Thoughts and Comments from Patients—2006

The Best of times...

- 12 years out – 58 years old – an MBA in my pocket – a great professional position – 21 years as a reserve deputy sheriff (and still catching crooks!) Riding my horse nearly every day – and loving my wife (my original caregiver) every moment of every day. Yes, there have and will be tough times, but thanks to Ollie Press and the rest of the staff at SCCA I’m living life large and living my dream!  Autologous transplant 1994

- After our three year “bump in the road” we are going to Ireland this summer and New Zealand next spring. My 5 year anniversary will be next June and I expect to be celebrating as a healthy survivor!  Autologous transplant 2002

- Each time I fill out your detailed questionnaire I feel so lucky and grateful that I can almost always mark the “no-box”!! Who would have imagined 22 years ago that I will do so well after I had so many problems with GVH for 4 years after the transplant?? Last week my husband and I celebrated our 22nd wedding-anniversary!  Autologous transplant 2002

- From the day I returned home my recovery has been remarkable. I resumed playing golf within 3 ½ months and fishing within 4 months. Every day my energy level increased as did my activities. Trying to follow the “do not do” list was very difficult. Did the best I could.  Autologous transplant 2005

- I am feeling great! Better than I have in years. Two years ago now since my transplant and I am still in complete remission. The only side effects I still have is neuropathy of the feet. But that is a small price to pay for my life. I am working full time as a construction superintendent, and enjoy every morning that I wake up.  Autologous transplant 2004

- I am very thankful to be alive, 3 years after transplant, and I plan to be able to dance at my grandson’s wedding – he’s 4 now.  Autologous transplant 2003

- I have enjoyed the birth of my first grandchild, sang at my son’s wedding, attended my daughter’s graduation from the university, continued to sing in my church choir and have published a book of poetry that chronicles my cancer experience (title: Unexpected Interruptions).  Autologous transplant 2003

- I have more energy than I did a year ago before my transplant.  Autologous transplant 2005

- I have not seen a hematologist in 5 years, I go to my primary doctor if I need to...The only stress in my life is whether the Mets win or lose.  Autologous transplant 1995

- I still think of you all as family...never been treated as well with such great respect in a medical community.  Autologous transplant 2002

- I went through a transplant in 1989 which allowed me to begin and complete college...and begin teaching...a dream come true. I found out that year, 1994, I had relapsed. After a 2nd transplant, I was able to teach Kindergarten and 1st grade, meet and marry my wonderful husband and adopt 2 beautiful children! The blessings that I have now are well worth the hardship and recovery of the transplants. Even if the transplant only gives you a few more years to spend with friends and family, it is worth all of it!  Pediatric Allogeneic transplant 1989

- I would trade my golf scores for my bowling scores. But I feel great with a better attitude and enjoy life more than I did prior to my cancer diagnosis and treatment.  Autologous transplant 2005

- I wouldn’t trade this past year for anything. I’ve had the chance to spend great time with my family and friends, move into my new house in my new community, play with my grandsons and have not spent one night in the hospital. I’m looking forward to the day when every appointment I make is not for medical reasons, being able to eat feta cheese and salads in nice restaurants, swimming, and finally getting the dog we have been wanting.  Autologous transplant 2005

- Just started grad school to become a physician assistant...Thank you all very much for your amazing care. In 2 yrs hopefully I will be graduated and providing the same to others myself!  Autologous transplant 2001
• I’m 62 now and every day seems so much more important than when I was 22. I do know that when you’re over
the hill, you seem to pick up speed! The wrong kind of speed to be sure!...By the way, since we moved several
months ago, this is the first time in the last 23 years that my primary care physician is not an oncologist.
Allogeneic transplant 1983

• I’m very thankful for being alive after 3 relapses and surviving 16 years from ALL. I love the martial arts and I
very much love fly-fishing, videogames, hiking, mountain biking... I would love to start being a positive role
model. Autologous transplant 1993

• In November 2005, I wrote the first draft of a novel and have been working on it since. It’s so much fun! I’m
still working full-time (we have another kid to put through college still, and I’m the bread winner), but I’m
happier than at any other time in my life. Maybe it’s not related, but it seems useful to me to think that it is.
Allogeneic transplant 1997

• It has been 2 yrs. since my bone marrow transplant. I’m back at school full time, work, play tennis. I’m truly
blessed – I have my life back...I’m 21 yrs old and have my mind on 21 yr old things – not cancer. Allogeneic
transplant 2004

• One major “milestone” - - Feb 26 marked 15 years since transplant, and the day passed without my even
remembering. First time (is that good or bad?) Allogeneic transplant 1991

• Our son filled out the questionnaire this year, with some input from us. At 17 years old, 15 years post-
transplant, he is a healthy, normal (as normal as a 17yr old can be!) young man. Pediatric Allogeneic
transplant 1991

• Perhaps it was the influence of pain killers, but as I looked up at the stem-cell bag hanging in my “tree”, I
thought for sure the attendant was putting Bloody Mary Mix in my Hickman Catheter. Given the success of the
past three years, I guess it wasn’t Bloody Mary Mix. Autologous transplant 2002

• This summer I plan to “compete” in the U.S. Transplant Games. Life is great! Allogeneic transplant 1990

• This summer I rode my bike from San Francisco to Los Angeles to benefit AIDS patients. Now that I’m about
to celebrate the 25th anniversary of my transplant, I’m more aware than at any other time in my life to be vigilant
of the after-effects of my treatment. I’m wary of the future but I still relish every day like I did 25 years ago.
Life is good. Pediatric Allogeneic transplant 1982

• When I look outside from my desk at work, I see beautiful Maple and Cottonwood trees shimmering in the
sunlight. I appreciate and savor each day, in a new light and in a new way. Allogeneic transplant 2003

The Worst of Times...

