Thoughts and Comments from Patients—2007

The Best of times…

- Sorry – forgot to send this in – too busy enjoying life to the fullest!  Allogeneic transplant 1990
- I just finished (with 3 friends) preparing and then driving a race car in a 13-hour race.  I drove the car for a total of 3 hours in a race where contact between cars was common and expected.  Not bad for a 66 year old transplant survivor.  Unrelated transplant 1997
- I am 3 years out and:  - Still sail extensively, and recently completed an 810 mile race from Ft. Lauderdale, FL to Montego Bay, Jamaica.  More racing planned in New England and on the Chesapeake Bay this year.  Allogeneic transplant 2004
- This past year I retired from my job, watched my son graduate from college, and took a 2-week trip to India – all things I could never have envisioned a decade ago when I was diagnosed with a rare and aggressive cancer.  Autologous transplant 1997
- I do more of what I want (quilting) and less of stuff I don't care about but always thought I should.  Autologous transplant 2002/ Allogeneic transplant 2003
- I am now 2 years post haplo transplant.  When the doctors said I would probably not make it to this point, I decided that I would tell cancer when I was going to die, not the other way around.  I am not a victim.  I am a survivor.  Allogeneic transplant 2005
- Just about the only time I think about my CML and Hodgkin's Disease is when my BMT anniversary rolls around.  My husband presents me with a dozen roses and you mail me the questionnaire.  Allogeneic transplant 1994
- I'm a teacher and a high school volleyball coach.  My days are full and I seem to always persevere with tons of stamina.  I often work out with my volleyball team and they are amazed at my level of fitness.  Allogeneic transplant 1986
- My ordeal with leukemia and the ensuing bone marrow transplant is so removed from my current way of life.  I am so healthy now that it seems as though those experiences don't belong to me.  Pediatric allogeneic transplant 1989
- I like to honor my BMT anniversary with something unusual – I’ve celebrated by riding in a hot air balloon & para-sailing.  This year I chose something unusual but much more tame.  While my husband and I were on vacation with our 2-1/2 year-old twins, I let a sea lion kiss me on the lips when we visited Gulf World.  Now that’s a memory!  Autologous transplant 1992
- Wow! What a difference three years makes.  Three years ago I was a newly-wed preparing for an autologous stem cell transplant.  Now I’m playing soccer twice a week, working full time, remodeling our house, a member of an oncology advisory board, and thinking about starting a family.  Autologous transplant 2004
- My daughter right now is playing with her Beagle – adopted from the FHCRC program that developed her cure!  We’ve named our Beagle, Hutch.  Pediatric unrelated transplant 2006
- My sister…17 years my junior, was a perfect 5 antigen match & my donor.  She now calls me her “Klone.”  Autologous transplant 1992
- I travel and climbed the leaning tower of Pisa in Italy – 310 stairs!  No problem.  Allogeneic transplant 2000

The Worst of Times…

- I've gone through the GVHD – prednisone cycle several times now and I am aware that my energy and attitude/outlook get low when the GVHD is strong, or when I'm at the end of the prednisone taper.  Now that I've figured that out, it helps me to anticipate these problems and to understand why I feel so bad, but I still feel bad, despite knowing why.  Unrelated transplant 2005
- I sometimes worry about the years to come.  There seem to be all of these long-term side effects that are coming or have already shown up and I'm afraid of what's to come in the future.  Pediatric allogeneic transplant 1987
• After almost 10 years post-BMT my MDS recurred approximately 8 – 10 months ago. Not identified at first, but confirmed by bone marrow biopsy. I was "cured" and had left MDS behind me as table talk. Now I, my wife, my family and friends have to go through it all again. Unrelated transplant 1996

• I suffer from chronic pain. I am a 64 year old woman in a 75 year old body. Autologous transplant 1993

• In comparison to how I felt prior to my transplant, I am living at about 60% of my potential at present. Fatigue, lack of motivation and decreased strength are my main complaints. Allogeneic transplant 2005

• GVHD (chronic) is my biggest problem – which leads to high doses of Prednisone. Thus triggering extensive bone damage and pain to my knees & hips. Previous FK 506 usage resulted in nerve pain to my feet constantly. Sorry about the poor handwriting, but, I hardly have the strength to hold a pen anymore! Unrelated transplant 2003

• I was told a million times over that I would/should be back to normal at my 1 year mark. I continue to feel weak, tired and overall "sickly" about 80% of the time. Autologous transplant 2005

• I always feel like I have a hangover and have had two pots of coffee all at the same time. Autologous transplant 2004

• Just because we can treat leukemia it does not mean that we should. The cure is still worse than the disease. Allogeneic transplant 2003

• I feel like a statue and GVHD is like this man chiseling away at me piece by piece – I am falling apart and losing my quality of life. Unrelated transplant 2004

• I have extensive AVN in both ankles that have collapsed & have fractures. 5 doctors, 5 braces/crutches later the only solution is a total fusion – I’m not looking forward to that. Allogeneic transplant 1996

