Thoughts and Comments from Patients—2008

The Best of Times...

- 36 years and still here. What a ride!!! Allogeneic Pediatric transplant 1972

- The social worker assigned to my team forewarned me that all patients experience some degree of depression. It has been 11 years since my bone marrow transplant and I’m still waiting. Allogeneic transplant 1997

- In a few weeks, I will be on my Harley, riding from Northern California through Oregon, through Washington and to Canada. I feel great and people say that I look better than I did before. I am 60 years old this year and am back on my 100 year plan. Allogeneic transplant 2005

- Last July I woke up one morning and felt good—normal—like before my double mini transplants. Just over four years and finally I felt good! Autologous and Allogeneic transplants 2003

- When I was diagnosed, I was told there was no cure for my non-Hodgkin lymphoma, and that I would die of the disease. Twenty-one years later, I am still here and disease free. Autologous transplant 1987

- I had been anticipating a relapse or secondary cancer for over a decade and have just now begun to relax and enjoy my life. I now have two young daughters and I no longer feel as though cancer is hanging over our heads. Allogeneic transplant 1991

- My biggest problem over the years is that my life is so normal. I sometimes forget that I ever had CML (accelerated stage) without a good donor match (4 antigens). Allogeneic transplant 1988

- Instead of checking “no” for almost every box, I’d rather just say that I am 100% normal again. Allogeneic transplant 2002

- For the last year and a half I have worked for a construction company lifting, carrying heavy loads. At first, I was unsure if my body could handle such work especially after five knee surgeries and one elbow. I can confidently say I have never been in better shape. Through increased muscle strength [I have] reduced pain in joints. Allogeneic Pediatric transplant 1990

- My family is growing and changing very quickly, but I am here, participating fully in every possible way and enjoying every moment of it. Allogeneic transplant 2004

- I gulp down a handful of pills in the morning and at dinner time but otherwise I am as close to normal as I can be. Allogeneic transplant 2004

- It is sometimes hard for me to believe how serious my condition once was. If you were to read my chart of May 2000 and then see me now, you would not believe it is the same woman. Allogeneic transplant 2000

- I play a lot of bad golf and for the most part, enjoy life. Would like to take less medication and see doctors less, but I guess that’s not in the cards. As long as the CMML stays away – life is good. Allogeneic transplant 2007

- I remember dreaming of the day I’d get to worry about the little daily things again! Allogeneic Pediatric transplant 1992

- I’m feeling so great – was I really that sick? Did I really have a BMT? Allogeneic transplant 1993

- This summer I went on a 10 day trip with 100 other people—we hiked Zion, Bryce and Grand Canyon. I was an animal! But wish I hadn’t run 5 miles down in the Grand Canyon keeping up with the teens – got a little heat exhaustion. Autologous transplant 1994
• When I read (question) E.1.9 I laughed out loud. During the past 4 weeks I had 13 days of company including children between 1 ½ years and 5 – six little ones. Calm was not an emotion I would describe those days --- but it was fun.  Autologous transplant 1998

• The only time that I recall having had a bone marrow transplant is when I receive this questionnaire.  Allogeneic transplant 1997

The Worst of Times...

• Every time I turn around it’s another disease, another pill, another limitation!  Allogeneic transplant 1998

• I challenge the word survivor.  I think it should be “existor” when you know the cancer will get you some day.  Autologous transplant 2003

• The one thing that bothers me now 17 years later is my lack of strength.  I feel 50% weaker and have never been able to get back the muscle strength I lost.  Despite trying for years with weight training and working out, I seem to be at my peak and it is disappointing.  Autologous transplant 1992

• I wish I had more happy days but I take them as they come.  There are days I just stay in bed and hope tomorrow will be better.  It’s hard to see life full of joy and fun when you have no job because of the cancer and having surgeries every time I turn around, the last two in three months.  Autologous transplant 2004

