Thoughts and Comments from Patients—2009

The Best of Times...

- 20 years – Celebration Year!! ...I am looking forward to 20 more great years. Allogeneic transplant 1989

- Newly retired and never thought I’d get to this stage in life. How grateful I am for the many wonderful, and unexpected, years of life given to me... Autologous transplant 1995

- The highlight of 2008 was hiking to the top of Mt. Whitney. I felt great – like I could have hiked forever, and I’m over 50! Autologous transplant 1987

- Since my transplant treatment, I have done triathlons, half marathons and last month climbed the highest peak in the continental US (Mt. Whitney) as well as married my best friend. Autologous transplant 2005

- ...I am looking forward to being 16 yrs. old & being able to drive... I get—winded. But this usually occurs after snow skiing for five hours in places marked “Danger Cliffs.” After completing this packet, I realized that I could be much worse off that I am now. Allogeneic Pediatric transplant 1999

- Last week I was skiing, dominating the mountain as only a 62 yo can do, when I realized that it was 12 years to the day that my brother’s cells were infused. Whodathunkit back then?  Allogeneic transplant 1997

- When I arrived in Seattle,... I was given odds of 20% for survival (I was told they were being generous). Along with all that, I was given the extremely long list of potential side effects. Well, it’s 23 years after “Day 0,” I’m alive, pretty healthy and I only have a small handful of those side effects. I may look “normal,” act normal, but I know that I got something special. I’m a cancer survivor and proud of it! Allogeneic transplant 1986

- When I was diagnosed in 2003, I thought that I would never see my 70th birthday. I’m going to make it in a few months with flying colors – no medications, aches or pains. WOW! I have put cancer on the “back burner,” and enjoying each day with all the “things” a retired teacher dreamt of doing when she was busy teaching. Autologous transplant 2004

- It’s been 17 years and I feel very healthy & normal...Did the Seattle stair climb for leukemia this year and encouraged 5 of my friends to become bone marrow donors!  Allogeneic transplant 1992

- I have learned that life is uncertain and that there is a lot to see & do. I have hiked solo thru some of the most isolated wilderness in the U.S. and have been able to travel abroad from Europe to South America and most recently to Vietnam.  Allogeneic transplant 1999

- Since I went through the transplant, I earned a bachelor’s in computer science. I’ve been enjoying a new career, and know that each day is a gift.  Allogeneic transplant 1997

- I know that some patients who have gone through a transplant have problems with memory, but I would like to tell you that currently I am attending --- Community College and made the Dean’s Honor Roll.  Allogeneic transplant 1999

- I celebrated 20 years post-transplant this year and I hardly notice that I was sick so many years ago...I am studying full-time towards my Master’s in Teaching at a Swedish university (in Swedish) with focus on Art Education.  Allogeneic Pediatric transplant 1989
My health is great. I’ve run 2 ½ marathons in my 6 years post-BMT and am now expecting my second baby, both conceived naturally. Life is fantastic. I know others are not as fortunate. Allogeneic transplant 2003

I just went out to Seattle for my 5-year follow-up. Dr. Flowers gave me the reassurance I needed by saying, “If I only had your current medical records in front of me, and didn’t know your history, I would ask you to consider being a donor.” Allogeneic transplant 2003

Every year on the day of my transplant, my mom sends me a rose for every year post-transplant, this year I received 26. Allogeneic transplant 1983

As soon as the trail for snow mobiles was established, I couldn’t hold back any longer, got my “Bearcat” and followed my husband up the snowy trail. Breathing fresh mountain air and seeing the beauty of snow-capped mountains made me feel strong and healthy again. Autologous transplant 2008

Compared to my friends my age, I have more energy and strength than most of them. Autologous transplant 2003

The Worst of Times...