• Since coming home from Seattle, I have processed though anger, paralyzing fear, depression, anxiety at facing even the simplest of tasks. It’s still one day at a time. I had a life before cancer that I know how to do. I do not know how to do this. To continue to walk with the fear. Other people are normal – taking days & weeks to come for granted. I cannot. Every week I see my oncologist & the fear is in my face again. I do not know how to do this. Should I spend the money to get my hair done, or is there no point. Will I be here to see my grandchild born in August? Will I be here for Christmas? Unrelated transplant 2006

• The worst part is not being “cured.” I feel like I live with a cocked gun pointed at my head every day. Some guy named CML has his finger on the trigger and it could go off any day. But, in the meantime, Carpe’ Diem. Allogeneic transplant 1998

• I am very disappointed with my health, both physically & mentally…I really can’t live my life the way I want it. No energy, no desire, I’m just not me…But I am grateful to be alive! Autologous transplant 1999

• The worst thing for my attitude has been my dealing with the Social Security Admin., as I have been battling for disability benefits for 6 years…the SSA continues to send forms that ask detailed questions that force me to grovel in my limitations. It has been fairly humiliating & dehumanizing and extremely frustrating. Allogeneic transplant 1998

The “New Normal”…

• Seven years ago I had a non-myeloablative stem cell transplant for CLL. My labs are normal; I feel normal without any GVHD. When can you declare me cured? Allogeneic transplant 2000

• Well one year is almost here, I have been given a life that I could have only dreamed of, it was always there but going through the BMT process made me realize it. I still worry about relapse and would be better if I didn’t always have reminders of what I have been through or the unfortunate news we get when others don’t make it and the way it makes you feel. All I do is just keep moving. I can’t control if I relapse, I can only control how I live today. I try to plan for the future but always with my eye on the present and living in the moment. Unrelated transplant 2005

• We all look in the mirror to see changes and limitations we might not like. One either rises to the challenge or is defeated. I have chosen to challenge, which starts with everything from dialysis to overcoming other complications to the simplest of everyday things. Autologous transplant 2005
• I have residual bladder problems – frequency and urgency since my transplant. I also suffer from sciatica, fatigue, and muscle cramps. As long as I pace myself, my life is very good. Allogeneic transplant 2003

• About six months ago, my husband stopped asking me "Are you alright?" at the slightest provocation, usually on a near daily basis. That makes me feel that I am becoming more normal. Allogeneic transplant 2004

• I am 65 years old now and I do have pain in some of my joints but I talk to people and some have worse than I but that is life and life goes on. Autologous transplant 2001

• I find myself without energy and motivation to get moving. My triplets will be three this month and I work three days a week. Not sure if energy issues are related to transplant or the kids! Allogeneic transplant 1998

• At 41, I act and feel older than my 67 yr. old parents at times. My life is good all things considered. Unrelated transplant 2002

• When I get sick - I always think the worst – everyone around me can have a stomach virus – I think my CML is back!! It’s been three years, I wonder if I will ever be able to “exhale!” Unrelated transplant 2004

• I’m learning to not plan too many things to do in a day. I’m also learning to look at what I did get done, not what I didn’t. Allogeneic transplant 1996

• I am happy and satisfied with my “rut.” I know my limitations and do what I can. Love my husband who is so supportive, and my dog! Still helping with charity – Christmas stockings for homeless children through the Coast Guard. Very fulfilling. Allogeneic transplant 1998

• Virtually everyone thinks I am “back to normal.” For the most part, this is true, but they don’t feel the balance problems, etc. Unrelated transplant 2005

• My son had his 1st visit/yearly with the LTFU oncologist at Children’s in August…I’m not as scared today as I was right after the August appointments, BUT, the fear never really goes completely away, does it? Pediatric allogeneic transplant 2002

• My biggest complaint is that after the 2nd transplant my golf game really stinks. But that’s no different than prior to the transplant so I’m just learning to live with it! Unrelated transplant 2005

• I look forward to the day when I don’t think about a recurrence daily. Every time I hear someone is diagnosed with cancer such a flood of feelings start rushing back. Then every pain and twitch is a reason for concern for a day or two. Normal? You tell me. Allogeneic transplant 2004

• Every day is a good day. Some days may just require more patience than others. Unrelated transplant 2004

Getting older...