• Never a problem until I took prednisone.  Massive effect on how I perceive and experience the world – I transformed overnight from cheerful, positive and enthusiastic to terrified, emotionally crippled.  Allogeneic transplant 2007

• Resuming one’s life is a misnomer.  Two and a half to three years post transplant I was ready to go back to where I was – but work had changed, personal relationships had changed.  You don’t just pick up where you left off.  And having lost so many years (chemo treatment followed by transplant), one’s goals and aspirations must change, too.  It’s harder than one assumes.  Allogeneic transplant 2005

• I am very discouraged because I had a recurrence of the cancer in December of 07.  My transplant didn’t seem to help at all.  Autologous transplant 2007

• The cure is still worse than the disease.  Life has been a struggle...If my AML were to return I would be at peace with death and a quick one at that.  Unlike many survivors at 5 years I am not grateful for the procedure.  Allogeneic transplant 2003

• My home doctor said, “The hard part starts after the first 100 days”.  He wasn’t kidding.  Allogeneic transplant 2008

• I can’t really believe that 7 years out I should still be so fatigued and hurt so much.  I’m tired and ready to go home to God.  Then I think “How ungrateful!  You were miraculously saved for a reason!”  What reason?  I’ve looked and looked and can’t find a good enough one to justify the misery – except that maybe my body helped multiple myeloma research move forward?  The kids?  Who knows...  Allogeneic transplant 2001

The “New Normal”...

• It takes time, a lot of time, before you get past the fatigue and other symptoms and feel somewhat normal.  Allogeneic transplant 2008

• I struggle with finding the “normal” post-transplant.  I never know “who” will wake up each morning – the 50 year old in the 90 year old body or just the 50 year old.  Allogeneic transplant 2007
• I still have many problems with stamina which prevents me from leading the full life I once had. I have learned how to manage my energy levels and shut down my activity when my body craves for rest. As long as I “listen” to what my body tells me, my life is fulfilling and most of the time I’m happy.  Allogeneic transplant 1999

• I have severely reduced lung capacity. But I’m happy, engaged doing things I like, so I just adjust my expectations of what I can do.  Autologous transplant 1998

• My advice to many of our “comrades” who are still suffering or struggling to deal with the aftermath of the BMT experience is: try to live a slower life and accept it as a norm; try to accept your body as an old house that has been through a storm and realize that your job is to do constant repairs and maintenance. Nobody can do the job better than you can and you must take control of the reconstruction.  Allogeneic transplant 1979

• I have come to realize and accept that changes to my metabolism are permanent resulting in symptoms which can best be described as accelerated and premature aging. Good energy in the morning – crash in the afternoon (or immediately after a physical task) – moderate energy after resting – crash again in the early evening. When I say “crash” I mean MUST stop and rest from exhaustion. I still have many hobbies which I do as much as possible as time and (low) energy permit. I am no longer meticulously neat, clean and organized like I used to be before cancer. Not even close – don’t care anymore – would much rather “spend” my limited energy doing the many other things I enjoy doing.  Autologous transplant 1991

• Life feels very normal now. I don’t have serious health issues. But the fear is always there, especially wondering if my disease will return or I will develop a new cancer. I try not to dwell on these thoughts but they creep in when I am feeling tired, which seems to be more often lately.  Autologous transplant 2004

• The question folks ask me most, “Given what you know now, would you do it again” YES. But I wouldn’t fly to Seattle with such a silly grin on my face. I expected by this time to be dead or cured... but, neither? I never contemplated that outcome. Terms like event-free survival, disease-free survival or transplant-related mortality attached to percentages by disease and demographic; the very statistics I studied and committed to memory prior to transplant mean nothing when one, as a patient, experiences these events 100% one way or the other. The stats say I should have died even before transplant, but definitely as a “transplant-related mortality.” I didn’t. However, neither have I managed much better than to survive, which is not what I consider success. If this is the “new normal,” I’ll choose “another normal.”  Allogeneic transplant 2004

Getting Older...