I have mood swings and now my family tiptoes around me. I am saddened by my change in personality and being alienated from my children for past blow ups. Allogeneic transplant 2003

As grateful as I am for this gift of life, my quality of life has become very poor. Allogeneic transplant 2001

After 20+ years of fighting this thing within me I am many things, but mostly I am alone. No one much cares anymore about my week-long hospitalizations, surgeries, shots, IV’s, the $670,000.00 worth of medications I now take or the side effects they bring. Autologous Pediatric transplant 1990

Cancer has advanced to liver. I’m receiving Etoposide at this time. I’ve been on it for 2 weeks. I’m running out of options/treatments. Autologous transplant 1992

Dental problems, infection, ongoing decay and lack of insurance to remedy these problems really gets me down and saps my energy. Autologous transplant 1994

I get bummed because I do not have the energy or stamina I used to have. It is hard to get moving in the morning. If it weren’t for the dogs insisting on being fed @ 7am, I may not get up until 10am. Autologous transplant 2007

This has been a hard year for (my husband). He has struggled with depression, and he is now very tired of doctors & being a patient. Allogeneic transplant 2001

Every year of BMT survival becomes more difficult. Fatigue, anxiety of recurrence, continuing debilities of GVHD, pain, medical bills that never go away, fear of trusting in someone, inability to work and make a living, chronic pain with providers unwilling to help aggressively … fear of going blind, sleepless nights (filled with worry and the knowledge I will never submit to this again if leukemia returns)… Allogeneic transplant 2003

If I had to do it again I would not…If I had known then what I’m going through now, no way would I go through a transplant, the cure is worse than the disease…I’ve lost my last three jobs due to my health, at the time of my transplant I was working for the government so I get a retirement I paid into, it isn’t much and I would love to go back to work if even it was part-time. I never dreamed I would have this many problems… Allogeneic transplant 1990
The “New Normal”…

- It’s been a slow climb during the first year after transplant. All my life, I was successful balancing a lot of things at a time, and was able to handle the unexpected in stride. After transplant, I felt very easily overwhelmed, not only physically, but mentally and emotionally. I finally feel that I am on my way to returning to “normal life,” deal with frustration, and starting to balance work vs. home, kids, etc. Autologous transplant 2008

- Also, as you can tell by this writing, I have a hard time putting my thoughts together & spelling, oh well, just the way it is now. Allogeneic transplant 2006

- Notwithstanding the incredible medical care I have received from doctors everywhere, I have grown very weary of visiting them or having to see new ones. This is not a complaint, just an observation. I hold my breath waiting for the results of every CBC. Allogeneic transplant 2004

- I searched for a category – excellent health with persistent fatigue. I have come to expect that being perpetually tired is part of my new normal. And, yes, I do exercise and eat well… I have learned to dole out my energy and to say no. Autologous transplant 2002

- I never expected to feel as tired as much as I do now, and never thought that I would still “not (be) whole” again this far out of my transplant. Autologous transplant 2008

- I am finally feeling like I have my life back. True, I am not up to par with someone my age – I’ve had a hip replacement, and decreased lung function keeps me from moving all that fast. But I am a full-time college student. Allogeneic transplant 2006

- Life has certainly not been as expected. I thought I would be teaching again in 1 year instead of finally being approved for Social Security disability. I didn’t expect chronic GVHD and hospital stays and tons of pills. I wasn’t prepared for the fatigue, sleep problems and pain. However, I feel so blessed to have time at home to spend with my children and grandchildren as well as being a foster parent to more than twenty children in need. Allogeneic transplant 2003

- Although I’m happy to be alive, it seems like it is a struggle everyday. One health problem after another. Dry eyes, joint pain, weakness, emotional ups & downs. I’m 22 years out and it seems like I’m swimming upstream everyday. Allogeneic transplant 1986

- I go to pulmonary rehab class twice a week. I would like to be able to do more, but lung function does not allow it. Thank you God for another year!! Allogeneic 1998

- I can do most things I did before… I do tire more easily when hiking, but if I take it slower, I do okay. Most of the things I want to do I am able to do if only a bit slower or with less intensity. Allogeneic transplant 2009

- I wish I would have known that the progression of dry eye could lead to this (wearing lenses, etc.) and had better information about what to do for it. Out of all the different problems I have overcome, I never expected dry eye syndrome to be so incapacitating. Allogeneic transplant 2001

- If a real solution for dry gritty eyes is ever found, I sincerely hope all post-transplant patients will be informed by you. Allogeneic transplant 1997

- My husband…continues on with his stent, pacemaker and defibrillator all working fine. His myeloma is at a low level and we plan for it to stay low. Autologous transplant 2004

- I live with a compromised immune system, several bad joints due to AVN, scars all over my body, and the fear of what will come next. I wish I could offer comfort to those going through similar things, but the only thing I can say is to take it one day at a time. The good days make the bad days worth it, and
the continual support from my friends and family make the bad days tolerable. Allogeneic transplant 2002

