Thoughts and Comments from Patients—2004

The Best of Times....

- I work full-time as an ER nurse. I exercise regularly (at least 6 times a week), and I’m only able to do these things because of my BMT. My motto is “what doesn’t kill us makes us stronger.” I believe each day is a gift that allows us to enjoy all the many things that surround our lives. I may be a little scarred, tattered and torn, but “hey I’m still here to share my story and talk about it.” Autologous transplant 1993

- I bought a Harley 2 years ago and I have over 16,000 miles on it already. My son is in college, and I am working full time. My husband and I celebrated 21 years together in December. Life is good! Thanks to my brother and FHCRC! Allogeneic transplant 1986

- I have competed in several national power-lifting events and broke the Master World Squat Record at the age of 40 (343 lbs/105 lb weight class)....At age 45, I weight train regularly, as well as in-line skate, bicycle ride, downhill ski (40 days last season), and ride my Harley. Allogeneic transplant 1989

- My second bone marrow transplant was 9 years ago. Things are going beautifully. I’m studying to be a pharmacist.... I have an active social life (that does not include drinking), a wonderful, very serious boyfriend, and enough energy to accomplish all that I want to accomplish. I can’t wait for summer so I can get back out on my water ski and spend a little time in the sun (with my SPF 45, of course!). Unrelated transplant 1995

- I went back to surfing 54 days post transplant, and now will be in my first surfing editorial spread in a nation-wide magazine. The transplant didn’t damage any of my balance or coordination on the water.... I think the SCCA should allow patients to be more physically active, sooner (before the 12-month cut-off). Autologous transplant 2004.

- I now am a plant superintendent in a furniture company, and I have about 120 people and 3 managers under me. I’ve worked there for 24 years. I think what I went through with my illness has helped me deal with people. I’m a people person. Allogeneic transplant 1987

- How much for another 20 years? Allogeneic transplant 1984

- I hiked the Grand Canyon (yes, all the way down) with my three sisters, and now I am beginning to train for a marathon, hopefully in 2005. You see, running is my way of celebrating life and is my time to thank God for all those who have helped me be here to celebrate life! Allogeneic transplant 1988

- I play soccer, ultimate Frisbee, tennis, biking, mountain climbing. I work out with weights strenuously twice a week....I only mention this because you said you wanted to hear some positive stories, not just problems. Allogeneic transplant 1981

- In July, I will celebrate the 30th anniversary of my BMT. I feel very fortunate that I have my good health and that my transplant has given me these 30 years to live life. I have 4 beautiful, healthy children. I have no health concerns. I’m not on any medications. I work part time and enjoy all the time. Allogeneic transplant 1974

- I have returned to my eight-handicap in golf, despite my loss of distance from the muscle and joint tightness. Working out at the health club has really helped my strength.... I still want to get my handicap down to five and make a hole-in-one. Allogeneic transplant 2001

- I am playing golf (had my first “hole-in-one” following my return from Seattle). Attended our son’s wedding and made it through a one-hour receiving line for the guests. It was a full three days of activities not to include a 6-hour drive each way. Autologous transplant 2003

- Last year—completed 40 paintings, 6 shows, 20 commissions, played in senior Olympics—4 gold medals (played 7 straight games for championship)—play basketball 5:30 a.m. 3 days a week—work from 8 a.m. till 10 – 11 p.m. 6 days a week. Sometimes I work all night. Allogeneic transplant 1986

- I was chosen as the guest speaker at National Cancer Survivors day last year. It was truly an honor. I have been blessed in my life. Allogeneic transplant 1996
The Worst of Times…

- I met a little girl who was diagnosed with leukemia and died a year later. It was the hardest death I ever had to deal with, since she was almost the same age I was when she was diagnosed. Allogeneic transplant 1981

- I would never have had the BMT if I would have known/been better informed of all the possible/likely side effects that I am undergoing. I still have severe GVHD and unendurable pain in my stomach; constant headaches; full-time numbness/tingling in hands and feet; severe short/long-term memory impairment; my eyesight has gone to hell; constant extreme fatigue and weakness every day of my life; have Addison’s disease due to all the prednisone to dampen down my pseudo-GVHD. Autologous transplant 2003