• During my first year post-transplant I wished for 10 more years. Of course, now, 17 isn’t enough.  Allogeneic transplant 1991

• I am now 66 years old, work full time in an ICU. I have some aches and pain and get tired but attribute it to my age and the 12 hour shifts I work. Thank you again for your part in my longevity. I have had 35 very good years, and raised an adopted daughter.  Allogeneic transplant 1972

• I’m 69 and enjoying my new souped-up Mustang, and I am contemplating getting another tattoo. One only lives once!  Autologous transplant 1998

• At 68, 18 years post-transplant, my health is very good. I feel fortunate to be able to exercise regularly-aerobic dance, weight-training and chi gong – and to continue my enjoyable leisure activities – gardening, teaching a writing class, tutoring at a homeless shelter, and helping with fund-raising for the local symphony.  Allogeneic transplant 1990
• I am healthy, live abroad, and I am a 12-year survivor of my stem cell transplant. I am 74 years old – active – recently remarried. I play golf and bridge and travel a lot. Autologous transplant 2008

• For a 73+ year old, I enjoy quite good health. I take Pilates twice weekly and walk several miles 2 – 3 times weekly. Allogeneic transplant 1996

• After my 50th class reunion last year, seeing the list of classmates deceased I feel really blessed. Allogeneic transplant 1990

• It took me a long time (3 to 3 ½ years) to get over major concern over aches and pains I had. Had a lot of trouble deciphering whether it was normal “old age” pain or if it was related to leukemia. It always has been normal “old age” pain. It still enters my mind but easily is brushed away now. Allogeneic transplant 2004

• I don’t believe any of my health issues are related to the CML or the BMT to treat it, but rather, to the fact that I’m just getting older. Thank you for the getting older part. Allogeneic transplant 1991

• As I am happily growing older, I am less and less affected by the challenges posed from my bone marrow transplant. I now have the privilege of acquiring common ailments such as hypertension, hypercholesterolemia, erectile dysfunction and sleep apnea along with many other Americans. Allogeneic transplant 1999

Some Expressions of Gratitude, among Many...

• I’m 60 years old now and still living a normal life!! Thank you Fred Hutch. Allogeneic transplant 1979

• I consider myself to be in partnership with the Hutch for the rest of my life. I’ve learned how essential it is to be proactive as a patient. To occasionally have a day when I can say “I thrived today” is a gift beyond words. Allogeneic transplant 1994

• I am one blessed woman. I am grateful from the top of my thinned out hair to the bottom of my swollen feet. I may forget to pick up milk, but I won’t forget how wonderful my life is. Allogeneic transplant 2000

• How do you say thank you for two years of life in which you experience your 5-year old grandson running to greet you in an airport with his arms out wide, in which you’re healthy enough to go on a week-long cycling trip in Northern California…. Autologous transplant 2006

• I have no signs or symptoms of leukemia – when God heals he does a complete job!! Fred Hutch gets some credit also! I turn 65 this year and I’m so healthy I may skip Medicare!! (No health insurance since 1991!!) Autologous transplant 1988

• They have really worked with me at my job to set up a safe work area and give me time off whenever needed, and yell at me when I go outside without my hat! Allogeneic transplant 2006

• My doctor [at home] always gave me hope. I think hope is probably the best medicine I received. Even in the hardest times I knew I would pull through. Allogeneic transplant 2004

• I feel that each day I am alive means another incident where I have poked the fates in the eye. Autologous transplant 2005
Exercise!!!...