- Other than the neuropathy in my feet, I am blessed with great health - golf twice a week but I’m still not very good, actually I suck! – walk five miles a day although my feet are “toast” later in the day – bowl tournaments again, however, am a bit limited due to numb feet... Allogeneic transplant 2006

- I applaud your research efforts to find less toxic treatments that can achieve the same or even better results. Yet the toxicity does have its merit: the patient gains a new appreciation of “normal” times in life and can personally relate to the famous Marine motto...”The best thing about pain is you know you’re still alive!” Autologous transplant 2002

- I am finally feeling very well. I had many problems along the way, but I am able to live my life. I’m able to do the things I’d like to do...I have a new “normal” and have embraced it + learned to live with it. Allogeneic transplant 2001

- The little things I live with such as dry eyes and mouth, or dry anything have just become a part of me, the alternative I consider much worse. Allogeneic transplant 1995

**Worries...**

- Though I know I’m “cured,” I continue to worry when something isn’t quite right with my body or a blood test, etc. Once a cancer patient, always a cancer patient, I guess! Autologous transplant 1998

- I had to have a mammogram, then a breast MRI. The mammogram showed an abnormality in one of my breasts. I had to wait all weekend for definitive results from the breast MRI. I totally panicked and lost it, especially because of all the radiation I’ve had. I am only 29 and the thought of having cancer a third time absolutely freaks me out! I guess that means, even at 8 years out, the fear is still there. Autologous transplant 2001

- I find that I constantly worry about my cancer coming back. I think it would be helpful to get patients involved in some counseling about being a patient & survivor as it really is life-changing. Autologous transplant 2007

- I am terrified of getting another cancer, but even more terrified of getting a cancer and not knowing about it until too late. I have been vigilant about seeing my dermatologist and getting skin cancers removed... Autologous Pediatric transplant 1990

- I still have so many symptoms and complications cropping up. The most difficult problem I have now is distinguishing which symptoms need to be reported, and which ones do not. Being a nurse makes this even more difficult. I have lost my sense of objectivity. I also feel a sense of guilt “bothering” the clinic staff, as I know their caseload is outrageous and there are pts. much more acute than I am...I am still sooo grateful to you all!! Autologous transplant 2006

- Section B.8.10 asks “If I am worried about my health.” Since mantle cell lymphoma cannot be cured with the Autologous transplant I received in July 2008, I am always aware that it will return. While my overall health is good and I feel well just knowing that I will face this disease again in 2-4 years, there is a dread each year when PET scans are due to be done. Autologous transplant 2008

- I’d love to see comments on how other patients deal with the fear of a relapse or new cancer. I go get tested if a “beauty” mark looks strange, etc. But still it is a haunting worry. Autologous transplant 2005

- It’s been 15 years and I still worry about when something else will go wrong! Allogeneic transplant 1994
Getting Older...

- Some of my “problems” are more age-related, such as cataracts & painful joints, I’m just wearing out! Allogeneic transplant 1981
- This is my 25th year post-transplant and I am forever grateful for the additional years I have been given to raise my son (now 30 yrs. old) and to experience a wonderful life... I can honestly say I am happy to get old and I am very much looking forward to a long life. Allogeneic transplant 1984
- I was told the transplant would age me 10 years and I found that hard to believe at the time, but it’s true, not bad, just true. More importantly, I have gained wisdom, patience and understanding. Allogeneic transplant 2003
- Most everything that happens to me now I blame on “aging.” Allogeneic transplant 1991
- I am tired of being tired, not having my old self back and having to limit my activities. Glad to still be around to see my grandkids, but, wished I could do more with them. I always wanted to be a fun grandma not the old grandma and that’s basically how I feel – Old. Autologous transplant 2007
- This year I turn 65...A few aches and pains, some neuropathy in my feet, a little GVHD of the fingernails. Caused by the multiple myeloma, the BMT, the meds, or just getting older? Who cares? Allogeneic transplant 2004
- Any research on conditional survival for BMT/CML patients – i.e. Given that the guy has made it 19 years into his 62nd year, how does his expected life span compare to “normal.” Allogeneic transplant 1990
- Do you have any info you could send or email about long-term survival rates? I’m nine years out and would like to know the odds of my making it to 10 years, 15, etc. I used to receive a publication from you that featured a 25-year survivor on the back cover. That was my goal – to get my picture and story on that page! Wish you would resume that feature. I’m over a third of the way there! Allogeneic transplant 2000
- I’ve been in remission for 10 years, but the rest of my body seems to be falling apart! It’s hell getting old! Autologous transplant 1994
- ...at 64, I’m in much better health and much less worried about “aging” than many of my peers. Aging (“gaining experience”) is now a thing to be deeply grateful for, and to welcome wholeheartedly. Allogeneic transplant 1997
- Pain, lack of energy & stamina are still daily challenges that I have learned to tolerate & live with. Judging by the way I move, the amount of activity I can do each day, & the number of times I must stop & rest – the best way to understand my life after transplant is to imagine being aged prematurely by a factor of 10 or 15 years. Autologous transplant 1991

