Thoughts and Comments from Patients—2011

The Best of Times….

• After over 3 years of not eating grapefruit because of cyclosporine, I am now obsessed with it. Grapefruit has been particularly good this year. Allogeneic transplant 1999 – now 63 years old

• Coming up on my 10-year transplant anniversary this next year----. I am one of the lucky ones to have the transplant and the entire experience a distant memory. I am 100% healthy, back to all crazy life activities & have two healthy kids – 9yrs. & 6yrs. My 6-yr old son was a surprise after we were told during the transplant process that there is a very slim chance we could have any more children. (And even if we did conceive, would the child be healthy, which he 100% is!) Allogeneic transplant 2001 – now 39 years old

• I climbed to Delicate Arch in Arches National Park this year! Swathed in long sleeves, long pants, wide-brimmed hat & lots of sunscreen, I made it – in 100 (degree) F heat!! It was just as stunning as it was 40 years ago when I was in my 20’s. I’m so thankful for having regained (mostly) the health of my youth. Allogeneic transplant 2004 – now 69 years old

• This past month (8 yrs., 10 mos. After PBSCT transplant/MUD) I was officially told to stop all immunosuppressant & related medicines…(my doctor) had to select a reason on the computer database. Guess what he chose? “TREATMENT COMPLETED.” Never in my dreams did I think it would happen. Allogeneic transplant 2002 – now 43 years old

The “New Normal”….

• At one year post-transplant, life is an odd mix of same and different. Back to work, travel, cooking, bike riding, family events, etc. But achiness and fatigue are constant reminders of what has happened. Still, I’ve had two clean scans so far, and life proceeds four months at a time. Autologous transplant 2010 – now 56 years old

• I decided to retire early at age 59 from my customer service job, with 27 years of service, due to my bout with leukemia in 1995 and BMT in 1998. Many “normal” people question my “folly,” but I guess that’s my new normal. I’m just content living every day. I do a little gardening, enjoy reading, watching the stock market, and helping my family. Also, trying to eat more vegetables & fruits and minimize meats, and having family do the same. Allogeneic transplant 1998 – now 61 years old

• I like two-thirds of my life. The other third completely overwhelms me. I’m paralyzed by it. So as the paper and minutiae of life forms piles on the seats of chairs & counter tops, I prefer to multi-task: to sit in my back yard listening to the birds sing and to watch grass grow while I enjoy my flowers. Allogeneic transplant 1998 – now 55 years old

• I was told it would take 3-5 years for the “new me,” and now at 4 years I get it. And I love the new me. I still have my issues, but I make the most of what I’ve got and I finally enjoy life again. Allogeneic transplant 2007 – now 34 years old

• I would do my treatment again – it has given me life. Though I live with bad legs now and constant pain, every day I awake is worth its weight in gold. Autologous transplant 2006 – now 54 years old

• It feels when I turned 55 yrs. old, someone flipped a switch and I got old. Autologous transplant 1990 – now 60 years old

• Still looking for the new normal. At six months I can do many of (the) things I could do before just not as often and they take twice as long. Allogeneic transplant 2010 – now 53 years old
The Worst of Times: Definitely Not the “new Normal”….

- (My husband) has experienced many complications since transplant 2 years ago. (GVHD, perforated colon/ostomy/ileostomy). Side-effects from steroids continue to cause serious problems with muscle damage, etc. Allogeneic transplant 2009 – now 65 years old

- I was diagnosed with bilateral breast cancer, almost 15 years to the day of my first cancer of Non-Hodgkin’s lymphoma…All I can say is “what the hell!” Allogeneic transplant 1996 – now 48 years old

- I would love to tell you more about my current battle, but I don’t feel very well and filling out this questionnaire has taken about all my energy right now. However, I want to thank all the people behind the scene that are still working to keep me alive. Thank you! Allogeneic transplant 1992 – now 58 years old

- It seems that the long-term effects of the BMT become more disabling as I age and decrease my physical activities because of pain and fatigue including sick feelings that make me not feel good at all. It is getting more and more prevalent as time goes on and survival continues beyond prognosis timelines. Autologous transplant 2003 – now 62 years old

- Was the BMT worth the suffering? Life is a struggle every minute of the day. Allogeneic transplant 2003 – now 55 years old

Ups and Downs….