- Five years from transplant and I feel wonderful. I walk several miles almost every day with my lab “Poppy”. Allogeneic transplant 2003

- Providence Hospital’s Oncology Rehab exercise class has been a great motivator to get in shape and to stay in shape. Medicare pays for only 20 sessions, however. Several of us in the Providence Hospital Rehab Program lobbied... for a maintenance program once the 20 sessions were over. A year later, we now have a punch card system in place and it is attracting many former Rehab patients. We’ll hope it continues to thrive and that the participants stay fit and healthy. Allogeneic transplant 2004

- Last weekend I ran my sixth marathon in NYC since my transplant. Allogeneic transplant 1998

- I have been going to a clinic for physical therapy for the past 6 months to work on core strength and correct gait problems due to neuropathy in my left leg. It has greatly improved my energy and posture as well as my overall strength. I wish I had done it earlier! I can keep up with my grandchildren now. Autologous transplant 2002

- Exercise has made an enormous difference in my recovery. Weekly, I train as follows: Cycling – 110 miles; running – 8 miles; rowing – 18 K; Yoga 2-3 hours. Autologous transplant 2002

Memory Problems and Coping Strategies...

- Becoming very forgetful, and a couple of times I have been driving and then realize I do not know where I am. It takes about a minute or two to remember. Autologous transplant 1991

- I tell my friends, “It sure is a good thing I was highly intelligent before all that chemo, because now I’m just a little below average!” Autologous transplant 2001

- My mental capacities, forgetting, not remembering, are troubling to me. My ability to do any kind of mathematics has gone from calculus to about fourth grade skills. Allogeneic transplant 2003

- I deal with memory issues such as an inability to multi-task, remember things, etc. I compensate by writing myself notes, to-do lists, etc. I don’t feel that those I interact with notice the memory issues because of the changes I have made to compensate for them. Autologous transplant 2006

Finance and Insurance Problems...

- Since I retired I cannot find an insurance company that will insure me. I am 60 years old with no insurance. It’s quite frustrating. Allogeneic transplant 1999

- When my husband retired, eight companies refused health insurance. I also am ineligible for long-term life insurance. Autologous transplant 1992

- My plan is to forgo my next CT scan due to cost and hope for the best. Each time I have one it ends up costing around $700. Autologous transplant 2005

- I am very disturbed by not having health insurance – May was the end of coverage – trying to get insurance – all but impossible. Autologous transplant 2007

- I had no idea that the dental problems would be so extensive and expensive. My medical insurance carrier REFUSES to pay toward this expense because it is dental, even though it was due to a well-documented medical/health issue. Allogeneic transplant 2001
• The problems I worry about are all financial and work-related. As a self-employed consultant the past 12 years I have never earned enough to cover my expenses, and instead have covered the difference by spending my life savings and increasing debt. The last five years expenses have sky-rocketed while income has decreased. My savings will soon be gone so I am frantically searching for additional and/or different work to earn more money. Autologous transplant 2005

• Folks like us who have gone through BMT, especially, are well aware of when we do and do not need to see a physician. But we are thwarted by a dysfunctional system, at the same time that we need to hold on to every dollar of coverage that many are lucky to have, all the while monitoring how close we are coming to reaching the lifetime maximum cap. Our survival comes with a price. Autologous transplant 1998

• I wish the subject of financial problems had been discussed and emphasized during my visit to Fred Hutch when I first consulted with Hutch personnel about the risks of an unrelated BMT. Money is more of a worry than relapse at this time. Autologous transplant 1994

• I’m at my 6 month mark and am feeling good to go. I can’t see doing even annual testing in the future due to exorbitant costs. I will likely take the “wait and see” route. Autologous transplant 2007

• Now that my son is getting older (now 18) I worry about future medical coverage for him and the high cost of his growth hormone treatment. After he graduates from high school, our family medical insurance will cover him while he is in college. Once he graduates, the cost of growth hormone will surely be a burden unless he finds a job immediately with insurance coverage. Allogeneic Pediatric transplant 2001—Parent

Other Problems...