Some Expressions of Gratitude, among Many...

- I have a much stronger relationship with my wife & children. I recognize the value of the little things. As Bonnie Raitt says in her song, Life gets more precious when there is less of it to waste. Extended family is much more important and we visit more often. Allogeneic transplant 2002
- First of all, I want to say I really appreciate the FHCRC and the time you take for long-term follow-up patients of FHCRC. FHCRC Long-Term Follow-up helps me to feel a little more secure and at ease when faced with somewhat scary or challenging health situations (such as I am currently facing). Autologous Pediatric transplant 1978
On my desk, I have photos of my transplant event & a jar with my Hickman chest line & a harvest needle – a little “altar” of gratitude for these years gained with your help. Allogeneic transplant 1988

(My daughter)...will be heading off to college this year with all the usual hopes and dreams of an 18 year-old woman with a bright future ahead of her. Thank you again for making this all possible!! Allogeneic Pediatric transplant 2003

While we were in Seattle we were always pleased with the desire of most all the physicians, nurses & other support staff to take all the time needed for an appointment & to make sure any & all questions were answered. We thank you for the personal, compassionate & very competent care as well as the efficiency with which our 4-1/2 month visit flowed. Allogeneic transplant 2008

Lastly, thank you for your interest of knowing how am I doing – that means a lot for me – appreciate your interest of the bit (of) information I provided... Allogeneic transplant 1992

I am very thankful that the LTFU exists...Knowing I can call the LTFU office regarding my health status and care is both mentally and emotionally comforting and helpful. Allogeneic transplant 2007

I have a friend (colleague’s friend) who just had a transplant elsewhere & his spouse emails me for help with everyday problems they are experiencing. This is a testament to how well your team prepared us for the process. Allogeneic transplant 2009

27 years! I’m now the same age my parents were when I had my transplant in 1982. As the father of a 4 year-old, I have a much greater appreciation of what my parents went through during those months. I thank God, my parents, and the Hutch for every minute, day, and year that I’ve been given since my transplant. Allogeneic transplant 1982

I fly frequently between Orcas Island and Lake Union on Kenmore Air float planes. There has not been a single time on any flight that I haven’t looked over to The Hutch and thanked God for my good fortune to have been treated by such a great facility and organization. Allogeneic transplant 1986

I always look forward to filling out my annual health “report card.” All A’s for me. I feel better than ever thanks to Fred Hutch & my donor! Allogeneic transplant 1993

Thank you for creating a healing atmosphere. Strange though it may sound, I think of my four and a half months in Seattle with nostalgia. How lucky I was to have a sister who was a perfect match, a mom who made our Pete Gross apartment feel like home, family and friends who supported me throughout. And the staff of SCCA to care for me. Allogeneic transplant 2008

Exercise!!!...

I do try and keep an active life by walking Green Lake at least three times a week and by taking a yoga class for women over 50. My husband (&) I took a trip to Italy this last year and I held up better than I thought I would...I hope that I will be here to fill out this questionnaire for many more years. Autologous transplant 1993

Goals: able to play tennis, basketball and golf with no limitations. Allogeneic transplant 2006

One year post-autologous transplant for Mantle cell lymphoma...my wife and I take Tango lessons twice a week and go out dancing once or twice a week...Our dog is my personal trainer; we go for a 2 to 4 mile walk several times a week. Autologous transplant 2008

I just have my “rut” and I’m very happy in it...I swim 5 days a week. Still can’t run the computer. Medicare doesn’t help everything!! Allogeneic transplant 1998
Memory Problems and Coping Strategies...