- I do get tired of being tired. It’s hard for people to understand I’m good one day and then down for several days because of exhaustion. I get frustrated with not being able to sleep at night almost every night. Allogeneic transplant 2001 – now 56 years old

- I relapsed two plus years ago. I then took part in a gene therapy protocol at SCCA. Since then I have had “no evidence of disease.” Autologous transplant 1996 – now 64 years old

- Broke my right humerus hiking Pike Peak last June. Summitted in 5 hours. On the descent, fell 2 ft. & broke right arm (due to osteoporosis). Hike out 2 miles with arm flapping like Jell-O. Ranger took me to base of mountain. Hospital couldn’t fix it without risky surgery, so we let it heal as it is. Nine months in a brace, it is OK now. Allogeneic transplant 2005 – now 55 years old

- Today is the 5th anniversary of my stem cell transplant for mantle cell lymphoma. They have been 5 years of freedom to do whatever I did or enjoyed before. “Thank you” pales in comparison. Unfortunately, I have developed stage IV pancreatic cancer. Even though I’ve been blessed with a wonderful life, I’m sad and feeling lost about how to deal with this diagnosis. Autologous transplant – now 66 years old

Worries….

- ...the possibility of recurrence of leukemia is constantly there, especially when I get pain in my joints. It plays with my mind constantly. Allogeneic transplant 2004 – now 47 years old

- In the summer of 2007 I...was hiking the trail from Logan Pass center to Hidden Lake in Glacier National Park. Hiking along on the trail, I met a couple from California that were touring the Park on their motor cycles. In a brief conversation, I mentioned my wife had hiked this trail the week before. I also mentioned that she was trying to get her muscle strength back after receiving a stem cell transplant the year before at Fred Hutchinson in Seattle. The wife quickly said, “28 years ago I had a bone marrow transplant at Fred Hutchinson for aplastic anemia.” At the moment I was so caught off guard that I didn’t think to ask for their names and address. They probably had no idea how much those few details meant to me. As you know, there
is always the thought of how long a person can live and the possibility of a returning problem. But the “28 years” settled our worrying over how long. Wife – Allogeneic transplant 2006 – now 67 years old

- My concerns are about my accelerated aging process. I look and feel so old compared to others my age. My memory & mind is so foggy. My energy and scleroderma problems keep me from doing a lot. Depression is always an issue. Allogeneic transplant – now 56 years old

Getting Older….

- 13+ years out – presently age 69 – people tell I do not look my age! I still ski 30+days/year on expert slopes, lift weights + walk (my hips are beginning to go, so I don’t run anymore). The other day my wife suggested I start playing basketball again (I played in college). I guess she doesn’t think I’m as old as I am? Allogeneic transplant 1997 – now 69 years old

- I am now 59, but feel I am aging more quickly than my non-transplant peers. Allogeneic transplant 1999 – now 59 years old

- I am working full-time and I manage to finish my work on time. Some days I have more energy & feel better, but there are days when I am just so tired, not sure if this is from transplant or just aging process... “Getting old is Great.” Allogeneic transplant 2002 – now 59 years old

- I did not like getting the longevity study. I found it upsetting...I found myself trying to calculate how many more years I had left. If the study had contained specific suggestions to improve longevity, if there were any, that would have softened the blow. It fractured my thinking that I would live a long time. I’ve let go of my feelings about it and I’m doing great! Allogeneic transplant 1999 – now 54 years old

- I still think about my cancer & treatment every day. People tell me I look great, but I physically feel twenty years older than I am (I’m 32). I have a sense of peace in my life right now that I doubt I would have had without this experience. Allogeneic transplant 2007 – now 32 years old

- I take one day at a time and am doing better every day. Life is not a sprint, it’s a marathon, steady, steady, steady!! Autologous transplant 2001 – now 39 years old

- Overall I appear healthy, but feel like I’m much older than I am (49 years). I used to be very athletic and full of energy. Now I’m tired all the time and in constant pain. It is not fun, but better than not being here at all. Allogeneic transplant 2008 – now 49 years old

- Physical appearance has changed due, I think, to length of time on prednisone for GVHD in the 2 years following the transplant. My eyes have bags under them. I guess the elasticity never recovered. Also, my hair is much thinner. Not complaining – I just accept it & happy to be growing older gracefully. It doesn’t stop me from buying all sorts of beauty products (that don’t work). Ha, ha, ha. Allogeneic transplant 2005 – now 50 years old

Into the 70’s and Beyond….