• In late October a routine mammogram showed an abnormality and I was subsequently diagnosed with stage 2 breast cancer. Neither I nor my medical team could feel the lump even when we knew where to find it. Please continue to recommend routine screenings! Allogeneic transplant 1990

• I have almost had to start making a new network of support for myself because so many of my friends just left when I became ill. Being what some people consider terminal is a real cut off. BOTTOM LINE – I AM STILL HERE!!! Allogeneic transplant 2005

• Bronchiolitis obliterans has now forced me to retire and go on social security. I am happy to be able to celebrate the ten year anniversary of the BMT. It is a shame my current state of health is so poor. I try to stay active but carrying a little oxygen pack is a drag. I have enjoyed so much in the past 10 years. God willing I will survive another 10 years. Allogeneic transplant 1998

• My PCP is not as “transplant-knowledgeable” as you all are, and then he guesses and my “Cancer Dr.”...barely gives me five minutes when I do see him once a year. I feel medically neglected, bottom line. Allogeneic transplant 1987

• The only thing that still bothers me is my stupid hair. It’s thin and nowhere near what it was prior to my transplant. I guess that’s a small price to pay for a second chance at life. Allogeneic transplant 1996

• I am still apprehensive about having a relapse. Allogeneic transplant 1998

• My worst problem is my appetite. I just don’t feel like eating or cooking because I’m not hungry. I usually eat something once a day but I know I don’t eat healthy. I’m alone and it’s hard for me to cook a meal for just me. Autologous transplant 2006

• I am so torn between returning to my former adventures in far off lands, and staying close to home in case anything should happen to me again. I just feel so stagnant here. Autologous transplant 2007
• Leg cramps persist. Heat seems to help most of all. I use a heating pad at night. I get regular exercise and massages. Autologous transplant 2006

• I am struggling trying to figure out what to do with this gift of a longer life. I am fortunate to have a good job with health benefits, but my heart is not in my work. I would like to do something that has less stress, but don’t want to turn my back on those who were so supportive to me and my family. Fortunately, I do have good health and the luxury of time to figure this out. Allogeneic transplant 2005

• I find dentists generally know little or nothing about CML or the effects of GVHD. Most are very reluctant to contact the Hutch. Dental is a big issue post-transplant. Allogeneic transplant 1996

• I recently found out I have breast cancer and I’m waiting for a date for my surgery. I was very thankful that I was able to call Fred Hutch and talk to people there about my cancer. My biggest concern was how much more radiation my body can take. Allogeneic transplant 1989

• For those of us that are highly active, being told that we have to avoid exposure to the sun is utterly daunting!!! There are some great informational brochures (www.at-risc.org) specific sunblocks developed that could greatly help transplant patients. Allogeneic transplant 2008

• My dry eyes have progressively worsened to warrant a trip to the Boston Foundation for Sight and the scleral lenses this clinic creates. The lenses are relatively new for me, and I continue to adjust to the lenses and the daily progress in the relief to my dry eyes and improved vision. Allogeneic transplant 1991

• I have noted a vast improvement in my energy level and mental outlook since stopping the sleep meds. Allogeneic transplant 1991

• After going to the dentist in June 08, just about every tooth is decaying. The question is can any/all be saved without a whole mouth of transplant, crowns, etc. or will all teeth be pulled and false teeth done. Suggest you stress to new patients the importance of fluoride toothpaste/rinses and stress the damage that chemo/radiation can do to teeth. Autologous transplant 2006

• My CML diagnosis was at age 18. I’m now 23 years old and wonder if I’ll ever feel at peace again. Will I always look over my shoulder and see CML trying to get me. Allogeneic transplant 2004

Pediatrics...