- As I said in the past survey 6 months ago, the treatment and possible cure of my disease is worse than the disease. If not for my 4-year old son who needs a father, I would not have agreed to this procedure. Every day I think how peaceful death would be compared to the daily battle of everyday life with uncertainty, pain, dry eyes, constant medication and doctor visits. Allogeneic transplant 2003

- If I had known prior to the transplant how poor my quality of life would be, I would not have had the procedure. I hate how I feel, look and act. I feel like I’m a lot worse off than before the transplant. Allogeneic transplant 2003

- We are now 2+ years post transplant, and this is the sickest I have seen my son yet. We have chronic blood infections, chronic GVHD problems, lung issues, pancreas problems and severe nausea that no one can seem to get rid of. I am scared for him and his health status. I worry that his body will get too worn out to fight all of these problems after a while. Will there really be an end in sight to all his continued suffering? I cherish each day and don’t regret the BMT, but I do regret all his suffering post BMT!! Unrelated transplant 2002

- Now a year post-transplant, I can find only two positives to my transplant experience—that I now have a topic for my college essay and that I have long beautiful nails. It has also given me a true appreciation for my grandmother’s one-year struggle with cancer. I had no idea how much she had to endure until I had to go through it myself. Allogeneic transplant 2003

- The biggest change I have experienced in the last 10 – 11 years is an overwhelming feeling of “not belonging” or not part of the group when it comes to both family and friends. I fell like an outcast. I also feel like I’m different than other people, sort of like a “freak.” Autologous transplant 1993

The “New Normal”….

- I am in sort of a weird stage now—not acutely sick, but not back to my “normal” self. But I am increasingly more aware that “normal” self is not there anymore. I have changed, if for no other reason than it has been 2½ years since I was diagnosed. I guess I would have hoped that I would have been past a lot of the issues by now. Unrelated transplant 2002

- I started telecommuting 2 weeks after I got home. My dog did not recognize me at first. Allogeneic transplant 2003

- I feel like I’m breaking out of the depression. Summer is my time to thrive—I sail extensively and am ordering up some UV-protective clothing. Selling my convertible for obvious reasons. Unrelated transplant 2003

- This past year, I think, is really the first year that I could say I feel great. In earlier years, I’ve always felt that I did not have a good energy level. I would get tired often, had little endurance and stamina. Now I feel that I am 100% myself again. Allogeneic transplant 1993

- I have strictures at 3 spots in stomach and duodenum. I have lost too much weight and no longer want to eat. My right lung is scarred from radiation recall. I’m in constant pain, have no energy, which causes depression. My quality of life has changed so much since the transplant. My memory is still poor. I have more or less accepted that this is as good as I will ever get. Guess I could be dead. Am grateful to see my grandchildren grown, but life is so different. Autologous transplant 1999

- Many things are related to the typical aging process, however, it seems these diseases may accelerate and mimic the aging process, especially in older patients. Autologous transplant 2002
I have trouble separating post-transplant problems from being 57—hair loss, impotence and a little fatigue might be appropriate for me regardless. Allogeneic transplant 1997

I’m 6 months post transplant. Even though the side effects are never-ending, I’m just glad to be alive and have learned important life lessons. Every day is a gift. Fred Hutch did a good job informing me that I would never be my “old self.” Otherwise, I probably would have been very disappointed about the continuous side effects. Allogeneic transplant 2003

After reading the comments, I have had all of the bad side effects at least once, and then some. My life has never been the same and never will, but I am alive, and I thank the Hutch for that. In the 17 years post-transplant, I’ve seen both daughters graduate from high school and one from college. Won a state championship and hosted several. Shared in my wife’s state championships and celebrated our 25th wedding anniversary with a 6,000-mile road trip to Niagara Falls and back. My life will never be the same after BMT, but my new life is good. Thank you for giving me a chance. Allogeneic transplant 1986

No, my health is not nearly as good as it would have been had I not gotten multiple myeloma, endured a BMT, and grappled with chronic GVHD for many years. But it is good enough for me to work part-time, play golf, hike, travel, and watch my children’s lives unfold. Thank you FHRC. Allogeneic transplant 1988

I can’t remember anything or follow directions. I have to write everything down, where I parked, where I am going, and even then, I still forget appointments, meetings. It is so hard to accept the “new” you. There are some very bright moments when I have a day I feel OK and smile because I am still here! Unrelated transplant 1995