- As I approach my 70th birthday, I look at my “peers” and see I am in much better health/shape than most! Maybe the transplant made me more aware of my health and keeping in shape. I want to show people that the transplant process didn’t mess me up at all! Allogeneic transplant 1997

- I can’t say I’d recommend the 3 months in Seattle as a vacation, but I met some wonderful unforgettable people and have many really happy memories at SCCA & “U-Dub” hospital. I cried “buckets” when I left for home. I completed a Senior Strengthening course 4 yrs. ago – now 82 yrs. old. Autologous transplant 2007
• Had CML & transplant 1990, had a 30% chance of pulling through and here I am now 73. Wow, I feel so fortunate, my transplant is behind me and when someone asks, I tell them it was someone else, it couldn’t have been me that went through all that I did. Allogeneic transplant 1990

• I golf once a week from April 1st to Oct. 1st, I walk (the) course about 50% of the time. I mow lawn, spade garden, saw, split, carry and stack wood during spring to summer months. I do not have the stamina that I would like to have - I think due more to 73 yrs. rather than treatment. Autologous transplant

• I have a moderate social life with family/friends and by pacing myself can do just about anything I want to do. Looking forward to traveling in Italy this summer! Autologous transplant 2005 – now 78 years old

• I remain cancer-free 3 years post-transplant...My wife has Alzheimer’s and I need to be here for her. Autologous transplant 2008 – now 71 years old

• I would like to feel good again and do more things for my family...I’m not ready to throw the towel in! 8 year survivor – age 79  Autologous transplant 2004

**Exercise!!!....**

• Exercise has been a huge ingredient to my health care. I utilized PT before and immediately after my transplant. I have continued to benefit from their advice. I walked the hospital floor during the transplant, slowly building up walking after – I was able to fully resume aerobic & weight lifting program 1-1/2 years after – still going strong. Allogeneic transplant 2005 – now 63 years old

• I do not monitor my physical activity nor do I have an exercise plan that is formalized. However, I am able to cut and split wood, do yard work, climb stairs (it’s 20 steps to my front door), walk to the post office, coach Little League, shop with my wife, hunt, fish, and generally lead what is considered a normal life in a rural setting. Allogeneic transplant 2008 – now 68 years old

• I exercise regularly (mostly dancing), but I miss distance running like I did before I got sick. I’m in good cardiac shape, but running still leaves me exhausted. Allogeneic transplant 2007 – now 32 years old

• I struggle with how much I should push myself vs. when to accept my new limits. Am I lazy or smart? I started an exercise regimen this year which helps. But instead of doing A, B, C and D in one day, I have to make choices. Autologous transplant 2008 – now 54 years old

• In the years before my transplant, my ability to do vigorous activities steadily declined. After the transplant (about 2 years), I was able to improve my physical activities, not at the level of others my age, but better than before the transplant. I walk every day between 3-6 miles – thanks to my transplant and my walking companion, my dog Max! Allogeneic transplant 2004 – now 49 years old

• This past year I’ve been unemployed – and attending college full-time. As a result, I’ve been walking much more than when I was working – and the exercise makes me feel great. My job required me to sit at a desk 40 hours a week. Autologous transplant 1988 – now 60 years old

**Some Expressions of Gratitude, among Many....**

• I had the first “normal” summer in two years this year. Lots of camping, hiking and vacationing with family and friends. I am at one year, cancer-free so far and hope to stay that way. My health is great! Now if I could just find the time to go to the gym more often, I might get back into really great shape! Looking forward to lots of winter fun teaching my 4-year old to ski this year. I owe that and much more to the wonderful teams at SCCA & Fred Hutch! Thank you!! Allogeneic transplant 2010 – now 38 years old
• I have reentered the life I choose to live. After 12 years of being controlled by my disease, SCCA has given me the reins back. I have reclaimed the gifts that my disease had stolen from me & for that I am eternally grateful. Allogeneic transplant 2010 – now 25 years old

• I thank the doctors & nurses every day. I was not suppose(d) to live to be 25. I turned 50 (on) 7/06/2010. It’s just a number, but it means a lot to me. 21 year anniversary & still going. Allogeneic transplant 1985 – now 50 years old

• I wish to sing praise for the value of the LTFU program staff who are always there to answer phone questions – no matter how small or large the concern. This “lifeline” call center really makes me feel secure & cared for, thousands of miles away! Allogeneic transplant 2009 – now 63 years old

• Thanks to my parents and husband for recommending SCCA. I’m very happy and grateful to be alive! I work for an airline and didn’t always love the idea of being open 7 days a week for air freight shipping. You can bet I have a different view on that now, knowing how important those medical specimen shipments are. Autologous transplant 2010 – now 43 years old

• My mother has Alzheimer’s – I am her only caregiver. This would not have been possible without you. Thank you! Allogeneic transplant 2006 – now 66 years old

• Today is my 25th anniversary of my BMT. WOW!! I’ve been living longer with my sister’s bone marrow than my own. Allogeneic transplant 1986 – now 45 years old