• At three years post-transplant, everything is miraculously normal. My son will start high school, he has surpassed me in height, and his voice is so low I sometimes think I am talking to someone else. Allogeneic Pediatric transplant 2005—Parent

• My biggest concern is my son’s difficulty making friends and “getting along”. He has hearing aids, glasses and is shorter than most peers – he is teased a lot. He prefers talking to adults – he seems wise beyond his 9 years. I ache for him when he comes home from school and is crying about “not fitting in”. Allogeneic Pediatric transplant 2002—Parent

• The older I get the more I realize how I was one of the lucky ones. Recently, I lost one of my close childhood friends to cancer. It was a shock and brought emotions back that I did not think were there. The reason I mention this is because the last questionnaire I wondered if I would ever feel “normal”. I know now that my own experiences have helped a very close family through their own troubled times. Without them I could not have helped them or become the man I am. Who is to judge what “normal” is anyway. Allogeneic Pediatric transplant 1994

• It is comforting to read the comments from other patients and know that there are BMT survivors out there that are still going strong after 30 some years. I’m glad to know that I’m not the only one out there who has survived that long. And – I am grateful to be alive and healthy. I work in critical care
and every day that I work I am reminded of how fortunate I am to be healthy. Allogeneic Pediatric transplant 1974

- I just recently found out I am 4 months pregnant! I am surprised, scared and excited. I had no idea. I was always told my chances of conception were very slim. Allogeneic Pediatric transplant 1986

- Since graduating from high school in June 07 I have been busy. I am saving money now to buy my first car. I would like to get a degree in graphic arts/gaming and design some day. I have lots of goals! Allogeneic Pediatric transplant 1996

- It has now been 7 years since our son had his transplant for myelodysplastic syndrome at age 15. Though he missed two years of school (8th and 10th) grades, he graduated on time with his class, took part in many school activities, got great grades, worked every summer and during his college years, spent a semester as an intern in Congress, and is now ready to graduate from college with a B.A. this spring. Allogeneic transplant 2001—Parent

- [My son] is well. His 5’6” stature is a pain for him. With all his brothers over 6’, he is the shortest male in the family. It was his choice to stop the growth hormone shots and this was over a year of discussing pro’s and con’s. Allogeneic Pediatric transplant 1996—Parent

- I am almost 21 now, working part-time and taking one class at a local college. I am thankful to God, to the Hutch, and my donor for my second chance at life. Oh yeah, and I bought my first car this year! Allogeneic Pediatric transplant 1996

- Being 23 years out from my transplant makes it difficult to relate to those who are struggling with their side-effects. I was 15 when I had my transplant and really was back as a “normal” teenager a year later. Now, as I approach 40 I wonder about long-term effects. Seven years after my transplant I had my thyroid removed due to thyroid cancer and a couple of years ago had 2 small skin cancers removed. I don’t dwell on these, but I do wonder how treatments and one cancer have affected the others. I’m happy to be getting older so I have the chance to think about these things! It beats the alternative. Allogeneic Pediatric transplant 1985

Children and Grandchildren...

- When I travelled to Seattle I did not believe I would see my youngest child graduate from high school. I am happy to say next month I will be attending his wedding. Allogeneic transplant 1997

- We’re working on adopting a baby finally and unfortunately, some agencies will not work with me due to my previous AML diagnosis/treatment. Autologous Pediatric transplant 1994

- I am still on 5mg of prednisone but that will stop in the next month. That will bring me to only having to take 3 pills vs. the 20 I used to take. We will be going to Russia to meet our soon-to-be children. We will be adopting two siblings and are so excited. If they didn’t already know their names as they are 3 and 4, I might have named the boy “Fred”. Autologous transplant 2004

- Twenty years ago my youngest child was 9 years old and I only prayed to live long enough to see all my children (8 in all) live to maturity and on their own. That has happened and I’m still going strong – expecting grandchild #15 this year. Allogeneic transplant 1988

Looking Back...