• I am grateful every day love to see people’s reactions when I tell them I am 79 years old. Allogeneic transplant 1994

• When I complain of memory loss, everybody in our office agrees that memory loss is a problem, so I am as normal as the rest of the age 50+ folks here. I complain of joint stiffness and they all complain of joint stiffness. I would like to think (and blame) BMT for growing older – but it’s probably a case of growing older. Allogeneic transplant 1987

• I have a few muscle aches & pains & stiffness when I get up – but what can you expect when you’re almost 80!!!! Autologous transplant 2007

• I was fifteen when I had my transplant. That was 25 years ago! I just turned 40 a few weeks back. Getting older feels better everyday. Pediatric allogeneic transplant 1982

• I am doing basically great. I can’t believe it has been 31 years. I’m getting older now with a few more pains but still feel very fortunate to be alive. Being sick is what made me who I am today. I owe my life to FHCRC and my mom who is 91 years old now reminds me a lot, and I’m almost 49 years old – approaching the big 5 0. Pediatric allogeneic transplant 1976
• One of the patients mentioned that her ex-husband (a physician) said that most transplant patients don’t live much past 60, since I’m 59 and still doing great let’s hope we can all prove him wrong! Allogeneic transplant 1979

• It is hard to believe 10 yrs. has passed since my transplant. At the time I was 49 and I hoped I would make it to 50, on June 25th I will celebrate my 60th birthday! I’m planning a year-long celebration! Autologous transplant 1997

• When I was diagnosed 18 years ago, the surgeon gave me about 3 years to live. But I wasn’t about to let my husband enjoy his retirement without me. Unfortunately, he died 8 years ago. Autologous transplant 1990

• You made me turn 65 which is an evil thing to do to a 12 year old spirit. However, I seriously operate on the theory that one must grow old but maturity is optional. Allogeneic transplant 2001

Some Expressions of Gratitude…(among many)

• It is hard to believe it has been four years. Thank you for the care and concern during my treatment at SCCA. Keep up the good work and maybe one day Alaska will have a facility to offer the same services as the SCCA. Autologous transplant 2002

• Thank you for your tender, competent care – Steve Petersdorf is completely wonderful! Unrelated transplant 2002

• My loving wife/caregiver was always there for me thru thick and thin, and my experience would have been a lot worse if not for her. Syngeneic transplant 2006

• I have had to let go of my skis, mountain climbing equipment and landscape business due to both continued fatigue and lymphedema in my arm. Thank you for all you do. It's because of you that I have re-gained a full life. It is a different one than I had – but it is full, worthy and joyful. What more can one ask? Autologous transplant 1997

• I would say that I have been very blessed. I escaped chronic GVHD and while I relapsed after 9 years, I have had a good success with Gleevec. I lead as normal a life as possible with lots of fun activity and no restriction. Allogeneic transplant 1990

• Overall I am grateful for energy to play golf several times a week, walk on other days, and participate in many community activities. My diabetes is more of a concern now than cancer. Unrelated transplant 2002

• My CML came back after sixteen years but I was lucky because now Gleevec is available. I feel a little afraid it might stop working, but am thankful for all the things I've had since 1989. Allogeneic transplant 1989

• I am so thankful every day for this time. Time to guide my three children through the precarious teenage years. Time to love my husband. Time to enjoy the beauty of the world. Time to give back and help others. Autologous transplant 2002

• As a family we never thought life could be so good after my son’s Wiskott-Aldrich syndrome was discovered. He had two uncles who died very young of this syndrome. What a wonderful thing you have done to give us all hope, and a victory for my uncles over this. Thank you for giving our son a hope and future that weren’t possible just a few years ago. Pediatric allogeneic transplant 2001

• I had my transplant in 2002 for acute myelogenous leukemia at age 65. My prognosis was very short! I was healthy otherwise, so was accepted. I am now 70 and have been through everything GVHD could throw at me. I suffer with fatigue and minor congestive heart problems, which I feel is a small price to pay for an additional 5 yrs. Unrelated transplant 2002

• What can I say? After 16 years of pain and suffering from autoimmune disease to aplastic anemia to avascular necrosis to the BMT and chronic GVHD, it's finally almost all gone. I have a little GVHD left in my mouth, but overall I have no pain at all. I sleep great, eat anything I want and have lots of energy. I wouldn't have been so afraid of the BMT if I would have known it could bring about this miracle. Unrelated transplant 2004

• A.M.L. was the worst at 32 yrs. old. The bright side was meeting the best nurse in the world and making her my wife. Meeting her as my nurse in NJ- she saw me thru my first chemo – a Hutch BMT and finally a relapse and a Hutch donor lymphocyte infusion. Allogeneic transplant 1997
Since my transplant, my anniversary date has been more important than any birthday. Thank you for giving me 21 years more than I would have had without the transplant. Allogeneic transplant 1985

Thank you – from the bottom of my stem cells. Unrelated transplant 2002

I am so grateful for every day and am determined to make the most of them by laughing and finding joy everywhere I can. Unrelated transplant 1992

I am in my second year of Internal Medicine Residency at the University of Pittsburgh Medical Center and currently applying for fellowships in Hemo-Onc. My experiences with aplastic anemia and my allogeneic transplant have really been integral in my career decisions. Thank you again and again! Pediatric allogeneic transplant 1983

Five months after transplant and I couldn’t be happier. Almost off the drugs, no GVHD, & blood counts returning to normal. I’ve started jogging & working out to get in shape. I fully expect to regain my FAA 1st class medical and resume my work as an aircraft captain. Couldn’t have done it without my RN, Jackie Saxon, & the staff at SCCA. Allogeneic transplant 2006

Exercise!...