**Memory and Fatigue Problems and Coping Strategies....**

• Fatigue is a major issue for me. I just do not feel at all like I did before transplant. I get (a) work out at work and after a 40 hr. week. I crash on the weekends. It’s sort of depressing. I hoped I’d have gained back more energy at 2.5 yrs. out from transplant and I’m still exercising in hopes that I will, but I’m just not sure. Autologous transplant 1992 – now 66 years old

• I do have memory issues but when I compare them to my friends’ comments, they appear normal. Allogeneic transplant 1992 – now 66 years old

• I had a lot of ongoing fatigue and other medical problems. Last spring I was diagnosed as hypothyroid. Within five days of treatment, dramatically improved. Allogeneic transplant 2004 – now 69 years old

• I have been back to work for almost 2 yrs. now. Getting “back to work” was by far the greatest challenge for me post-transplant. I still am trying to manage my decreased ability to multi-task & concentrate, especially @ work. I also have to work on my emotional ability as I catch myself being less patient & sometime more irritable than what I was pre-diagnosis. Allogeneic transplant 2008 – now 44 years old

• Memory issues still bother me. I live with little notes scattered about, and keep a notebook at work to remember various procedures. I cannot play music by memory anymore, always need the printed music in front of me. Sometimes people question my abilities because of the little notebooks I rely on to do my job. But I am still working. I do my job well. And still play the piano, carrying my books with me when I go to play at events. For this I am grateful! (And sometimes someone at work who doesn’t know how to do something will ask me what I have (in) my notes – ha!) Allogeneic transplant 2002 – now 55 years old

• My short-term memory is not what it used to be, but I guess that’s why they invented sticky notes! Allogeneic transplant 2010 – now 38 years old
Finance and Insurance Problems….

- An article on the SCCA/Hutch website about bankruptcy rates among cancer survivors was the “permission” I needed to face facts that bankruptcy was the right answer for my financial situation post-cancer. Autologous transplant 2008 – now 41 years old

- I’m grateful for the superb care I received throughout the transplant process. Finding out how much was not covered under the contract rate has produced a great deal of stress. Allogeneic transplant 2011 – now 68 years old

- My health is good! I have diabetes now, but under control. The only bad thing is all the medical bills! Very stressful!! Just glad to have one more year with my family (kids)! Allogeneic transplant 2003 – now 36 years old

Other Problems….

- Am I…the only patient suffering from PTSD? After 14 years, I still jump & squeal at every loud noise. Allogeneic transplant 1997 – now 61 years old

- I am having a hard time adjusting with my new me. It seems like most of the time I have aches in my body and my teeth (have) gotten weaker – lots of dental work. Allogeneic transplant 2001 – now 67 years old

- My greatest complaint is my dry eyes. I have tear duct plugs and cataracts. Even with the plugs, my eyes continue to be dry. I never leave home without my Refresh Plus. Leg cramps still plague me if I don’t drink enough water. Allogeneic transplant 2002 – now 58 years old

- I still carry an extreme amount of guilt that I survived. Allogeneic transplant 2006 – now 47 years old

- I take very good care of my teeth, however, my dry mouth and GVHD have taken a toll on my mouth health. My gums are receding. Allogeneic transplant 2004 – now 51 years old

- I would do anything to not have to wear sunscreen all the time. Allogeneic transplant 2011 – now 21 years old

- I’ve developed a lung problem diagnosed as Bronchiolitis Obliterans. I now require oxygen at night & when I do any amount of walking over 5 mins, even around the house. I’ve never smoked, so the doctor said this is definitely due to GVHD. It is becoming increasingly difficult to fight depression which is not my nature. Allogeneic transplant 2001 – now 68 years old

- I have lost all the fat pad on my feet. It makes it very hard to do any walking because it is very painful! Allogeneic transplant 2001 – now 66 years old

- It’s been 13 years since my transplant and I’m still battling GVHD. Does it ever end? Allogeneic transplant 1998 – now 59 years old

- My mental health has been subpar for about half of my time since my recovery. I have been struggling to return to being a productive citizen. I am unable to provide for my family – I don’t know how I will be able to continue. At age 55, even though I have no physical health issues, I can’t seem to get it together. Allogeneic transplant 2003 – now 55 years old

- I have had mouth problems because of exposed jaw bones. Three dentists have told me that Fosamax is the cause of the jaw bone problems. I stopped Fosamax in October, 2010. My mouth has gotten much better. Autologous transplant 2004 – now 78 years old