- Having leukemia was the worst thing that has ever happened to me but the best experience of my life! Allogeneic transplant 1999

- I felt utterly hopeless and jaded after/during the first year post stem cell transplant, but this second year I am appreciating and in awe of this medical miracle. Allogeneic transplant 2006
• It was a long, bumpy road filled with potholes. However, now it’s nice to be on a smoother track. I hope it stays that way. Allogeneic transplant 1991

• I’m always taken by surprise when this questionnaire arrives. I no longer “remember” the anniversary of my transplant. Eleven years…it’s part of a different lifetime. Autologous transplant 1997

• My wife and daughter were in the restroom at Albertson’s changing the IV fluid pump and a lady came in and watched them. After watching a while, she said, “That brings back memories. I went through the same thing 10 years ago.” She had had a bone marrow transplant at the Hutch. Allogeneic transplant 2006

• I notice questions don’t go at the positive end of emotional spectrum enough. Many of us are transformed by this experience; life has new meaning/purpose and wouldn’t it be great to capture that, too?? Allogeneic transplant 2001

• My life experience has given me the patience and stamina to move beyond some of my own personal anxieties. I’m better at my job, as a mom, and as a wife. Allogeneic transplant 2003

• I was 24 years old when I had my BMT. This is the 24th anniversary. I have now lived as long post-transplant as I did before. The saying goes you only go around once in life. Well, I have gone around twice and am aiming for three. Allogeneic transplant 1984

• I am a 23 year survivor of a mismatched allogeneic transplant. Have also survived septic shock, hepatitis C, hip and ankle replacements, and more. And am in great shape, work full-time and make a contribution, and got to be there while my children grew up. I’m a different and much better person for these life experiences. Thank you. Allogeneic transplant 1985

Compliments, Complaints and Suggestions...

• A new MD every month wasn’t a bad thing. It allowed for a new set of eyes and a fresh perspective on my care. Autologous transplant 2008

• As an RN, I say the nursing care was exemplary. Allogeneic transplant 2007

• More work could be put forth into making people more aware of the impact on their sexuality and emotional health, as well as solutions for dealing with these issues. Allogeneic transplant 2004

• As an accountant I am amazed at the apparent disorganization of the billing system at UW. After all, this university offers post-graduate degrees in accounting. Allogeneic transplant 2007

• Thank you for the near universal habit of not shaking hands when meeting. At first it seemed awkward but it did remind me to be much more attentive to the role germs are spread by hand contact. A deliberate mention of this policy during orientation might be an idea, too, so new patients understand the reasoning. Autologous transplant 2008

• Even 5 years out, having been treated at several medical centers, I’m still extremely impressed with SCCA’s ability to run on time for appointments. You guys don’t seem to miss a thing; my mom and I never had to manage my care the way we do everywhere else. What’s your secret? Allogeneic Pediatric transplant 2003

• I didn’t feel adequately informed about what to expect after we left the Hutch in 2/07. (The set backs, long term drug side effects, average GVHD duration being 3 years) I thought things would just get easier. Allogeneic transplant 2006
About the Questionnaire...

- This questionnaire used to give me anxiety and would bring up painful memories. This is the 1st one I’ve filled out feeling like a “survivor”. Allogeneic transplant 2001

- I love reading the comments sent in by others because it creates so many healthy feelings in myself: gratitude that my experiences have been less painful and stressful than for many; compassion for those who are struggling; laughter to see how some folks have managed to appreciate small twists of what they formerly accepted as their right; wisdom to realize that life is mostly good, no matter how our individual script develops. Autologous transplant 2005

- I am normally happy to receive this packet and read all of the comments. But this year, in addition to arriving on my 9 year anniversary – there was a comment from another patient stating that he had relapsed at almost 10 years – just when I thought I could relax and breathe again! Allogeneic transplant 1999

- For my 25th anniversary I would like to answer the questionnaire online! Allogeneic transplant 1984

Giving Back...

- My nephew was diagnosed with CML this year and because I was the poster child for how to recover from leukemia, I took the role of confessor and counselor. We don’t get to choose the things that happen to us in our lives. We do get to choose how we want to deal with them. Allogeneic transplant 1997

- I consider myself cured from cancer thanks to you folks. I’ve been talking to two friends about their cancers. It reminds me of my troubles “back in the day”. They see me and I know I give them hope. Autologous transplant 1996

- My family and I participated in the Leukemia and Lymphoma Society “Light the Night” walk. Supporters carried red balloons and survivors carried white. I was proud to hold that white balloon but sad to see so few. Allogeneic transplant 2005

New Medical Careers...