Hooray for Andrea – PT consult before and after transplant is vital! Allogeneic transplant 2005

Why don’t you ask questions about exercise (cardio and strength training)? Autologous transplant 2006

I have been able to recondition and generally improve my fitness level by 5-6x/week workouts in the gym. After the bilateral hip replacements due to avascular necrosis, I started doing water aerobics and now lift weights and do other cardio workouts. Unrelated transplant 1998

I turned 61 Dec 2006 thanks to all of you at SCCA and U of W – Four years since my stem cell transplant and 6 years since my diagnosis of non-Hodgkin lymphoma. I’m on the Team in Training with the Leukemia and Lymphoma Society for the half marathon May 6, 2007 in Vancouver, BC – Ain’t life grand! Autologous transplant 2003

At 7 years post, age 62, I run, hike, ice skate and jump rope. I still have back pain and poor sleep, but carry on. Keep on keepin’ on! Autologous transplant 2000

Last October I did a 14 mile backpack trip with a 45 lb. pack and hike from 7,000 feet to 9,000 feet. Thank you for saving my life! Allogeneic transplant 2005

I started ballroom dancing again after 18 years and that has helped my mood and kept my weight down. Unrelated transplant 1997

Thank you to Andrea Leiserowitz, the physical therapist at the Fred Hutch clinic who did not take "I can’t" for an answer. Through her efforts I was able to regain my physical strength and positive attitude. It has been 6 months since my peripheral blood stem cell transplant and as a result of daily exercise (walking, yoga and strength training classes) I am feeling stronger and healthier every day. I recommend starting patients on physical therapy the day they start prednisone and not waiting for signs of muscle weakness. A room at the clinic with exercise equipment would be of great benefit to all patients. Allogeneic transplant 2006

“Thanks to you,” I completed my first marathon (26.3 miles) this past January. Autologous transplant 1987

I…also ran in the Donor Dash in Denver, CO with my brother, who was of course my donor. Allogeneic transplant 2004

I found that physical therapy gave me a way to actively do something to improve my health. So much effort is put into just keeping us alive, I think the secondary health effects (loss of muscle mass, aerobic ability, etc.) is often overlooked. I believe exercise was critical in my recovery. Additionally having more facilities available would be beneficial – especially during months with inclement weather. Allogeneic transplant 2006

I am a navy seal and trying to get back into shape to be operational (ready to be called for war). I can run 5-6 miles without stopping and I am lifting weights about 3x a week…I think the vigorous exercise helps tremendously both physically and mentally. Allogeneic transplant 2007
Memory and Strategies for Coping...

- With writing, words are misspelled, can't recall spelling of words which used to be a strength. Words end up missing from the sentence. I make sure to re-read what I’ve written to make sure of clarity and not be embarrassed. Allogeneic transplant 1978

- I still have significant memory problems – short term, long term, names, dates, finding words. Concentration still a problem. I realized that I'm 52 and can expect some of this as natural aging process but these problems started during my BMT and have continued since. I have developed compensating techniques (notes, calendars, palm pilot, notebooks in which to jot things, alarms on my computer, etc.) but without them I would be lost. Unrelated transplant 1998

- I...retired from my job as Executive Director of a non-profit...due to problems processing information and short-term memory loss, forgetfulness, inability to stay on tasks, and having a hard time filtering out distractions has caused me to spend about twice amount of time to get work accomplished. Autologous transplant 2005

- At times I will come across a word I have used all my life and won’t remember its meaning or how to pronounce it. Allogeneic transplant 1999

- I laughed when another long-term survivor mentioned seeing a movie a second time was like the first time!! This viewing a second time (because you have no memory of the first time) has been true for me also, from time to time, with art exhibits, movies, restaurants, etc., much easier to laugh than to let it upset you. Allogeneic transplant 1989

Financial and Billing Problems...

- I continue to appreciate the excellent care I received at SCCA. Unfortunately, I can't say the same about the billing which caused me great distress after being contacted by a collection agency. I have AAA+ credit with literally no debts and a sizeable estate, so this action was not well received. Autologous transplant 2006

- The challenges I faced almost immediately after diagnosis were each compounded by the financial burden. It was such a stressor all these months, and continues to be. I'm afraid health care is only going to become a bigger and bigger crisis for our country. Allogeneic transplant 2006

- Big thanks for the improvements made in your billing dept. The focus on improved customer service has been noticed and is appreciated. Autologous transplant 2004

- Your Billing Dept. is the worst! I went to U of W Transplant Clinic for two months after SCCA. Their bills have date, service performed, and amount billed. SCCA just says pay me. Sad, when all else is so professional at SCCA. Autologous transplant 2007