- I think I’m finally becoming accustomed to my “lesser” brain. It’s hard to say whether my impaired cognitive skills + memory loss is due to transplant + chemo brain remnants OR just being in my 40s – might have happened anyway. Allogeneic transplant 2005

- I was diagnosed at age 19 while studying abroad in Spain...Spain is waiting for me! Through my whole experience with leukemia, I have decided to become a medical interpreter in Spain...I have always prided myself in my intelligence, and I feel like with every chemo transfusion I had, my brain would increasingly turn to mush. Through my entire ordeal, I would have to say memory loss has been the hardest thing to deal with. But at least I’m still here to forget things! Allogeneic transplant 2008

- My favorite part of the comments is reading about people having problems with concentration and memory loss. It makes me feel good that I’m not alone. I always read those comments to my husband who often becomes impatient with me. Autologous transplant 1989

- ...I think this side effect (memory loss) has the greatest impact on my life. My husband finishes my sentences because I have difficulty staying on track, can’t remember long enough to finish speaking a thought. Autologous transplant 1997

- I have largely adapted to the cognitive changes I incurred, but am increasingly concerned about my increasing difficulty with memory. At age 50 this is a serious concern. I’m having trouble getting doctors to take this seriously. I am so grateful to SCCA/FHCRC for saving my life and providing my 4 children with a mother. Their new and improved mom is kinder, gentler and a lot less inclined to get caught up in the little stuff. After AML and BMT – the rest is little stuff. Allogeneic transplant 2004

- My only “complaint” is that my handwriting is totally illegible and unpredictable since my transplant (small price)! Oh, yeah, and I forgot what I was going to say about my memory and cognitive skills... Autologeneic transplant 1993

- I have tried to hold down numerous jobs, not even in the field I went to college to study. It is very embarrassing and makes me feel worthless when I think of the host job (restaurant), bartender and numerous sales jobs that I was fired from due to forgetfulness, not being able to keep up with tasks and having to do numerous job-related activities. Allogeneic transplant 2003

- My concentration and memory skills are in the toilet and everyone tells me “it is getting older.” I am only 33. No one seems to respect/understand the long-term effects and chemo, TBI, and steroid treatments. Allogeneic transplant 1999

- When I returned to work 4/2009, I was having difficulty remembering things pertaining to my job. For 2 weeks I just got by doing small assignments. During the third week, I was asked a technical question and in one moment it all came back! This wasn’t simple “oh ya” but it felt like a portion of my mind suddenly turned back on. I have never had this feeling ever before or since. It was so intense I went back to my desk and sat down for a few minutes. This feeling was like finding a door in your house you have never opened, opening it and finding everything you have ever lost. Autologous transplant 2008

- I am very scared about my memory and retention. I have lost 2 jobs in the past 6 months – due to this issue. I am only 60 yrs. old and must bring in an income. Autologous transplant 1997

- I am concerned about my lack of mental focus. I now have the attention span of a squirrel and terrible memory problems. I do spend a lot of time worrying about my future, and every visit to the doctor brings on a lot of anxiety...Is my husband tired of all my aches & pains & complaints? You bet. So am I. But, that’s life. I had trouble concentrating, so I went back to school and got an MBA...If nothing else, I am learning to be patient. Allogeneic transplant 2006
Finance and Insurance Problems...

- My health and finances continue to stress me everyday. I just wish I knew what the future would be for me and my family. Adjusting our financial plan is most difficult as I continue with my disease. Autologous transplant 2003

- I’ve only had health insurance for six years of my life (I’m thirty). My husband & I would like to move & he would like to change careers, but we stay for the benefits. Allogeneic transplant 2007

- Financial concerns are a big issue. People need help navigating Social Security, Social Security Disability, health insurance, long-term health insurance and household budgeting. Allogeneic transplant 2000

- Really would like to have a baby. Need some help w/cost. Allogeneic Pediatric transplant 1992

- Besides having MM (multiple myeloma) and going through 2 transplants, the worst thing is dealing with the mounds of paperwork (disease info, bills & insurance forms) generated due to the treatment. Autologous and Allogeneic transplants 2009

- Insurance after a BMT is a problem. Autologous transplant 1992

Other Problems...