It seems to be harder the farther out of transplant. All these “small” weird things are happening to my body (cataracts, avascular necrosis, menopause, elbow contractures), all at 28 years old. However, when reading the responses from all the other patients (which I love and appreciate that you all give us the opportunity to read) I am so grateful for my now “little” challenges and wish the best for those with much bigger challenges. Unrelated transplant 1999

I’ve made tremendous progress, even though from the outside my accomplishments probably seem very small. It’s hard to feel heroic when all you are doing is trying to get back to the place you were before you got sick. For all the work I’ve done to try to become the person I was, I know I can’t be that person again. I’m a little sadder now, but at the same time, I’m happier too. Allogeneic transplant 2001

Tired, poor, lonely, but ALIVE! Glad to be alive! Struggling to earn a buck. Short-term memory loss has cost me one job already. I try to write study notes. Dental expenses for the last year average $350/month. Employer and I pay for medical and life. Otherwise I’d be uninsured. I have to keep working. Husband (well, “ex”) passed away 5 months ago—of cancer. Interesting…. Son in Baghdad…I pray, a lot. It’s all in His hands anyway. Autologous transplant 2000.

My problems are pretty much the same as the last questionnaire: no sex life, feet bother me a lot, but otherwise OK. I am also 8 years older since my treatment, so who knows what I would be able to do even if I never had cancer. I live and enjoy each day as it comes. Thank you for my life. Autologous transplant 1996

My doctor told me that long-term survivors have been reporting joint pain. I have chronic tendonitis in both elbows. My attitude about all of this is, it’s not cancer, only pain, and I can live with that. Unrelated transplant 1992

I see it this way: “Bald is beautiful, and way better than being dead.” They make so many wigs that allow us to swim, run, dive, etc. Besides, instead of getting up at 6:30 – 7:00 a.m. to get ready for work, I can get up at 7:30 and be ready by 8:00 with beautiful up-to-date hair! Autologous transplant 1994

Some Expressions of Gratitude…. (among many)

I feel like I owe it to the first patients who tried this treatment, to live my life everyday to the fullest. They were the true brave souls who made it possible for me to do the things I love. I suppose I complain more than I should about my “broken” hair, when it comes right down to it, me and my fuzzy little head are sure thankful for you at the Hutch. Autologous transplant 2003

I’ve officially made it one year (my first one) without a cold—not a single sniffle! JACKPOT! Thanks Fred Hutch! Unrelated transplant 1993
• I have been helped a great deal in the latter stages of recovery by attending a cancer wellness support group. By sharing similar experiences with other patients and caregivers, I have received the spiritual and psychological support needed to get over the final “healing” hump. Unrelated transplant 1999

• It’s so wonderful to realize that a stranger from another country volunteered to give me a new life. Unrelated transplant 2002

• I have a secret weapon that has carried me this far; I am married to an angel. Allogeneic transplant 2001

• Judy Campbell is an angel. Allogeneic transplant 1991

• God blessed me with these additional years, but you were the Angels that guided me through the Valley of Death. Allogeneic transplant 1989

Memory and Strategies for Coping....

• I am shocked at the number of comments about memory loss. I have regained my full mental ability. There were the “moments” during transplant and the first 100 days where things were pretty vague, but I don’t believe there are any long-term effects. During transplant, my wife did beat me at chess almost daily, but I was never very good at it before. She was merciless. Allogeneic transplant 1999

• I feel fabulous! My only complaint is more mental clarity than physical. I still get confused and can only do one thing at a time—I cannot longer “multi-task.” Unrelated transplant 2002

• I went back to work banking just 6 months after my BMT and was ashamed to collect my paycheck, as I felt I hadn’t earned it. My short-term memory was terrible. I couldn’t remember anyone’s name and lost my train of thought easily. Had I realized this was a common problem for us (BMT) patients, I could have continued on disability. I’m glad we are now learning more about such common challenges. Allogeneic transplant 1993

• My work depends heavily on a detailed and accurate memory, and it has clearly suffered after the transplant and the chemo leading up to it. I still have memory, but forget obvious things that I would have remembered before the transplant. For example, talking to the druggist on Saturday about medication, being told a little while later that the med would not be ready until Monday and driving up to the drug store drive-in window a few hours later (still on Saturday) and asking the druggist for the prescription, and not even realizing we’d spoken on the phone when I talked to her again. Autologous transplant 2003