- Chronic worry and problems with insurance and medical bills becomes an unfortunate fact of life following transplant (1992). Now that my son is an adult, insurance and financial difficulties are even worse. He began a new part-time job which will give him health benefits but will need to wait 3 months for the insurance to begin. And with his "pre-existing condition" I'm sure nothing will be covered. Pediatric allogeneic transplant 1992

- At my entry to the SCCA system your Patient Financial Services people, after checking, stated that Medicare and Tricare would pay all the expenses at SCCA/UW. As of this date I have a bill from SCCA for over $3,000. I just placed a second call to them to find the reason for the bill – the first one last week was not answered. Autologous transplant 2007

- Rowena Fish was amazing in helping me navigate all the insurance issues we had and I could not have asked for a more compassionate person to work with. Autologous transplant 2006

- All my paperwork seemed to be accurate and done on a timely basis. Even the deposits you required were handled just as I was told. Refunds on my deposits were returned on time and all my questions were always answered promptly. Autologous transplant 2004

- My insurance company...has paid $1,000's for my care. They do a terrific job keeping up with the forms and paying my bills. For some time they have paid 100% of my care. Autologous transplant 2007
I received a bill from SCCA for $1066 with no explanation, date Oct. 2005. I don’t pay bills without an explanation and my insurance should have paid. Unrelated transplant 2004

Billing problems with SCCA still emerge from time to time. Recently we received a statement for a service date on which I was nowhere near SCCA – who knows what it was for? Fortunately nothing was owing but one wonders why statements appear out of the blue a year after we were told all of our financial obligations to SCCA had been met. Unrelated transplant 2005

Recently we have received substantial charges – not covered by the insurance. These bills are dated from a year ago – without individual names, code, or money amount broken down. Allogeneic transplant 2006

Other Problems...

Sometimes I feel guilty about surviving when lots of other fine people don’t make it. I realize that I am lucky and I have been given a wonderful gift of time that I didn’t expect to get. So I am grateful and usually quite positive and chipper – but I still feel guilty. People I talk to about it say I shouldn’t, but they haven’t gone through this. I suppose it’s pretty common. Unrelated transplant 2005

I continue to be frustrated with new friendships and people not having a clue to my limitations. If I would have had family or close friends see the transplant process, and major surgery and chemo before that, I’m sure I would have a better support system. Unfortunately, I went through it all by myself; no husband or children, and no close friends. Autologous transplant 2001

Hoping for a smooth transition from pediatric care to adult care for medical follow ups related to my unrelated bone marrow transplant. Pediatric unrelated transplant 1996

For a long time I felt tired all the time. Napping didn’t help, though I did it frequently anyway. It was a complete and total exhaustion like I had never felt before, and upon waking up I would feel no more rested than before I had gone to sleep. Once I finally got on thyroid hormone replacement, I was like a new person! One pill seemed to solve all my problems. Is it just me or does this survey feel shorter every time I complete it? Pediatric allogeneic transplant 2003

My daughter looks – and acts – like a 12 yr. old, so she doesn’t fit in with her 20 yr. old peers. She has few friends. We have talked about it, but she doesn’t want to (or can’t?) change. I’m wondering about counseling. Do others have this problem? Pediatric allogeneic transplant 1988

I am to the point that I don’t know if a lot of my problems have come from the transplant or is a part of the natural aging process. I know I spend too much time and energy planning on what I can provide for my wife and family after I’m gone, instead of planning for today and next week or month for what we could be doing or where we might go just for the fun of it. I thank the Lord for today but I’m not sure if I’m using it wisely. Allogeneic transplant 2003

Last time I filled out this questionnaire, I reported that my health had improved to the point that I could make multiple life changes. In a 3 month period: new job, new domicile, and above all, 2 babies (twins). Since then, while exciting and fun, I also am chronically exhausted, sleep and food-deprived, and curiously depressed. This is one question you don’t ask. “Have you seen a therapist...” Unrelated transplant 1997

One thing I’m not happy about – my hair! It is straight and very thin. I get a perm and color but it’s not ever going to be like it was. Allogeneic transplant 1997

At times I can feel fed up and just simply "tired" of having to constantly handle "problems". If you could quantify the feeling, it would equate to a constant low-grade dull headache that eventually wears you down. Allogeneic transplant 2000

My child is having a great deal of trouble with her schoolwork. She is highly motivated, works extremely hard, but still not passing. It breaks my heart. Pediatric allogeneic transplant 1998

I struggle to "climb out" of the self-perception of victim and needing special care. Surely, I do need more rest, have ongoing symptoms, and am at higher risk. But I want to regard myself less and less a "victim", so that the healthy process of joining –up with the rest of humanity can continue and develop further. Allogeneic transplant 2005
A routine blood test with plummeting counts was a major shock and turned my year upside down. The mistake I made is that as each blood test passed with stronger and stronger counts and I continued to get A+ assessments from the doctors, including those at the Hutch during my 1st year assessment, it is too easy to forget that you can still be carrying around a time bomb waiting to go off again. I’ve certainly learned my lesson. I DREAD every new CBC and always will. Allogeneic transplant 2004