• I just completed my first year at the University of Maine with a 3.93 GPA. I also just celebrated my twelfth year
as a post BMT patient. Even though I have a great family, donor, very caring friends, and I have had great
success in my academic life, I still feel like an outcast. The longer I have been a post transplant patient the
harder it is for me to connect with people. I often wonder if I will feel “normal.” Pediatric Allogeneic
transplant 1994

• Between no sleep and painful joints, I have become a cranky old woman who likes to be left alone. I don’t
socialize or interact with people anymore. I do push myself to walk everyday with my four legged friends.
Allogeneic transplant 1981

• At 2 yrs. post-transplant, things have not gotten better. I am a 32yo woman trapped in the body of a 75yo
woman. As time passes and things don’t get better, the depression gets worse. Sometimes I do think if I had to
“do over” I would not do an allo again. Allogeneic transplant 2004

• I’m so tired all the time. I’m glad to be alive – but it is only a half-life because of EXTREME FATIGUE...
Autologous 1998

• I wish I had never had my transplant. The world has changed and all I ever do is have doctor appointments.
Have started back on Rituxan once a week for 3 months. Too much problems with GVHD!! Am not able to
work or do a lot of social activities. Am having deterioration of my jaw bone and teeth. Had 2 molars pulled
and a bridge – but still a lot of problems. Allogeneic transplant 2003
Life after transplant is horrible. I lost another job and I’m fighting with Social Security. I have severe tremors to my hands and feet, I can’t concentrate. My sex life is all but gone; I don’t know why my husband stays with me. What have you done to me?  Allogeneic transplant 1998

The frustration is not so much the physical ailments… as much as the inability of people to be able to treat and/or recognize survivorship after BMT as being very challenging…I am ever so thankful to have my life…but I continually ask…does each day really have to be this hard?  Allogeneic transplant 1999

The problems (physically and emotionally) came with the mega doses of prednisone (180 mg) causing osteoporosis – causing bone fractures, back surgery, and excruciating pain…Right now I’m acting like a 90 year old invalid. And I question my decision to have a transplant. I was an extremely active 61 year old woman working full time. Where is quality of life?  Allogeneic transplant 2006

The mental/emotional part of this whole process has been the toughest for me. Adjusting back to “normal” life has been difficult. One would think this would be easy but having such a different perspective on things now it has been quite a challenge for me.  Allogeneic transplant 2003

The “New Normal”…

Have some unexpected trepidation about returning to the clinical environment at SCCA – having control over my daily life is precious and handing over to SCCA, even for a week, is a bit scary!  Allogeneic transplant 2005

I am coming up on day 3650 later this week, but I have just realized that I finally stopped thinking about the transplant sometime during the last year.  Autologous transplant 1996

I believe this current state is not the new normal. Our journey continues toward purpose, fulfillment and joy!!  I look forward with anticipation to the complete withdrawal of prednisone in 15 weeks and then the progressive withdrawal of Prograf will then allow the withdrawal of the anti-virals and antibiotics. Then, I will consider “the new normal” and see God’s continued purpose in my life and the good He has accomplished in my family and in the lives my life has touched.  Allogeneic transplant 2004

I feel very fortunate to be feeling as well as I do. I believe I am suffering from fibromyalgia and/or neuropathy. My feet hurt and cramp up a great deal and I need trigger point injections 1-2 times a year in my back.  However – I am happy to ever be here to be able to complain about it!  Allogeneic transplant 1982

I have finally learned to trust my body and not “beat myself up” because I don’t understand how I can possibly feel a lousy as I often do. The “why” is often unexplainable – I am learning to “go with the flow;” “to trust myself and realize that it isn’t in my head, that I will feel better soon, and that I’m not a wimp…Some days I kick myself for choosing transplant – but only really bad days.  Allogeneic transplant 2001

I look forward to the comment section. It reassures me that I’m not crazy. Being tired and forgetful is normal. After 22 years I guess I should be grateful yet sometimes it’s frustrating as hell. Nobody understands that I’m physically tired as well as mentally tired. I have a foggy brain and “zone out” more each year. I’m here still plugging away. Please write more on the worst of times and the new normal. It really is comforting.  Pediatric Allogeneic transplant 1984

I lost 2 beloved friends who had stem cell transplants when I did, I miss them. Why did they die and not I?  Autologous transplant 1997

I seem to keep waiting for what will happen next. I’m not sure if this is common or not. One thing for sure is that a bone marrow transplant will forever change your life! You appreciate everything – but on the other hand more cautious and worried about other cancers.  Allogeneic transplant 1996