- …I had a liver biopsy which I have every 5 years due to Hep C being present in my system. I had to begin Hep C treatment in December. I have just completed 9 months of Ribavirin and Pegasus interferon. I believe that I have handled the treatments very well. I have had a lot of joint pain and extreme fatigue, but nothing
compared to treatment that goes along with transplantation…. Allogeneic Pediatric transplant 1989 – now 40 years old

• My husband tells me that “I smell.” I couldn’t figure out what was the problem - I took showers. Last year, I read that a female patient who received stem cells from a male donor had an odor which was new to her. She and I and many, many others have the male donor’s odor. I had never read that before so --- thank you, I can check that problem off my list. Allogeneic transplant 2001 – now 68 years old

• The dermatologist found that I am allergic to oxybenzone (a common ingredient in sunscreen). I now use Vanicream + a few other screens that contain only titanium and/or zinc oxide. I now have had no flares and only a few rashes in last 6 months. Allogeneic transplant 1998 – now 63 years old

**Pediatrics…**

• (My daughter) has done exceptionally well. We were given a 10% survival rate upon arrival (1999). She is now 13- years old and lives a normal life. (She) continues to love to read and is very active on our ranch. She rides horses helping to move cattle and work cattle in corrals. She’s helping to train a young filly. Autologous Pediatric transplant 2000

• (My son) has had an amazing recovery. He is the picture of health! He was 12 days shy of his 2nd birthday, so he has no memory of his journey. The ONLY problem I have is getting him to wear sun block, especially since we now live in Hawaii. Allogeneic Pediatric transplant – now 13 years old

• Never thought anything like this would ever happen, but now that it has, it has been both the best and worst thing that has ever happened to me. Allogeneic Pediatric transplant 2010 – now 13 years old

• In a previous survey, I wrote about my (then 7th grade) son’s problems at school. A Quest article helped us realize it could be due in part to his cancer treatment. We got him in for a neuro-psych evaluation. He was only 1-year old when he was treated, so it wasn’t possible to compare before & after treatment, but they could compare his results against norms for his age. Result: he’s very bright, but has deficits in some areas – fine motor control, short-term memory, plus a couple others – that match the cancer survivor profile exactly. The psychologist gave him some suggestions for ways to work with or around his deficits. Now in 9th grade, he’s making A’s and B’s in all subjects – may even pull straight A’s this semester! He no longer thinks he’s “dumb.” Autologous Pediatric transplant 1998 – now 14 years old

• We are very fortunate that (our son) continues to be active. He runs x-country & plays soccer in the fall, skis in winter. Track and mtn. bike in the spring. Summer – hikes, climbs mts. Active in Boy Scouts, jazz band & does very well in high school. Allogeneic Pediatric transplant 2005 – now 15 years old

• I am happy to be cancer-free for more than 9 years now, but continue to deal with the ongoing repercussions of the chemo and radiation treatment for both cancers I endured! I deal with chronic severe bone pain from the avascular necrosis all over my body. I have learned to take one day at a time! Tomorrow is a new day! Allogeneic Pediatric transplant 2002 – now 21 years old

• I am 11 years post-transplant. I have not looked like a cancer-kid in years, but it is still an influential part of my identity. This summer my boyfriend’s friends asked if my scars were from an accident. I am so different from my peers or wiser, it makes life harder (because) I don’t have patience for things that don’t matter. At the same time, I am less judgmental and more patient with myself. I am terrified of doing cancer again. I struggle with a different memory and what feels like ADD attention spans. It makes me feel better that I am not such an oddity. That lists, talking out loud are not so bad. It is really hard to learn to do new things. It can be so frustrating, especially (because) I forget that I am different. Allogeneic Pediatric transplant 1999 – now 25 years old
Although I am very grateful to have my life and have the experiences I’ve had (college, travel, etc.), it is hard to try and create that “American Dream” – starting with finding a life partner/man who loves me and my overwhelming baggage – (not being able to have kids, sexual dysfunction, chronic diarrhea, etc.)  But I’ll still move forward toward that dream as best I can by myself.  Autologous Pediatric transplant 1994 – now 31 years old

I was in Seattle for 4-1/2 months.  In hospital for 69 days.  Nearly died from GVH.  I was home for 6 weeks and relapsed.  My mom had the doctors put me back on chemo.  I was given 2-6 weeks to live – I was 5-1/2 years old.  Did chemo for two years, cancer free.  I was taken off of rejection meds when I relapsed and have never been back on it.  I get GVH in my mouth.  I am healthy except for type two diabetes and happy to be alive.  I am 32 years old.  I was 19 months when I started chemo.  Allogeneic Pediatric transplant 1983

Over the past year, I was able to have a series of sessions with a cognitive behavioral therapist regarding my illness, both during and past.  This therapy was essential for me to gain an understanding of what happened and how it affected my family and I.  Allogeneic Pediatric transplant 1989 – now 34 years old

Children and Grandchildren....