- The strangest is that I don’t smell like me anymore. I never had any armpit or foot odor and now I do. I smell like a guy! I’ve asked another PBSCT patient who also had a male donor and she was surprised to hear that. She noticed the same problem. Allogeneic transplant 2007

- In my case I made it a rule to be up, dressed and ready for the day by 9 am. I decided that I had to get out of the house and into public at least once a day. It is such a powerful thing when someone says, “How have you been, we have been looking for you.” Allogeneic transplant 2000

- It is hard as a patient doing the “marathon” run through GVHD treatment to deal with the frustration of not being listened to or respected. Allogeneic transplant 2007

- I have regained 20 of the 40 lbs. lost in treatment (I shall not try to regain the other 20). Autologous transplant 2008

- Shingles infection on face became/led to secondary infection of cornea, causing slight permanent loss of vision, a real pisser for a bird watcher! Autologous transplant 2005

- When we beat my aplastic anemia in ’78 and I was still fine 5 years later, my doctor said “well just go on with your life.” ...In 2005 I decided to open a door in my head where I had stored all the emotional things about my time there in 1978. All the things that I went through and all the kids I watched never leave. Allogeneic Pediatric transplant 1978

Pediatrics...

- The first year post-transplant was hard & busy. I thought it would never end. The second year flew. Now I just look at him and almost start to cry because he is still here. Sometimes even the sibling fights make me smile! Allogeneic Pediatric transplant 2007

- 39 and going strong!!! Allogeneic Pediatric transplant 1974
• (My daughter)…is 10 years-old now and in 5th grade…She rides her bike, loves to take walks and even played baseball…In January of 2009 she did have a relapse…but she is now all clear on her last CT & MIBG scans.  Autologous Pediatric transplant 2006

• (My son) was diagnosed with high-risk ALL at 6 months of age.  (He) is now 9 yrs. old and though is small size has the largest personality at school and never stops!  Thanks!!!!  Allogeneic Pediatric transplant 2001

• (My daughter)…is a totally normal 6 year-old – people can’t believe she has a medical history with Wilms and has had a stem cell transplant.  Autologous Pediatric transplant 2006

• I also am struggling with relating to my peers because I feel so much older.  I also am having some trouble in the transition from Ped to Adult care.  Allogeneic Pediatric transplant 1999

Children and Grandchildren...

• I am thankful always to FHCRC for allowing me to walk my only child (daughter) down the aisle later this month.  I can’t wait for grandchildren!  Allogeneic transplant 2005

• I have a 3 yr. old granddaughter that has blessed me with a new enthusiasm for life.  When my birthday comes around someone might ask me what I want for my birthday, I usually keep it to myself, but a day without pain would really be nice.  But when that little girl looks at me with a smile and says “I love you grandpa,” I will fight to be a part of her life as long as I can, or until she discovers I’m not cool, just an old fart.  Allogeneic transplant 1989

• I had my transplant in 1982 for AML.  I had 2 small children at the time (daughter (2) and son (4 mos.).  I am 54 and soon to be a grandmother!!  Allogeneic transplant 1982

• When I left Seattle in 2005 after two transplants, I was told that I would go into early menopause and having a baby was not a part of my future.  In Jan. of ’08, I began not feeling well and my doctor was unable to find the source of my problems.  Fearing the worst (cancer had returned), he sent me to have a PET/CT scan in March ’08.  To our astonishment, they did not find cancer but they did find a “fetus.”  I’m amazed at the healthy baby boy I hold in my arms everyday.  Autologous transplant 2004, Allogeneic transplant 2005

• I just spent a few days with my grandsons at the beach.  There was a time, a few years ago, that I didn’t dare to dream of that happening.  Allogeneic transplant 2005

• Good days – Bad days.  You gave me the blessing to live to become a grandmother.  I plan to dance at his wedding.  Allogeneic transplant 2001

• In the past 9 years, I’ve danced with 3 sons at their weddings and held 3 grandchildren.  Thank you, Hutch staff, for all that!  Allogeneic transplant 2000

• This year was my 18-year post-BMT anniversary.  It was a very special one because my daughter and son-in-law presented me with my first grandchild…  Allogeneic transplant 1991

• Again, my heartfelt thanks for all you did in extending my life.  At the time of my transplant for … aplastic anemia in 1990, my youngest of six children was 2 yrs. old, and I prayed I’d be there to see him graduate kindergarten.  He will graduate magna cum laude from the University of Notre Dame this May.  Allogeneic transplant 1990

• 2009 will be the year I turn 40 (back in Feb.), hit 5 years since my Allo transplant, and, God willing, my twins are born (due in October) via gestational carrier… All HUGE accomplishments, considering no one thought any of them would happen at diagnosis in 2002.  Allogeneic transplant 2004
Perspectives from a Distance...