I still worry about cancer, but there are days when I forget I have/had it. That’s normalcy.  Pediatric Allogeneic transplant 2003

If I look back at the last 11 years since transplant I realize that I was continually recovering until about 3 years ago, when I finally started feeling normal. Only the rashes and the challenge of memory remind me that I had the treatment.  Allogeneic transplant 1995

If you have to be blue, be a bright blue!  Allogeneic transplant 2003
• Overall, my life is wonderful, and I am adjusting to a new “normal”. I have had to accept that I’m disabled due to AVN in multiple joints (shoulders, hips, knees), but am not as angry about it as I was the last couple years. Being thankful about what I “can do” instead of what I “can’t” do keeps things in perspective. That, and just being alive! Allogeneic transplant 2002

• Sometimes it feels as though I am living inside a bubble and no one can see me – day to day life, I’m trying but feel as though I’m failing in identifying my value or worth in the world today. I’m not crying the blues – It’s just the way it is and I can’t seem to find a way to change things. Allogeneic transplant 1995

• There are days that I forget I have limitations from my transplant, other days I am fatigued and not feeling well. However, every day is a blessing to me. I choose to make every day the best day it can be. My limitations are there, but don’t keep me from living and doing whatever I enjoy doing. I try to set a goal for each day and accomplish it. My life is a different kind of normal than before my transplant. I appreciate all the little things of life and enjoy spending time with family and friends. Allogeneic transplant 2001

Getting older...

• I’m glad for this five years and am hoping and praying I’m around for the next five. I want cancer to be part of the past. I want to grow old. Autologous transplant 2001

• [I] had my stem cell transplant at the age of 65!...I read two discharge notes written by [my transplant doctor] in which he said, “this is an old woman.” Another comment he made, “fragile appearing and appears older than her stated age.” Tell [my transplant doctor] I am challenging him to an 8-mile walk in the State of GA (where the sun is 110° and the humidity is in the 70’s!) tell him to let me know when he wants to walk - - we will see who is old! Allogeneic transplant 2003

• Approaching my 30 yr anniversary and in general feeling very well. I attribute most of my aches, pains and memory loss to “getting older”. Autologous transplant 1976

• As long as I can stay at home as a wife and mother, I’m fine. But I have so many physical imitations (eyes, hips, feet, back) that you’d think I was 20 years older than I am. I’m trying to figure out how to get back into the workforce doing something enriching (personally and financially) that is realistic for my “new normal” physical condition. Allogeneic transplant 1998

• I am truly blessed to be alive. While others dislike birthdays and getting older, I relish that I am here having birthdays and getting older. Autologous transplant 1991

• I look at me in the mirror every day for signs of GVHD but I only see my old self, getting older...My strength is back, my memory still lagging behind. I now live a normal life (wish I could lose those extra pounds...) Allogeneic transplant 2002

• It took me 4 full years to recover enough strength and memory to work. But I started and completed grad school 1 year ago! (I know my body is about 10 years older than my chronological age, but it hasn’t stopped me.) Pediatric Autologous transplant 1994

• Many things are related to the typical aging process, however, it seems the disease, treatment, after-effects and side effects of medicine may accelerate and mimic the aging process, especially in older patients. Autologous transplant 2002

• I wonder if some of the complaints are due to natural aging or are problems a “normal” person might have. Now that I am in my 40’s, most people I know have a lot of the same problems! Allogeneic transplant 1984

• In spite of my age, I’m now 70, and the health problems I’ve overcome, I still make plans for “tomorrow”. This is the gift all of you at the Hutch gave me four years ago. Allogeneic transplant 2002
Some Expressions of Gratitude...(among many)

- I am very grateful to all of you at “the Hutch” for the treatment I received, the plan of care, and your continuing support and advice. For me, these 2 years (since transplant) – even with my relapse – chemo and donor lymphocyte infusion (one year ago) have all been “found” time – time I would not have without the treatment and follow-up care you have provided. For this, you have my profound thanks. Allogeneic transplant 2004

- I am writing to share with you the sad news that my wife has died...I understand that stem cell remains controversial for breast cancer patients and while it certainly did not constitute a cure for my wife, I firmly believe that the treatment she received at Fred Hutchinson prolonged her life for a number of years. For that, she was grateful and I remain grateful for that gift. Autologous transplant 1999

- I can’t stop praising the care I received at both FCHRC and the U of WA Med. Ctr. So many caring people. Every one was pleasant, helpful, smart, dedicated, the list goes on and on. And I mean everyone: janitors, café workers. I’m from the E. Coast. We’re not used to that! Allogeneic transplant 2006

- I could never have survived the recovery period without the care of my husband. You cannot go through a transplant on your own. I know in my heart that I would have died without his care. Unfortunately I lost him to cancer two years ago. Allogeneic transplant 1997

- I don’t know why I was one of the lucky ones to survive but never forget those who are not as fortunate. Allogeneic transplant 1999

- I pray that God will shower with blessings my wonderful 42 year old German donor, and I hope to thank him personally someday. Allogeneic transplant 2005