- The Hutch should be proud because you folks had a lot to do with our daughter’s desire to become a nurse. She was able to observe, on a daily basis, the care and compassion of staff like Diane Fye, Bob Lemon and others. My treatment has had far-reaching effects that we could never have anticipated when we made the trip out over 25 years ago. Not only did you save my life, you provided an inspiration that continues to grow and serve. Allogeneic transplant 1983

- Getting through all the hard times was well worth it. My older son has recently completed medical school and will be going into family practice. He has also provided me with three granddaughters. My younger son is a teacher and is well on his way to getting his Ph.D in education. Allogeneic transplant 1990

- I have been accepted into a Ph.D program at the University of Connecticut in the field of Human Development and Family Studies. I plan on doing my dissertation research on adult survivors of pediatric cancer and the developmental issues they faced which have affected them into adulthood, with the hopes of developing interventions to address these issues. Allogeneic transplant 1999
• The BMT changed my career. I now work in a medical school studying risk communication to cancer patients. My personal experience motivates my work and grounds my understanding of what cancer patients do and do not need. Reading each year’s quotes and seeing the stories of those who genuinely feel they didn’t know how bad it could be reminds me of the work to be done. Perhaps if all stays well, I’ll do a bunch of it. Call it my karmic contribution. Allogeneic transplant 1999

• I just graduated from PA school and will be working in adult stem cell transplant. I’m very excited – the best job a new grad could ask for. Allogeneic transplant 2001

• Doing well. In my last year of medical school and planning on a career in pediatric hem/onc. Allogeneic transplant 2002

• I was 5 when I had my transplant 35 years ago. My donor (my older sister) was so inspired by my transplant that she became a surgeon. Allogeneic Pediatric transplant 1973

Donors and Care-givers…

• Believe it or not, my donor is an FBI agent in Thailand – he sends me wonderful Christmas presents each year. Allogeneic transplant 1996

• I just got back from an annual family vacation that my unrelated donor now joins us on annually! Amazing! He is now part of our family. Allogeneic transplant 1999

• A bittersweet note – my boxer – a dog I bought a year after my transplant, passed away this year. His name was Hutch. I depended so much on him as I was recovering. I had to walk him, etc. and he was always there to hear my complaints! His passing marks a new chapter of my life – one with few reminders of my leukemia and BMT. Allogeneic transplant 1996

• 22 years. Wow!! Called my brother (donor) thanked him over and over again. Asked God to bless him. Told him that I love him! Almost started crying because I remember the picture of his back with all the bruising. He told me that he would do it again if he had to. Then I did start crying. What a brother!! Told him that I would give back if he ever needed it as I was just his storage bank. Allogeneic transplant 1986

A Final Thought…

• Twenty years ago I was in my twenties, scared and uncertain about the future, not knowing if I was going to live or die. The transplant was my last ray of hope and it saved my life. ...What I would have missed: finding the love of my life and celebrating our 15th anniversary (he fell in love with me when I was still hairless). I would have missed hiking in the Sierras and Idaho wilderness, skiing at Squaw, Alta and Alpine, sharing companionship with 3 great canines, canoeing in Oregon lakes, and a road trip from California to Canada. I would have missed becoming an Aunt, now a great Aunt. I would have missed attending nursing school shortly after my transplant, becoming a nurse to work with AIDS patients, cancer patients and the elderly. I would have missed chocolate, the song of the sparrow in the spring, the rainbow at the end of the rainstorm. I would have missed my mother and father growing older, the wisdom of great Aunts, and hugs from old friends. I would have missed my sisters all becoming mothers. I would have missed the sweetness of my friend’s viola in Mozart. I would have missed being part of others’ lives, however small. Thank you for giving me back a wonderful life. I would not have changed anything. Autologous transplant 1987