I am now 21 years post-transplant.  My six kids are now independent young adults, and we are expecting our seventh grandchild.  There was a time when I never thought (I'd)live to see my children grow and certainly never hold a grandchild.  Allogeneic transplant 1990 – now 63 years old

This week we are going to our youngest daughter’s wedding.  What a wonderful thing when I didn’t know if I would have a chance to put her on the kindergarten bus.  Thanks again  Allogeneic transplant 1984 – now 65 years old

I was pregnant with my son when I was diagnosed.  He was 6 months old when we came to Seattle.  He’s starting college in 3 weeks.  Allogeneic transplant 1993 – now 44 years old

I was told we would never have to use birth control, and now we have a newborn son.  Allogeneic transplant 2004 – now 35 years old

My husband & I have been trying to get pregnant.  We tried IVF with a donor egg.  On our first try, I became pregnant, but had a miscarriage early on.  Our second try was unsuccessful.  With each try, my endometrial lining never becomes as thick as expected despite significant amounts of estrogen.  My doctor wonders if this might be due to fibrosis secondary to my transplant.  Allogeneic transplant 2002 – now 29 years old

I have watched both of my daughters grow up – at the time of my diagnosis with CML they were 2 and 10 years old.  I have watched them both graduate from high school and college.  I walked them both down the aisle at their weddings.  Two months ago I held my first grandson.  Allogeneic transplant 1987 – now 53 years old

Still trying to find help in having children.  I think this is one of the hardest things for me.  Allogeneic Pediatric transplant 1992 – now 32 years old

The one thing that still pains me after 29 years post-BMT is that I could not have any children after the BMT.  Yet I have read of others who were able to.  That is the saddest thing for me.  I truly think that you should advise patients while in the family meeting before the BMT, to harvest eggs or sperm for later use.  I wish I was given that chance!!!  Allogeneic transplant 1982 – now 55 years old

My infant son learned to walk right after my BMT, now I have the joy of watching my granddaughter growing up.  Thinking about how those 30 years might not have been, makes me appreciate the gift of life so much.  Allogeneic transplant 1981 – now 57 years old
Perspectives from a Distance....

- Eleven years out, I still get skin GVHD and must stay covered top-to-bottom in the sun. I must be careful about what I eat. I have less hair than I did 3 years post-transplant. BUT, my grandchildren – all 4 born since transplant – make up for everything! Thank you. Every day is a gift and every year is a miracle. Allogeneic transplant 2000 – now 67 years old

- For the 1st time since transplant, 6 years ago, I totally forgot to recognize & celebrate the day. I take that to be a sure bet that the trauma & upset of transplant & healing are behind me & at last, I am back to normal. Allogeneic transplant 2005 – now 63 years old

- I lament the fact that I feel worse after having the transplant, however, I really don’t know how I would be feeling today if I had continued on the journey with MM without the transplant. I think I made the right choice. Autologous transplant 2010 – now 66 years old

- Leukemia taught me that life is too short to go around with a “chip on the shoulder” and to be more caring for others. My wonderful wife of nearly 30 years has recently got me to take more time to stop and smell the roses – how sweet they smell!!! In spite of the bad things that have happened, I now have a great life thanks to the people who took care of me and showed me that survival is not a futile thing nor is enjoyment impossible to achieve. Allogeneic transplant 1980 – now 49 years old

- My short-term memory could be better, my finances are headed down the drain, parts of my abdomen are essentially duct-taped together, but my heart is good, humor intact, my friends close, my family still eccentric but they’re mine; so, overall life is good and I have you guys to thank for that. Autologous transplant 2000 – now 53 years old

- Transplant was the hardest, painful & most difficult thing I have ever endured. When I reflect on the transplant – such terrible thoughts of it race thru my mind! I now have 8 grandchildren – the light of my life. The transplant was a small price to pay for LIFE! Autologous transplant 1999 – now 67 years old

Compliments, Complaints and Suggestions....