- I thank God every day for the skill and caring I received at Swedish Hospital 16 years ago during my BMT. Every June I look through my photo album at all the photos of my caregivers and remember the TLC they gave me. Allogeneic transplant 1990

- I was 24 years old when I had my BMT for CML. That was 22 years ago. Since I will soon match my lifespan prior to transplant, I’ve decided to throw away all my FHCRC receipts. No refunds will be necessary. All that stuff is crinkly and yellowed by now anyway. Thank you – it appears this just might work! Allogeneic transplant 1984

- I’m very grateful to the doctors, nurses and other staff members but especially my sister who was my donor. We will always have this special bond between us but what she did for me will never be forgotten. Allogeneic transplant 2005

- Looking back now it’s hard to believe that I went through this disease at only 21. I’m not one of those people who changed my life. I’m just more grateful and I take in a lot more. Allogeneic transplant 1999

- My sweet wife (caregiver) said I was ugly to her in Seattle but I have no memory of that. I told her I had a brain on drugs (legal ones) but she is still mad at me. I love her and hope she can forgive me some day. Allogeneic transplant 2004

- My wife and I have had many conversations over the past couple of months reminiscing over what we were going through a year ago (a very exciting time!) We are so happy with where we are today. Allogeneic transplant 2004

- My wife, caretaker, and Love of my Life still watches over me like I [just had the transplant] today! Side-effects, problems, treatments, yes I have them all but I also have LIFE!! Allogeneic transplant 1991

- Others question me occasionally about my health post-cancer –I practically have forgotten that I once had it – how I do appreciate all you did for me. Autologous transplant 1997

- THANK YOU! I cant’ believe it’s been 20 years!! The transplant is a distant memory that I rarely even think about...My husband and I are very active and planning for our long term futures together 40 years from now. Allogeneic transplant 1986

- Thanks to all there at the Hutch, especially Ian Anderson the RN who saw me though every day of the 100 days – and to Troy the scheduler-extraordinaire – Ian and Troy brightened my every day at SCCA. Allogeneic transplant 2004
• The LTFU program is critical to maintaining my health, and literally resolved 2 life-threatening problems by assisting my community physician with lab analysis, diagnosis and treatment recommendations a couple of years ago.  Allogeneic transplant 1997

• The SCCA infusion room nurses are angels!  Allogeneic transplant 2004

• There are days I forget I had a transplant but I never forget my anniversary date.  My mother was 57 when she passed away from cancer.  Next year I will be 57 and I am so glad that I was given the last 22 years to experience life and love because of my transplant and the after care I have received.  Allogeneic transplant 1984

• When I read about all the survivors who have multiple problems, I realize how truly blessed I am, so my problems seem very, very small. My prayers go out to those who truly suffer every day. Allogeneic transplant 1988

• When I took the ATG treatment in 1981 for aplastic anemia caused by my rheumatoid arthritis drugs, I was not a candidate for a bone marrow transplant (no perfect family match).  At that time, I was given a 40% chance of seeing my 35th birthday and a 0% chance if I didn’t take the treatment.  Needless to say, I took the ATG treatment.  Today I still have rheumatoid arthritis but my next birthday will be #60 so I think I beat the odds.  Thanks to all of you at the Hutch.  ATG treatment 1981

• I’ve been married for over a year to the most wonderful, intelligent, beautiful woman.  She makes all this worthwhile...I never suspected that 6 years out I would still be battling GVHD.  But I keep fighting and because of that I’ve found the love of my life.  We are trying to have a baby, and I’m determined to finish my degree and get into medical school.  Allogeneic transplant 1999

Exercise!...

• For all the patients who come after me, be strong, disciplined, determined and never, ever give up.  Exercise regularly.  Get a treadmill and use it.  Reach out.  Be patient. You will get there – recovery and a second chance to live.  Keep your mind active and focused.  Read.  Allogeneic transplant 1996

• Concur that a regular consistent conditioning program is very helpful – suspect most of us need more structure to really incorporate this into our lives and persist over time.  Would recommend that all patients and families get this message before BMT and reinforced on F/U written communication.  Allogeneic transplant 1998

• I exercise at least 4 times per week for at least 45 minutes each time.  Allogeneic transplant 1998

• I feel great...play racquetball a couple of times a week.  I get tired sometimes, but just work through it.  Autologous transplant 2004

• I now go to an exercise club which has helped me considerably.  Autologous transplant 1986

• My husband, the caregiver, would like me to comment on the fact that there is no exercise facility available to the caregivers.  We heard several people say they gained 10 lbs the first week they were there, and they would love to continue their workout regimen.  Allogeneic transplant 2006

• Please convey my greetings and best wishes to Dr. Flowers and Dr. Martin.  I am exercising as ordered!  Allogeneic transplant 2000

• This year I have made exercise a priority and am feeling stronger and more energetic.  I am ready to go on vacation to Europe with my family.  Allogeneic transplant 1993

Memory and Strategies for Coping...