- Thanks so much for the services you provide. It feels good to know that I haven’t just been dropped. Survival after transplant is not simple or easy… I am learning that this survival holds many more lessons and opportunities to grow and live a more meaningful life. Allogeneic transplant 2008

- Now 34, I’ve lived a whole other “life time” since I was transplanted at age 17! Allogeneic Pediatric transplant 1992

- My perspective on life has changed since becoming ill. Now every day is a good day. I used to dread birthdays, now I’m very happy to see them come around. It means I have lived another year. Autologous transplant 2004

- Sometimes I forget what I went through, but at the end of the day I ask myself, did I make today count? The answer is mostly yes. Allogeneic transplant 2002

- I feel as if I have been in a healing cocoon for four years and am just beginning to wake up. It has been a long road, but worth it. Autologous transplant 2005

- I notice that the farther I get from transplant, the less interested my oncologist is in me. Hopefully, he pays enough attention that if something is wrong, he will notice?... This was still the best experience of my life. I would never want to experience it again but good things came from it. I have a new/renewed appreciation of life & don’t take anything for granted! Autologous Pediatric transplant 1994

- This is my 5-year anniversary of the transplant. It really is only in the last 9 months that I have been able to reclaim my life…I bought my first home & I have met an amazing man. It was a long & difficult road to get here though. Autologous transplant 2004

- I try to do what I did not before I got sick – to take a moment each day to breathe deeply and smile at the world. Autologous transplant 2006

- The 25th anniversary is the biggest one yet. I was 24 when I had a BMT for CML. Have now lived longer post-transplant than pre-transplant. I can offer care and comfort to so many others. Never far from my mind are the experiences I went through 25 years ago. Allogeneic transplant 1984

- I thought four years from transplant I would be living life to its fullest. Instead I’m dependent on others to get me places and mostly wheelchair bound. I’m happy to be alive and to have had four more years to watch my children grow and laugh and play. I wouldn’t trade that for anything. Allogeneic transplant 2005

- My 4 year post-transplant date --- came and went without me remembering it until 2 days later. I figure that’s a good sign. My chronic GVHD in the form of scleroderma is somewhat limiting but, overall, I am still one lucky man. The past 4 years of survival have been a blessing. Allogeneic transplant 2005

- I have 3 wonderful children, all under the age of 8, & a wonderful wife. Though life isn’t ever going to be easy, it is always going to be joyous. Also spent 10 days on my Harley last summer traveling to Sturgis with my dad & 2 great friends. There is so much I could have missed out on. I would go through it all again for just a minute of the happiness I have now. Autologous transplant 2005

- It hasn’t been easy and I am not the same woman I was. The after-effects of chemo and radiation and, of course GVHD, are daily companions. I accept their presence and while not welcoming them, they are reminders of how far I’ve come. The price for living was high in terms of suffering, but what I’ve gained is so precious. Allogeneic transplant 2005

- I don’t wake-up screaming at night…It took me 3 years post-transplant to even think about the future, and then 23 more years whizzed by. Yikes! Allogeneic transplant 1983
Compliments, Complaints and Suggestions...

- If you are still rotating patients through team members on a monthly basis, good for you. I found that the interaction with multiple oncologists to be beneficial. Autologous transplant 2002
- I do not agree that the first thing on your recommendations is to remind us survivors that we have an increased risk – we know. I do agree on reminding us to use sunscreen, protect from sun, other preventative measures, but the suggestion that we could ever get cancer again is hurtful. Allogeneic transplant 2001

About the Questionnaire...