- As a physician, I am still amazed at the logistics, organization, & skill of all facets of the care delivered at the FHCRC/University of Wash. during my stem cell transplant. Allogeneic transplant 2010 – now 52 years old

- Consider giving anti-depressant & anti-anxiety medications when on prednisone. If I’d known sooner, my life would have been so much easier during the steroid treatment. My marriage almost did not survive the high dose steroid treatments until I was given relief with those drugs. Allogeneic transplant 2009 – now 62 years old

- I also believe my commitment to good nutrition and exercise has been extremely valuable. I had strong support from SCCA Physical Therapy Program prior to and after my transplant. The expert advice assisted (me) physically as well as mentally – many times when my health was out of control, I could always control my exercise. I strongly believe this should be an essential part of the transplant program. Allogeneic transplant 2005 – now 64 years old

- I don’t mind responding to this questionnaire, but in reading other people’s thoughts and comments, one can’t help but get emotional. I don’t like to be reminded and I don’t like to know that I’m at greater risk for other forms of cancer and heart disease. Allogeneic Pediatric transplant 1991 – now 29 years old

- I feel as though the concerns of younger adults (say 25-40) are not well-addressed in treatment and in your selected comments (meaning, those diagnosed/treated at this age). No one seemed prepared to address my concern with being responsible for the care of a young child during recovery. I also would be curious to hear related experiences regarding balancing childcare, avoiding illness, working & Dr. appts., and attempting to
“exercise” and “rest” at the same time. I constantly feel 2 steps behind due to fatigue & medication/GVHD side-effects, yet logistically unable to scale back any obligations (without severely overwhelming my already stretched-thin husband!). Allogeneic transplant 2010 – now 36 years old

- I recall being told as part of post-BMT outpatient by the dietician to “forget the American Heart Association diet” and to concentrate on calories and protein – which I did. Perhaps at some time I should have been told to no longer forget the American Heart Association diet. Allogeneic transplant 1993 – now 62 years old

- I’d like a support group where it’s about health survivors not sick ones – don’t really want to be part of the cancer world. Autologous transplant 2007 – now 54 years old

- Once I reached LTFU care, I feel like my contact has been minimal from the Hutch in comparison to my earlier care & involvement with the FHCRC. I have a great oncologist, but feel almost abandoned by my doctors at the Hutch. I don’t know how others in my situation feel. Is this typical for LTFU? Allogeneic Pediatric transplant 2002 – now 25 years old

- Your billing department has really improved & love the online payment option. Allogeneic transplant 2004 – now 44 years old

**About the Questionnaire….**

- I am very happy to see you have included a section on spiritual/religious questions. I am convinced that my faith played a large part in my recovery and continued health. For my part I consider that I have been the recipient of a miracle. My current oncologist told me that I am “not supposed to be curable.” Autologous transplant 1998 – now 67 years old

- I like reading comments from other former patients – esp. the memory/cognitive comments. This has been a real frustration for me – keeping my brain on track. Somehow, I can forget whole conversations! Ugh. But if that’s all I’m dealing w/ - I’ll take it!! Allogeneic transplant 1992 – now 41 years old

- Many thanks for continuing to send the questionnaire – no one else in my life, besides my doctors, ever asks this much about me & how I’m feeling. My friends do check in with me, but only a few understand how important my good health is to me. Thank you for continuing to improve the process for current patients too! Allogeneic transplant 1994 – now 48 years old

- Sorry it takes so long for me to respond. Because you did such a fantastic job with my health, I am very busy living life. It is difficult to find time for surveys. Allogeneic transplant 1999 – now 47 years old

- Thank you for this yearly questionnaire, it really puts into perspective how well I am doing and things that I need to work harder on, such as better eating habits and exercise. Allogeneic transplant 2005 – now 43 years old

- You need to have a section on caregivers. They have a lot to do with your recovery. Allogeneic transplant 2006 – now 66 years old

**Giving Back….**

- I spent my transplant birthday with my husband at a camp for teenagers learning about wellness. I was a guest speaker. I shared my story & explained what cancer is & how it affected my family, how I’m alive & how to prevent it. They really paid attention & had great questions. It was an awesome way to spend my day! Allogeneic transplant 2005 – now 36 years old
• Last fall, I ran a ½ marathon benefitting the Leukemia & Lymphoma Society. I cried the first couple of miles—remembering how far I’ve come in 14 years. My family was there cheering me on. I am so blessed! Allogeneic transplant 1996 – now 37 years old

• The longer out I am, the more fortunate I feel to be alive. Though I’m not capable of doing the work I did before the transplant, I have found great joy in volunteering at a pre-school. The children’s spontaneity and excitement for life has given me a quality of life I never dreamed possible. Allogeneic transplant 2005 – now 63 years old

• I accomplished 2 major milestones this year, my oncologist said I no longer needed to see her and I began working a year ago, per diem, as a hospice nurse... I feel like I’ve come full-circle with this job. Autologous transplant 1997 – now 63 years old

New Medical Careers....