• I often tell people that I have the brain of an extremely old woman, as I forget things often.  I have to write everything down and I have my staff at work do the same, or it’s as good as gone.  This works well with my “Type A/checklist” personality, but I certainly do not feel as sharp as I once was – and I’m only 27!  Allogeneic transplant 1992

• For many aspects of my life, I can’t tell if my problems are from the BMT, or from just getting older?  Memory loss and lack of concentration are both getting worse.  Memory loss is getting worse.  (Did I just say that?)  Allogeneic transplant 1999
• During the past year, I was diagnosed with adult A.D.D. (Hence the prescription for focalin and now Wellbutrin.) I am not fully convinced of the diagnosis (made by a psychiatrist) as I lack a few of the common traits such as childhood trouble in school and in the workplace. I definitely have many of the symptoms though – difficulty staying on task, forgetfulness, scatterdness, general ineffectiveness, not living up to my potential. I don’t attribute this to physical or emotional issues, and wonder if this is not A.D.D. but rather related to my BMT. Regardless of the cause, the symptoms have made my first two years of marriage and my first year as a mother less fulfilling than expected. Allogeneic transplant 1989

• I feel that my memory/concentration is very compromised. My friends and family call me “Dori” – the fish in “Finding Nemo” that has no short term memory. My miracle baby is 8, beautiful and a genius (I think I gave him all my brain cells). Allogeneic transplant 1998

• I have to also say – the really frustrating thing is my memory. It SUCKS. I can’t seem to remember simple things – it’s quite annoying! Ahhh well.....in the BIG picture – that’s nothing! Allogeneic transplant 1992

• I went back to work for the benefits! To my surprise, my fears that I wouldn’t have the energy or the cognitive functioning to do the job have evaporated! It seems that the work has sped up the final stages of my recovery better than a daily walk and doing crossword puzzles were doing! Allogeneic transplant 2004

• Memory is still a problem but I don’t let it bother me as much. In some way it’s cool for new movies and TV shows. Re-runs are all new to me. My wife says I’m like the girl in the movie “51 First Dates.” Allogeneic transplant 1997

• My overall health for the past 28 years has been pretty good, but my memory and concentration has been well ah...what were we talking about? Allogeneic transplant 1977

Financial and Billing Problems...

• All that I had been told was that everything was pre-approved and would be covered at 100%. The reality is that not everything was covered and there were expenses that I incurred that could have been avoided had I been given accurate information. Autologous transplant 2005

• Being unable to leave a high pressure high stress job simply because you can’t survive or afford your meds without the insurance doesn’t improve the situation. Sometimes I wonder why I fought so hard to survive cancer if my life afterwards has to be spent fighting so hard to survive being alive. Autologous transplant 2005

• I have to add that working with your billing dept has been a nightmare. After many letters and phone calls, I finally received a refund on my deposit (minus expenses). However, I will never be convinced I received the right amount. Allogeneic transplant 2004

• I would add that your billing department needs to come up with a better system. Statements do not include dates of service or the services I am being billed for. With so many bills coming in, it is hard to track and check them for accuracy. I find it very confusing, and I used to do medical billing for a living! Autologous transplant 2004

• Immediately after my last year’s rant about my problems with the billing/insurance department, I received a call from Eric Neal. He listened and said he would take care of it. He did! No more problems...Thank you, Eric! Allogeneic transplant 1996

• Kaiser Permanente has decided to discontinue following me with their health coverage after quitting the company plan I was with. The company was sold and needed an individual plan. I was denied because of risk of other cancers. Allogeneic transplant 1987

• Nothing can prepare you for the financial hardships my family is experiencing. Allogeneic transplant 2003

• The billing/finance operations are the only unprofessional feature of the SCCA and the Hutch. Get it together, folks! Answer phone, return calls, answer questions, and be as professional as your medical colleagues! Autologous transplant 2005
Other Problems...

- I have a lot of problems with my teeth. I’ve lost all of my upper teeth to my canines, and have a lot of chipped or broken teeth due to not having good dental insurance. I can’t eat that much because I’m afraid of losing my teeth that are left. Autologous transplant 1993

- I have been taking IV Pamidronate for 10 yrs. now due to prednisone-induced osteoporosis. Now I’m reading about avascular necrosis of the jaw related to taking these meds. I’m wondering if the Hutch is doing/following any research in this area. Allogeneic transplant 1996

- I have found the most amazing relief from leg cramps by eating yellow mustard. As soon as they start I grab the jar and take about 1 tablespoon. Within 60 sec. The relief is felt. Allogeneic transplant 1997

- I suffer from extreme leg cramps and have solved the problem by taking Boiron metallicum zinicum homeopathic pills. It totally enabled me to sleep again and not suffer from the leg cramps. Allogeneic transplant 2000

- I look forward to when I can get off prednisone permanently. I call it the “awful wonder-drug”. Allogeneic transplant 2003

- I returned to my pre-BMT job, maybe a little too soon, and have had to take two additional leaves of absence. It is hard to explain, but it seems the support has dwindled somewhat. I almost feel some people might think I am taking advantage of the situation while I feel I have done the best I possibly could at being a productive employee. Allogeneic transplant 2003

- I think my biggest issue is that I never stop looking over my shoulder and, more or less, expect leukemia to return... I will feel so incredibly betrayed and let down should my cancer return. Allogeneic transplant 2005

