sorry about the messy writing, the wonderful Hawaiian winds are moving my papers as I sit in Paradise celebrating life. Allogeneic transplant 1989 - now 59 years old

- How can I complain? If I lived 25 years earlier, I’d be dead now. Medical advances are why I am here today! Every birthday is not a time to lament getting old, it is a celebration of another year of life I wouldn’t be having had It not been for medical science advances. Allogeneic transplant 2000 – now 60 years old

- I just celebrated my 20-year re-birthday. To commemorate it, I participated in the LLS “Big Climb.” I climbed the Columbia Tower (69 flights of stairs) in 17 minutes, 34 seconds. I just like to prove to myself that I’m normal! Allogeneic Pediatric transplant 1992 – now 37 years old

- On August 26, I set out from Pamplona with my husband and 23 year-old daughter to walk from Pamplona, Spain to Santiago de Compostela – along the Camino on the Way of St. James. Most days we walked 10-12 miles, some days, 15 or more miles…We celebrated the 15th anniversary of the transplant in a tiny Spanish village, drinking a local brew/liquor called quemada. Not sure what we’ll do for the twentieth anniversary, but we have five years to plan. Allogeneic transplant 1997 – now 67 years old

Tributes to Dr. Thomas….

- With Dr. E. Donnall Thomas’ passing, I looked up his original 1957 NEJM publication on early marrow transplants at the “dawn” of this technology, and I realized what a leap in thinking this was at the time. So, to him as well, a very big posthumous “thank you.” Allogeneic transplant 2004 – now 70 years old

- I have been extremely fortunate to have had two BMTs and to be absolutely normal 27 years after the last one. Thank you to all associated with FHCRC and to the legacy of Donnall Thomas. Allogeneic transplant 1985 – now 57 years old

- 33 years after BMT, it means to me 33 years of life that FHCRC and Dr. Donnall Thomas have given to me. I’m saddened to hear that Dr. Thomas has passed away a few days after my 33rd anniversary of new life, but I think he should be proud and comforted to know that many of us carry on living our life to the fullest. Thank you all. Allogeneic transplant 1979 – now 59 years old

A Final Thought….

- Having defeated AML despite long odds, I came home from Seattle six years ago. I had absolutely no idea that the battle to overcome AML would take less of a toll on my life than the subsequent years of dealing with GVHD. I am finally recovering from skin GVHD, but I had to stop working, can’t read books, do needlepoint or anything requiring good close vision, because of dry eyes. I wear PROSE (contact lenses), but they don’t give me 20/20 vision. I say it’s the price I pay for being given more years to live. It’s a high price, but I’ve made accommodations, have support from friends and family, and accept “it is what it is.” At the end of the day, we all have stuff. Look around. Where I grew up, people would often say “could be worse” when they’d hear bad news. Yes indeed. Allogeneic transplant 2006 – now 61 years old