• I am currently in my first year at Washington State University Tri-Cities College of Nursing. I plan to be a pediatric nurse and possibly go into oncology. Allogeneic Pediatric transplant 2004 – now 24 years old

• I am working on my PH.D. in Rehabilitation Sciences studying mothers with cancer (my daughter was 1 when (I) was diagnosed and 3 when I had my PBSCT. I am also an asst. professor of Occupational Therapy. Autologous transplant 2002 – now 40 years old

• I was accepted to the University of Washington this last fall and am pursuing a career in counseling to work with oncology patients and their caregivers. Autologous transplant 2007 – now 26 years old

• I...decided to return to school to become an oncology RN. This meant retaking A&P’s, micro...even an algebra class...lol! (Hadn’t had microbiology since 1975 when a senior in college...my, oh my, how the world of DNA has exploded since then!). Anyway, just finished last clinical rotation a week ago, now onto the NCLEX! Who knew RNs had to know about so many things?! Allogeneic transplant 2004 – now 56 years old

• I graduated from nursing school in April of 2011. I am currently working on the pediatric hematology/oncology floor. I am really enjoying my job. I feel my firsthand personal experience can allow me to be a great nurse. I will keep you informed of my progress. Allogeneic Pediatric transplant 1979 – now 40 years old

Donors and Caregivers....

• I had a liver transplant in Aug. 2010. My son, my hero, was my donor. I have had yet another chance at life since my bone marrow transplant in 1982. I am truly blessed and “life is good.” Allogeneic transplant 1982 – now 56 years old

• I had no idea when I was preparing for the transplant that my greatest challenge would not be getting rid of the cancer or surviving the transplant, but would be repairing the relationship with my spouse. A diagnosis of cancer will shock most relationships. Prior life experiences usually do not adequately prepare us to effectively cope with being a cancer patient or the spouse of a cancer patient... We experienced several years of watching and waiting followed by several years of chemotherapy and now have experienced several years of transplant and recovery. The accumulation of almost seven years of fears, expectations, unmet needs, at times loss of hope and at others afraid to hope, depression, concerns for the future, concerns for the children and their future, failed treatments, guilt for thinking of one’s own needs first, and guilt in general, had taken a toll on our relationship as well as all the things that were said or not said, done or not done. Allogeneic transplant 2009 – now 52 years old
The Reunion….

- At the patient reunion this past July, I told my nephew, who came with me to the dinner at the Sheraton, that Disneyland wasn’t the only place on earth where dreams come true. Mine did on the top of First Hill in – 1994! Autologous transplant 1994 – now 61 years old

- I was able to fly to Seattle for the Survivors’ Reunion. I was anxious & uncomfortable going back to “The Hutch.” I’m so glad that I did. It was wonderful to meet other patients, and gave me so much hope. I always feel my time is slipping away & I’m waiting for the next catastrophe in my health. Talking to long-term survivors gave me hope for a future. I now know that studies & statistics are a guideline and will not determine how healthy I will be for the remainder of this life. Allogeneic transplant 2006 – now 38 years old

- The 2011 Survival reunion held at the Hutch this July was spectacular. It was one of the most inspirational gatherings I have ever attended. Being able to see first-hand the statistics that were provided to us was so great. I had no idea how normal my survival symptoms were. Many of the statistics and facts were some of the same things that I encountered. Allogeneic transplant 2001 – now 62 years old

- The reunions we’ve attended have been a blast! At the last one, my wife and I were accompanied by our two daughters who were with us for my BMT. That reunion was a great experience, a kind of closure for us all. Our youngest daughter is now a Supervisor of Child and Family Services, dealing with problem juveniles for a local county. Our oldest daughter is a Nurse Practitioner in Oncology. She specializes in the diagnosis and treatment of breast cancer and is the coordinator of a program that provides post-treatment care and support for cancer survivors. Allogeneic transplant 1983 – now 67 years old

A Final Thought….

- The journey to my “18th birthday” has been comprised of many elements of a long-term, autologous survivor: fibromyalgia, young physicians telling me they read about patients like me in medical school, attending my children’s college graduations, my daughter’s wedding, annual “Hutch” LTFU Patient Recovery questionnaire, dry eyes and dry mouth, dancing in the kitchen with my husband, playing ball with the dog, learning to garden, exacerbated heat intolerance (irony: I live in the desert), life celebrations with family and friends, and prayers of gratitude for all the healers that have shared their gifts of knowledge, hope, compassion, humor, and truth that have made the journey a possibility. Autologous transplant 1993 – now 57 years old