- I’ve had problems with my teeth and will need to have implants in 3 or 4 teeth...If there are ways to have insurance (medical) cover some of the cost, it would be great to know how to do this. I don’t have dental insurance and this will be costly because I also have to have bone supplemented in the gums. Allogeneic transplant 2001

- My mother brightened my day on the first day she saw my bald head when she said, “You look just like you did when you were a baby.” Allogeneic transplant 1991

- No one told me about the terrible tooth decay I might incur. Oral Medicine did say how important dental hygiene is. After 8 2-3 hour appointments and $6,000 of dental work, I do still have all my teeth, but there are a few which may not last much longer. We have no dental insurance and medical insurance refused coverage in spite of the fact that the causes of decay were clearly medical. Allogeneic transplant 2004

- The only compliant or desire to change, is the fact that my libido is very low. Am not certain which path to take in changing this. However, it is not improving. Any suggestions, I am glad to hear/try them! In a way, it’s comforting to know that I am not alone with this issue. Pediatric Allogeneic transplant 1981

- The prednisone is giving me boobs! I’ll need a bra soon. Allogeneic transplant 2005

- The questionnaire came at a bad time since I got bucked off my horse and broke bones in both hands, plus four ribs. If it wasn’t for the accident, I would rate my health as excellent. Autologous transplant 1999

Pediatrics...

- [Our daughter] is a wonderful, bright, active healthy 13-year-old. She gets straight A’s (not even an A-!), was on the gymnastics team and is now on the volleyball team. We can no longer keep up with her on the ski slopes. Pediatric Allogeneic transplant 1993

- [My son’s] daily life remains a struggle – stomach distress, neuropathy in his feet, dealing with a [tracheostomy], fatigue, unwanted weight gain, memory and concentration difficulties; yet he continues to fight. Two more hurdles lie ahead – removal of the cataracts and hopefully the trache. He has not been hospitalized for ten months and we are grateful for that. If the coming year brings as much progress as this one, a more normal life may be within reach. Allogeneic transplant 2004
I am happily the mother of a daughter who is 7 years post transplant – and it feels great just to say it. With each post transplant day, then month, you let the line out on hope. I will never be without some neurosis regarding her health, to which she usually responds with “Mom, I’m just a normal kid”. Pediatric Allogeneic transplant 1999

My daughter was 16 months old when she had her cord blood transplant – she is now 5 ½...Our family motto is “celebrate life” and we daily thank God for his many blessings. Every time she does something new or special I think “I almost missed this”. We are so happy to have her. Pediatric Allogeneic transplant 2002

Children...

22 years ago, I asked God to let me have time to help raise our youngest son – then 10 years. He answered that request – and then some! That son is now 32, and the two last grandchildren are his – joining the eight grandchildren supplied by a daughter and another son. They tell me my job is not done, as I have to “help” raise all these also!! Autologous transplant 2001

I am currently 25 wks pregnant through donor egg IVF. I couldn’t be happier. I have twin girls who just turned 4yo. (Also through donor egg) I hug and kiss them 10-20 times a day and thank God my husband and I were blessed with such good fortune. Autologous transplant 1987

I have just celebrated my 22 year anniversary...I have three beautiful healthy children...Having a son that is the same age I was when I was diagnosed, I cannot even imagine what my own parents went through. Pediatric Allogeneic transplant 1994

I know all my medication and appointments and treatments have been worth it when my 7 year old daughter, who was one at the time of the transplant, hugs me and tells me how very happy she is that I am alive. Allogeneic transplant 2000

My husband and I just completed the home study process to adopt a child. It’s amazing to think I may become a parent! Autologous transplant 2004

Shortly after I replied last year, my son was born – 10 days early and 8 lb. 3 oz. Just celebrated his first birthday – a happy, healthy, loving little boy who keeps his parents in a constant state of amazement and joy. For the past first 16 years, I thanked the Hutch for my life. This year, I thank you for his as well. Allogeneic transplant 1989

The experiences [my children] had at the Hutch were incredible. They talk about the classroom teachers, the doctors they met, and the mascots from Seattle that visited them. My son is now planning on going into medicine. Both of them admit their desire to go into medicine was the result of all the experiences they had during my stay at the Hutch. Autologous transplant 1991

Perspectives from a Distance...

As I think back over the past 9 years since my BMT, and read the comments from other patients, I feel I am fortunate to feel so normal now. I have to admit that the first three years after the BMT. I wondered if all the horrible side effects would ever go away. You can’t really explain the living hell you go through to other people who haven’t experienced it themselves. Autologous transplant 1997

Being a survivor of a stem cell transplant does not define me, nor does it haunt me. It was simply something that happened and I intend to move on. Autologous transplant 2006

Cancer and the BMT have changed me: I laugh more and give love and affection more freely. I take nothing for granted. Everything and every day is a gift and a blessing. I couldn’t have made this journey without my faith in God and a sense of His loving presence even in the worst of times. Autologous transplant 2005