Could not figure out why I was spending so much time in bed, and skin drying out – big change for the better after getting on thyroid drug. Autologous transplant 2006

I am very aware of my depression & am under my Dr.’s care. I try to keep busy. The weather plays a big part in my mood. Sunshine is important to my mental state, the temperature doesn’t matter. Autologous transplant 2002

I have been diagnosed with myelodysplasia, but after going through my 1st transplant, I know I am strong enough mentally, physically, and spiritually to fight this new issue. Autologous transplant 2002

When I tell doctors of problems I am having, I invariably hear, “THAT’s not GVHD.” Which is mostly fine, but a little bit frustrating and even a little scary. Not much can be done about it except to be glad I don’t HAVE GVHD. Unrelated transplant 2007

It is slightly frustrating that I have to wait an additional 4 months for my 1-year appointment at SCCA because of SCCA scheduling. It would have been nice to know I needed to call 4-6 months in advance. Autologous transplant 2005

I still have to take a sleeping pill every night to sleep and I sometimes find it difficult to remember things but this hasn’t really been a problem for me. I went back to work 9 months after my transplant and have done well since. I had to beg my doctor to let me go back to work that soon but everything worked out great. Allogeneic transplant 1990

My son is currently undergoing an educational assessment because he has had a decline in his grades over the past 3 years. He seems to have to work very hard at school now and is struggling with math. Pediatric unrelated transplant 2001

Plain yellow mustard works very well for easing or completely getting rid of leg cramp attacks. Allogeneic transplant 1978

The time between doctor’s visits has finally gotten longer – 4 months. The only real issue seems to be crazy muscle spasms in my back, legs, feet and abdomen. So far I haven’t found much to stop them from happening but they are not slowing me down. Unrelated transplant 2001

I have had some dental problems & had a tooth removed & have developed osteonecrosis of the jaw which apparently is a side-effect of the Zometa infusions for multiple myeloma patients. So far, neither my doctor or dentist have any idea how to treat it. Autologous transplant 2004

Looking back at my transplant at the Hutch, I remember having hot flashes, at the time I thought it was due to my medication. Now I realize that I was having the symptoms of menopause. I think it would be beneficial for women patients who have a stem cell or bone marrow transplant to be informed that they will become menopausal and that treatment for osteoporosis could be started before that disease is developed. Autologous transplant 2000

I have never had a physician who has had anyone who has had a BMT...It has always seemed like I have had to be the teacher Allogeneic transplant 1996

I was declined a new life insurance policy because of leukemia 18 years ago. I thought after 5 years you were clear. Autologous transplant 1990

After my autologous marrow transplant in 1996, the lymphoma returned almost immediately – clearly that part of my treatment was not successful. Autologous transplant 1996

I will be attending college full-time this fall, but I don’t know how well I will be able to connect with people around me. People don’t know what I’ve been through. Explaining everything is a chore, and I don’t want any more sympathy! Not from people I don’t know. I feel like maybe I should wear a sign: COMES WITH EXTRA BAGGAGE. Or maybe: I HAD CANCER. YES, I’M FINE. NO I WILL NOT TELL YOU ABOUT IT UNLESS
YOU'RE INTERESTED IN ME, NOT THE CANCER. Or just: BEWARE OF RABID CANCER SURVIVOR.
Unrelated transplant 2006

- My problem has been a vicious circle with chronic GVHD = Prednisone = spinal fractures and we start over. My hair has not grown back due to the GVHD as well as it should have – I still have bald spots. The good news is I am alive and I’m a fighter. I expect to be back to the "old me" soon. Unrelated transplant 2006

- Recently I...had thyroid surgery. The nodule was cancer. The thyroid was removed. My doctor was very pleased that I can talk again, because it was doubtful that I would. Now I will be able to sing to my granddaughter. Allogeneic transplant 1991

Children...and grandchildren

- This is the longest period of time that I’ve been cancer-free in my 13 year marriage. My son turned 9 years old three days ago. I’ve been able to celebrate 5 birthdays, at least 40 ice hockey games, 8 school concerts/open houses, countless (ok...1812 days!) of picking my son up from school, hugging him, laughing with him, watching him grow!! and (obviously) an equal amount of time being able to care for my husband, the true love of my life! Unrelated transplant 2002

- I’ve walked my last daughter down the aisle, saw two more grandchildren born & two go off to college: all & all it’s a good day every day I push the grass down instead of up. Unrelated transplant 2004

- Life is great. My wife & I are empty nesters now so thanks for keeping me alive to see my kids grow up! Allogeneic transplant 1999

- My two grandchildren are the same age that my 2 daughters were when I had my transplant. How blessed I am to have been able to watch my children and now my grandchildren growing up. Allogeneic transplant 1995

- Recently adopted a daughter from China at the ripe old age of 50...feeling pretty confident about my long-term good health! Unrelated transplant 1990