- I’ve been done with my survey for a few days now, but I left this blank because I wanted to say something profound. But I’ve been too busy running my kids around, keeping up with the house, doing a painting for commission, getting my 20 miles of running in per week to get to it. I realize that is profound enough. Allogeneic transplant 2000
- I look forward to your questions each year, although as one ages, the answers become more complicated. For us seniors, I’d suggest that you change the “Yes” answer to “Damn right.” Allogeneic transplant 1983
- I had a bad day yesterday, very “blue” and tired, but getting this (questionnaire) today perked me back up and helped me regain proper perspective. The past 25 years have been a great gift and I will continue to do my best to be worthy of it. Allogeneic transplant 1984
- Thank you for sending this questionnaire. I really enjoy connecting every year in this way. It’s a celebration of life for me. My life has definitely changed over the years and I am limited in certain things, but I have adjusted and adapted to a new way of life. Allogeneic transplant 1977
- It seems that every time I fill out this questionnaire I have to state that I am depressed. It is hard to live a “normal” life when my breathing is so poor…However, 18 years post-transplant & counting! I feel like a champ. Allogeneic transplant 1991
- I still very much enjoy the yearly questionnaire. It helps to remind me of where I was, and how far I’ve come. It reminds me that in comparison, I’ve had a really great 10 years. Very few complications post-transplant, no relapse, no significant daily difficulties. If all I have to deal with is bad memory, some stiff joints, and poor lung function, then I think I’m pretty damn lucky. Allogeneic transplant 1999

Giving Back...

- ...in the past two years I have had a son donate his bone marrow and another son donate his blood stem cells to help someone with leukemia. I’m truly grateful that in some small way they have given back what a stranger gave me. Allogeneic transplant 1989
- “Giving Back” after stem cell in 1999, joined Angel Flight of New England. I fly cancer patients to & from treatment…I (have) done over 100 flights… Allogeneic transplant 1999
- I feel extremely blessed to be filling this out almost 19 years after my BMT. I have lost several friends to leukemia over the past 5 years and I was able to give them some hope & support for a good period before they passed away. Allogeneic transplant 1990
New Medical Careers...

- At the time my twin daughters were 8 years old. I have lived long enough to see one of them become a registered dental hygienist and the other one is one year of residency from becoming a doctor. During my transplant I prayed to see them through high school. Now I’ve seen them through college and they have become successful, productive adults. You do so much more than just fix sick people. You make families whole. Thank you! Allogeneic transplant 1991

- Both of my children are in a medical field and I owe that to the experiences they had at the Hutch. (My daughter) is a nurse practitioner at a coronary hospital. (My son) is in his 2nd year of medical school... Autologous transplant 1991

- My daughter was about 1-1/2 (years) old at the time of my transplant and is now 29 years old and a medical doctor now and is in a plastic surgery residency program... Allogeneic transplant 1981

- The greatest blessing I received from my BMT, aside from being a 21-year healthy survivor, is my wife...she decided she needed to become a nurse. So after seven years of school as a working mother, she received her RN and immediately began work at ----Cancer Hospital... Allogeneic transplant 1988

Donors and Care-givers...

- 25 years later I am married to the girlfriend who saw me through it all, with two children born of the sperm we stored before the transplant and two adopted. Allogeneic transplant 1984

- For caregivers: ...it has taken me two full years since my husband’s transplant to “find” myself again. My own interests & pursuits were neglected for so long I forgot who I was...I’ve learned to let go... Allogeneic transplant 2006

- I am thankful I have been granted a(n) extra lease on life, because now I am giving back to my mother who was my caregiver at SCCA. She had hip replacement in April, now the left knee and the right in the spring. I am her caregiver now. Thank you! Autologous transplant 2006

- My husband & I went to meet my donor for the first time in December of ’08. He was ordained as a Presbyterian Minister, Raleigh, North Carolina. It was great to be invited to attend & meet all of his family – very emotional for me & my husband. Allogeneic transplant 1999

Final Thought...

- Hurray!! Thirty years post-transplant and counting. There is life after transplant! I remember my first Christmas out, wondering if I would be here next year to decorate the tree. I too have had times when I have been anxious about relapse or as the years have gone by being scared that I would get another form of cancer or problems as a result of all the radiation and chemotherapy. I just decided it wasn’t worth spending my time and energy worrying and stressing about it. If something does come up, I’ll just have to deal with it and go on. If I died tomorrow at least I was given 30 years I would not have had otherwise. I have outlived my parents, my husband, aunts, uncles, cousins and most recently my best friend of 42 years. Who’d have thunk-it? Allogeneic transplant 1979