If you don’t laugh you’d cry. Autologous transplant 1998

I am currently recovering from a partial mastectomy and preparing for chemo. After 1979 I know I can handle this. I have learned to live with the mild allergies and constant shortness of breath on exertion as minor inconveniences. Everyday is a gift and I make a point to live it as fully as possible. Pediatric Allogeneic transplant 1979
• I am not yet ready.... to be like Lance Armstrong and say cancer is the best thing that ever happened to me, but I am glad to have had the opportunity to reassess my priorities in life and to have survived to experience all that life has to offer to me now. I hope to always remember to cherish this chance to “live again”. Allogeneic transplant 2005

• I’ve changed in a lot of ways, physically, mentally, emotionally, spiritually. I am having to reevaluate life and the direction I want to go with this second chance at life. I feel like I’m a different person and like I’m having to get to know who I am all over again. It’s difficult. But I’m trying to take on the new challenges and enjoy this new life as much as I can. Allogeneic transplant 2005

• I’ve wondered if I had known how hard it would be, if I would have gone through with the transplant. I’ve decided yes, I would have. I chose life and that was what kept me going. It was worth it in the end, but when you are going through the hard times you wonder if there will ever be a light at the end of the tunnel. Allogeneic transplant 1997

• It’s been 20 years since my BMT. Every year I receive “the packet” and never could I bring myself to read the comments. This year was different. It brought back so many memories, both good and not so good...I think it’s so important to not focus on what you no longer can do and focus on what you can do and still have. When you mastered that you just about forget what you can’t do. Allogeneic transplant 1986

• My transplant helped me to dig in and find me! Every part of my life was changed. I look for friends who make me laugh. I’ve put my life into working with people with mental disabilities. My life with my kids is 180°. And I decided to look for a partner who would give me emotional support – something I did not have going through my transplant. Autologous transplant 1991

• My transplant was unsuccessful, yet the process was successful. Many good things come from facing trial and tribulation. My experience at Fred Hutch was enlightening and profound. Through God’s infinite grace my family (husband and 3 children – 14, 12, and 10) and I have another day and another moment. Autologous transplant 1998

• My wonderful ex-husband (Johns Hopkins educated physician) told me 6 years ago that transplant patients such as myself would not live much beyond 60. Is this true? This tidbit of information should answer your question as to why I avoid doctors like the plague. Autologous transplant 1991

• This may seem odd, but my time at FHCRC was the best ever. My treatment/disease caused a lot of pain and was pure hell but I now know that the saying “what doesn’t kill us makes us stronger” is 100% true. I’m a stronger and better person for my experience and I never want to forget a moment of it. I never want to live in the past but w/out it I’m not who I am today! Pediatric Autologous transplant 1994

• Whenever I get overwrought with the unimportant superficial parts of life, I have a very powerful reminder that puts my life in perspective. Thinking about my cancer experience then causes me to pause and take a deep breath and say a prayer of thanks. The gratitude I then feel always brings a sense of peace. Allogeneic transplant 2003

• While I still need money, a house, a car and the things that allow a degree of comfort, they are not the drivers in my life anymore. God, family and relationships are the drivers for me now. I don’t know when I will die – but who does? I will try and live every day left to me with dignity and honor and try to leave a legacy for those whom I love and love me. Autologous transplant 2005

• Last year’s questionnaire was washed away with Katrina...Our home in St. Bernard Parish, LA had over 10 feet of water in it for 2 weeks. We eventually made it back and I went through the house a few times attempting to salvage what we could...Our BMT experience has helped us in learning to cope with long-term issues. Allogeneic transplant 1994

• While marking the 12th anniversary of my BMT, I reflected back to how humbling it was to spend time both in out-patient and in the hospital with some of the bravest people on the face of the earth. Autologous transplant 1994
Compliments, Complaints and Suggestions…

- I have seen Dr. Flowers a number of times- she is an incredible lady. And it is such a comfort to know that I can call LTFU with questions at any time. Allogeneic transplant 2003

- Establish an Email address to which I can ask questions, and post on the LTFU web site. No one answers when I call; I always end up leaving voice mail. Simple questions and/or initial contact could be effectively addressed via Email. Everybody has Email… but not you. Autologous transplant 1991

- For those of us who are computer literate, I would recommend the ability to complete the LTFU Questionnaire on-line. Completing the survey on-line would certainly be cost-effective, patients could complete at their leisure and the responses would probably be submitted and tabulated on a more timely basis. Autologous transplant 2002

- I think SCCA, specifically the Hutch, needs to put more emphasis on physical therapy and exercise... I think all patients should see a therapist throughout this 3 month post-transplant period. There should also be more exercise equipment at the hospital and a full-size gym at the clinic. Given how prednisone affects muscle loss, it’s shocking to me that P.T. isn’t as required as medications. Allogeneic transplant 2006

- It would be nice it the P.A’s didn’t change every month. You just get time to know the person and then they move on. Autologous transplant 2006

- My suggestions would be to share with prospective transplant patients the stories and words of those of us who are doing great as well as those with difficulties. I realize that there is a need to be realistic about difficulties, but showing the hope of a less than difficult time is also worthwhile. I was so fearful of the side effects and difficulties that I didn’t realize it could be so easy. Autologous transplant 2005