- I was diagnosed 2 months before my wedding. We just celebrated our 22nd anniversary and have the world’s most precious 7 and 4 year-old children. Unrelated transplant 1993

- Having a stem cell transplant is all about living. Without question I would not be here today had I not had my stem cell transplant. Sure I have less energy, have chronic GVHD, but I have had four grandchildren since my transplant in 2003. I am thankful for every day GVHD and all. Unrelated transplant 2003

- My husband and I adopted our nephews (twin boys, 9 years old) last spring. It has added a lot of stress as well as good times to our lives. I think maybe I survived cancer to be here for them. Autologous transplant 1995

- My youngest has 3 more years at home & will be out on her own. I could never have accomplished this without you. Autologous transplant 1994

Perspectives from a Distance...

- I am blessed to be amongst the fortunate transplant recipients who have virtually no sequelae of having been given a new immune system 10 years ago. I look forward each year to completing the questionnaire as it has become my way of commemorating the gift of another year of life. Each year I reflect upon whether I have made good use of this gift, with hopes of making better use of it next year. I am forever grateful to everyone at FHCRC and to my donor, who as yet remains unknown to me. Allogeneic transplant 1997

- I admit that years ago that suicide crossed my mind once but thought it out and figured it is not solving the problem and if I was not supposed to be on earth God would have taken me years ago. He left me here to be a fighter and that is what I do! Pediatric allogeneic transplant 1978

- My doctor said to me the other day (in an effort to summarize what a stem cell transplant patient realizes once they have survived the procedure) that “stem cell transplant patients look quite normal & healthy on the outside, however, heal slowly inside both physically & mentally. It is the patient’s choice & attitude to adapt to their ‘new’ body with enthusiasm or anxiety. They must accept that they will be working within an almost new lifestyle – one that has changed as a result of this life-saving procedure.” Allogeneic transplant 2005
• We are celebrating 5 years post-transplant! My son has put it all behind him and resumed being a teenaged boy. I still struggle to not dwell on how sick and close to death he was. It gets better every year, but will never be gone. Pediatric autologous transplant 2001

• I estimate in the last 7 years I’ve taken about 31,000 pills (wow!). Unrelated transplant 2000

• I enjoy our five cats even though they are a lot of work. At least there are no college expenses. Allogeneic transplant 1996

• It’s interesting to me to see people who have recently gone through the transplant process to refer to SCCA and how great they are. You’re all right, they are great, but I will always think of it as “The Hutch.” Pediatric allogeneic transplant 1985

• My mother said in April how grateful she was that I was around to see my kids grow up, because she didn’t expect that. A brother says that because I am working, traveling, etc., I am “an inspiration” to others in the family. But I always feel very ambivalent when doing the Leukemia/Lymphoma walks & carrying a “survivor” balloon. What were my choices? Of course I worked to survive, stay healthy, be happy – why should I get any credit at all for that? Allogeneic transplant 1997

• I know I was not the easiest person to get along with. I baffled Dr. Thomas by being the first patient with chronic GVHD. But look, I am still here. Pediatric allogeneic transplant 1977

• Tonight I saw a shooting star and at that very moment I knew that the pain, the memory problems, and the fear...were worth everything. I am surrounded by people I love dearly and if I die tomorrow I would die a happy person. I think of the friends I had made, the ones that taught me so much and didn’t make it and I am reminded that they were unafraid to go. That comforts me. I will never forget them. Allogeneic transplant 1987

• It wasn’t till I was a senior in high school that I could even say that I had leukemia and try to talk about the painful memories I experienced at such a young age...this is only the second time I have filled out a questionnaire because it has been too painful. Pediatric allogeneic transplant 1982

• I had my first consult at Fred Hutch in late July 1993 with John Hansen. As we got into different treatment options, there was a huge BOOM! The windows shook, the tissue box moved around the table, and for about 30 seconds, you couldn’t hear yourself think. It quickly occurred to me the noise was a function of the visiting Canadian Snowbird precision flying team recruited in lieu of the Blue Angels for Seafair. It quieted down enough to resume the conversation. Just as our conversation started again, another loud BOOM shook First Hill. After the 4th and final BOOM, I looked at Dr. Hansen and just started to laugh. I said, “This is exactly how it’s going to be, isn’t it? All will be going according to plan then, WHAM, out of nowhere, all Hell will break loose. Then after a bit, all will get back to normal.” Dr. Hansen gave me a smile and said well, perhaps. Autologous transplant 1994

• I have a new perspective on family, what’s important, and the work-life balance. Unrelated transplant 2002

• Getting leukemia at any early age was a very valuable life lesson and fortunately, thanks to the Hutch, I have been able to stick around and put that lesson to good use! Pediatric allogeneic transplant 1992

• 20 years ago today I was in a LAF room, anxious, sick and scared, holding onto my stuffed pig (my only real comfort I had in my sterile room)...funny, I still sleep with that same pig. Allogeneic transplant 1987