• If only my life could have been saved, my body healed, without killing my brain cells. Allogeneic transplant 1996

• I had a battery of tests by a psychologist to try to pinpoint why my memory is so bad. It seems that I do have a processing problem with retaining what I’ve just seen. I know that many people have memory problems after a transplant, but this has helped to determine where the problem lies (not that it helps much). Unrelated transplant 1997

• It drives me crazy when I can’t pull up an everyday word or remember things that happened not so long ago. Allogeneic transplant 1981

• The biggest thing that I struggle with is memory loss. For example, recalling someone’s name that I just met or remembering if I have done something, like shut the coffee off or locked the door. My husband has bought me a coffee pot and curling iron with automatic shut-off to avoid any disasters in the home!! He still hasn’t come up with a solution when I forget to lock the house, but I am quite sure he working on a solution to that as I write this! Allogeneic transplant 1988

• I do find humor in the questionnaire asking if I have memory issues, and then expecting me to remember everything that I have had done in the past year. I do have short-term memory issues, so I answered the question as best as I could remember. Unrelated transplant 1997
Problems with Billing....

- The Drs. billing system needs to be updated for dummies like me, to be able to pay everything at one place. Unrelated transplant 2003

- We had, and are still having, a very difficult time with regard to billing for the donor search and pharmacy. In July 2003, we were required to put up a deposit to begin the search and then understood that money was applied to our deposit/retainer at the pharmacy. Every time we went to the pharmacy, we did not know if we would be asked to sign for the prescriptions or asked to pay. Still very confused as to where our account stands. Unrelated transplant 2003

- I had a difficult time with SCCA and its associates with their billing departments. I had my annual follow-up in mid-March, and after countless calls to Seattle and to my medical insurance company, all the claims from Seattle were finally processed 6½ months later! My medical insurance information that I presented when I first arrived was not transferred to all the different places I had procedures. So these different places had my old medical insurance information, and one of the different places asked me for my insurance information. Doesn’t this information get spread to the places I have procedures automatically? Allogeneic transplant 1996

- We have found the billing process of SCCA to be an extremely painful experience. One visit results in numerous bills from different organizations, with minimal information as to what the bill is for. Sometimes, we can’t reconcile the bill, and some of the organizations are unable to provide any assistance when there is a question about a bill. Allogeneic transplant 2000

- The billing has been confusing at best. Unrelated transplant 2004

Other Problems....

- I have been on Aredia for 10 years.... and now, my bones are breaking. The bone being laid down is a more brittle bone. Something should be done to address this issue. Allogeneic transplant 1993

- In August, I went to see a dermatologist because somewhere I had read that I should have a mole check within a 5-year span from my stem cell transplant. I am so glad I went! He found a suspicious mole that turned out to be stage 2 melanoma. He did a 2nd surgery and got all the cancer out, so all is well now. Autologous transplant 1998

- I had a liver transplant in 2002. Hep C was the cause of my liver failure. I went through 4 months of treatment because my Hep C has been attacking my new liver (Interferon/Ribavirin). It did not work. I am now on doses of Interferon with the goal of slowing down the disease. Allogeneic transplant 1976

- My son (age 5) continues to have speech difficulties, for which he sees 2 speech therapists. We are beginning to see some of his learning disabilities. He is able to write his name, but he can’t tell you all of the letters in his name (he can’t spell his name out loud). Unrelated transplant 1999

- My only disappointment is that my donor has not wanted to get in contact with the person she gave life to. Unrelated transplant 1998

- We can’t afford coming to the Fred Hutch. Everything we owned is in my body. Insurance Co. won’t touch any of my bills related to my transplant. Unrelated transplant 1997

- One big concern I have is my insurance coverage, most of all, script coverage, which at the present moment is NONE. I pay for ALL of my meds, which averages to about or more than $500 a month. What can I do?.... I am too young to qualify for some coverage or provision in my state, and I spend a lot of money on necessary medication. Allogeneic transplant 1978