- Once again I am disappointed that so little focus has been given to Mental Health issues. As medical professionals, you must realize the importance treating both body and mind as one. Allogeneic transplant 1984

About the Questionnaire…

- After 22 years I can do without the comments page. After one or two I usually don’t read them. Although the emotional component is relative I feel very removed from the technical aspect of the transplant with all the new things that are happening. Allogeneic transplant 1984

- After reading all the comments from all the other BMT Patients, I feel like the most blessed of all people. I only wish I could express myself in a way to help other survivors. I so enjoy reading all the success stories and grieve with those that are not doing so well. I feel a part of a very close family with every comment I read. Autologous transplant 1992

- After reading the “Thoughts and Comments” section, I suggest you give these to new patients to read. When you are diagnosed you don’t know what to ask…don’t keep this wealth of information under wraps – it would have helped me enormously. Most people think after BMT its all good but these words will help them understand better. Allogeneic transplant 1998

- Each time I hear from you is like hearing from a friend who understands exactly what I went through years ago but continues to support me throughout the years of my progress (which has been fantastic). Allogeneic transplant 1994

- I find it curious that you don’t ask about status of cancer and treatment of cancer. Do you assume we all are cancer free or do you just not care about cancer treatment? Allogeneic transplant 2004

- I hate filling out this questionnaire as fears flood back in. Allogeneic transplant 1989

- I like the fact that you share the feelings, progresses and ill-effects of other patients. They may not know each other on a personal level, but it creates a “family like” bond for those of us that are dealing with diversified disease and have chosen the hope of recovery through transplant. Autologous transplant 2003

- I read the LTFU Survivor Comments every year and thank God that I fall into the “Better than Before” category. Allogeneic transplant 1997
• I feel very vulnerable filling out this form to the point of tears. I know it’s important, but it doesn’t help me. Autologous transplant 1990

• It is interesting to fill out the questionnaire. I am reminded just how lucky I am to check “no” to so many complications. Everybody walking around should be given this questionnaire to see just how lucky they are! Allogeneic transplant 2004

• Thanks again – have just read all through the comments. You are so thoughtful to share them with us – as with many others, there are very few people with whom to share the experience of BMT, and many other cancer survivors feel that their experience was different and that I can’t relate. But the LTFU comments are from a peer group that I didn’t get acquainted with in Seattle, but am happy to know now. Allogeneic 1997

### Giving Back...

• A group of women from my Church and I are making blankets for the hurricane victims. I am beginning to add a thing or 2 each month. Being busy for others seems the best way to break depression and build strength. Autologous transplant 2005

• During the fifteen years since my transplant, I have been a volunteer with a national organization (NBMTLINK) that provides support and information to patients going through transplantation. Recently I addressed an audience with tales of my experiences as a transplant patient in Seattle – the anxiety, the humor, the hope, and ultimately the gratitude. Allogeneic transplant 1991

• I continue to work part time which affords me the opportunity and extra time to be a SCCA patient/family volunteer, teach piano at the Hutch School, and serve on the Volunteer Advisory Council. Giving back for all that Fred Hutch did for me is a privilege! Allogeneic transplant 1997

• I develop materials for NCI and I think my experience has made them even better than they could be. I put my heart and soul into them and have lots of people at the Hutch to thank for giving me the chance! Allogeneic transplant 1990

• I started a web page last year mdssurvivor.com so I could help anyone going through a BMT from a patient’s side. I know from reading your “comments” section each year how much it helps to know others are going through the same things you are. Only a BMT person can “really” know what it is all about...I know what it is like to hear the words – “you have MDS and need a BMT” out of the blue. Allogeneic transplant 2002

• I walked the ½ marathon in Alaska last year for the Leukemia Lymphoma Society. Allogeneic transplant 1995

• I’m now doing a lot of volunteer work and started a woman’s cancer support group at Sequim’s new cancer center in January. It’s going great! Allogeneic transplant 2004

• In addition to my 2 adopted teenage sons, I now care for my 88 year old mother who cared for me during the transplant. I am grateful and glad to be alive and well to return the favor. Autologous transplant 1987

• In October 2005 I spent 3 weeks as a Red Cross volunteer in Louisiana and was physically able to work 10 to 12 hr days during that period, so feel that I do have the physical stamina when needed. Thanks to the transplant and wonderful treatment I received 11 years ago, I was able to help others after Hurricane Katrina. Autologous transplant 1995

• Twice a year I collect for the Leukemia Society. It’s not easy knocking on peoples’ doors. But if in the end we are one step closer to finding cures, and better treatments, all my wishes will come true. Thank-you again for my life. I could not have done it without you. Allogeneic transplant 1991

### A Final Thought...

• The older I get, and the farther removed I get from my BMT experience (10 yrs ago now), the more philosophical I get about life and my cancer experience. I am beginning to believe now that cancer was part of my destiny. Cancer was the wake up call that I needed to completely transform my life. Now I am focused on finding peace and happiness by connecting with my spirit. My new quest is to go inside myself and find out who I am. It has been a marvelous journey so far. Allogeneic transplant 1996