• I’m less “sharp” than I used to be and boy do I forget things, but in some strange way I feel almost “fortunate” to have had CML. The experience taught me so many things about myself and life in general. Fair trade for memory loss, GVHD, etc. I must be a glutton for punishment. Allogeneic transplant 1998

• I think I’m fairly healthy, physically and emotionally. Life is pretty good, my golf game is OK, and I still think it was an excellent idea for the Hutch to save my life! Allogeneic transplant 1983

• I hate the word survive – I want to thrive!! Autologous transplant 1999

• Cancer is not fair or selective of its victims. What our family has learned through this journey is that we control our attitudes. No matter if our lives are long or cut shorter than normal, we can choose to be happy and thankful for each day. Pediatric unrelated transplant 2000

Compliments, Complaints and Suggestions...
I hated the "Doctor-of-the-Month" club. I did not get a chance to really bond with my doctors, and as a result, I did not trust them as much as I should have. I trust my hometown oncologist more than I did any of the doctors at the SCCA.

My days normally began in the waiting area of the lab on the 1st floor. I’d watch the constant stream of patients coming in; each at different stages of treatment. It was overwhelming to see the number of patients. Then, when I was in an exam room, conference room, infusion room, etc., I was always treated as if I was the only patient they had to see that day. That was amazing!

Received wonderful care. The only thing I didn’t care for was the constant “changing of the guard” with reference to nurses, doctors, etc. Continuity was missing.

I believe all females returning for a post transplant check up should be referred to Mary Schubert as a routine. I had questions answered that I didn’t even know to ask until we were chatting. Mary, my husband thanks you, too.

My 2 frustrations as a caregiver are 1) inconsistency and conflicting information among providers, teams and consultants, leading me to fear no one is "connecting the dots"; and 2) the contrast between the respect/pressure on me as a caregiver and the lack of regard some providers give me when I try to share my concerns/perspective – mixed messages.

Please be more aggressive with discussing sperm/ovum banking with patients.

### About the Questionnaire and Comments…

Filling out this questionnaire and being able to check "NO" to most of the symptoms and medications makes me realize how much I am taking for granted. This is the twenty-sixth extra year of a healthy, fulfilling and happy life.

Thank you for the comments from other transplant survivors. I always find them inspirational and energizing.

I believe that you will receive more responses if patients are able to fill out and submit a web-based LTFU form.

The questionnaire does bring up the cancer specter that lies quietly in the background much of the time. I suspect it's healthy to look it in the eye now and then.

I want to thank you so much for including the comments from patients. I read them all sobbing the whole time. I can't tell you the feeling of reading the success stories. There just isn't enough of that kind of communication out there. It lifts the cloud that is always hanging over you.

Sometimes I feel like I want to stop receiving the questionnaire, because I feel anxiety when I read through the questions. Some of them depress me, it's a grim reminder of what my daughter went through, and I just want to move on. I only read the positive feedback from other Fred Hutch patients, because I don’t want any negative in my mind.

The comments…remind me of the sufferings I have been through and reassure me of the potential in me to overcome difficulties in life.

I always laugh and cry a little when I read through the comment section of this questionnaire… Thank you for renewing this powerful perspective every year.

I was disappointed that only 15% of this year's published responses came from fellow "auto" patients. It felt like the choices you made to share mostly comments from "allo" patients supported the opinion my 1st oncologist expressed to me once, that I hadn't had a "real" transplant since it was only autologous! I'd like to see the physical therapy component of the transplant experience beefed up significantly to support people such as myself who want to be more proactive in their recovery.

### Giving Back…
• Since my life was spared I have tried to do something to help others – my wife and I raised about $6000 for "Relay for Life" last year through yard sales. I am also still here to donate to my favorite charities – "Feed the Children" and "World Vision". My wife is able to give to "St. Jude". Unrelated transplant 2004

• My wife & I raised $4000 for the Leukemia & Lymphoma Society Team in Training. We walked a 13.1 mile half marathon in San Francisco Oct 2006. It took us 4 hours and 20 minutes. We crossed the finish line hand in hand. Unrelated transplant 1999

• I volunteer for Chemo Angels. I angel a 4 year-old boy in Maryland who has leukemia Allogeneic transplant 1986

• I belong to a knitting group that knits chemo caps for the infusion centers in Anchorage, and the 10-12 participants have recently passed the 3000 chemo cap number. Unrelated transplant 2004

A Final Thought…

• As the last bag of my sister’s stem cells was being infused into me, my doctor left me with these words, “Now all we need is patience and stamina.” They became a small but enduring mantra for my recovery. Twenty years later I do not often find myself thinking about leukemia or transplants or even being a cancer survivor. Yet I live every day in the knowledge of how much illness and survival changed my life, of what I do for a career (social work), of how my family has evolved (two adopted daughters), of how I conduct myself (with more balance, I hope).

Patients, stamina. Those words have lost none of their power in twenty years. Allogeneic transplant 1986