- I concur with many of the comments about the devastating financial impact that accompanies a BMT. Many times I wondered how I could even afford to live. Although given the additional years, I have never fully recovered financially nor been able to get back on track occupationally due to the cancer stigma. If not for the love and caring provided by my wife and family, I probably would have given up long ago. I don’t know how those that are alone survive. Allogeneic transplant 1988
• I am amazed that there are no questions related to neuropathy, which continues to be a notable side effect of the drugs/radiation that I have had, beginning about 2 months after the transplant. Allogeneic transplant 1998

• The neuropathy in my feet and fingers never dissipated. Concentration is difficult and very frustrating. I have aches and pains I never had, and I feel like a four-cylinder car trying to keep running on one cylinder. Autologous transplant 1999

• My biggest complaint is neuropathy, which prevents me from working, as I cannot be on my feet for long periods of time. I do have fatigue and have to nap daily. I had some memory loss the first couple of years, but it has improved as well as my eyesight. My hair is thin, but I no longer wear a wig. Allogeneic transplant 1999

• My son is leaving for Iraq the day after Thanksgiving. He is in the bomb squad and will be gone one year…I’ve been concerned about my son and would appreciate prayers for him. Allogeneic transplant 1997

• Please accept my apologies for returning this questionnaire so late. Due to the hurricane, we had no mail service. Allogeneic transplant 1989

• Please excuse the delay in returning this form—we’ve been dealing with the aftermath of 2 hurricanes. Unrelated transplant 1993

• After BMT, one of the biggest medical problems I have to deal with is the severe dry-eye problem, which nearly destroyed my corneas in 1983. But fortunately at the time, Dr. Kim Jack of Seattle was helping FHCRC to deal with post-BMT patient’s eye care. With his help, my corneas were eventually prevented from further damage by the bandage contact lenses. Who would believe that protection of a person with dry-eye problem could actually wear contact lenses and have her eyesight recovered? Allogeneic transplant 1979

• Both myself and my caregiver have been nervous, and at times, in conflict about how carefully (or not) to follow the immunosuppressed guidelines—where the line of risk is. Unrelated transplant 2003

• I concur with many of the other patients who have stated it is especially hard on the caregivers. To this day, if a doctor leaves a message on our answering machine, my wife assumes the worst. Allogeneic transplant 1996

• There is no way you can talk about the process of a stem cell transplant with people who have not gone through it, because there is nothing comparable in most people’s lives. There is no real way to bridge that gap. Autologous transplant 2004

• Losing my fertility has been a heart-wrenching, devastating experience, which is renewed with each family member’s pregnancy and each friend adding more children to their families. I am grateful for every day I have that I am healthy, and we just celebrated our miracle chemo-baby’s 5th birthday, but the longing for another baby never leaves. I wonder if it ever will. Allogeneic transplant 1999

**Children, Grandchildren…and Great-Grandchildren…**

• After my transplant, a friend asked me how long I thought I would live for, and I told him if I could make it to forty years old, I would gladly take it. It would have been long enough to see my son reach 8 years old. Well, he just graduated from college with a degree in Marine Biology. Allogeneic transplant 1983

• My transplant was truly a life-altering event, which had a great impact on me and my family. I was 46 years old at the time and had 8 children (23, 22, 20, 19, 16, 14, 12, 9). My greatest desire was to live long enough to see all my children to maturity, and my desires have been granted. Allogeneic transplant 1988

• I worked until September 2003 and retired at 65 years old. Enjoying swimming, golf and people. Most of all I’m enjoying being with my wife who was my dedicated caregiver in the sterile room for 45 days. The transplant allowed me to see 4 great-grandchildren come into this world. The last 10 years are priceless and looking forward to more. Unrelated transplant, 1993

• I don’t feel the same as I did before the transplant, but I feel better than dead! I have 5 wonderful grandchildren now. They would never have known me or how much fun a grandmother could be without my BMT and the Fred Hutch, and most of all, God. Allogeneic transplant 1992
• My husband is 67 years of age and works circles around ‘most anyone of any age. Transplant time: one of our 5 children married, no grandchildren. Now: 5 married, 14 grandchildren. We are very blessed. Autologous transplant 1986

• I’ve seen my youngest daughter graduate from high school, and new grandson and a great grandson born. My husband, who was also my caregiver, and I celebrated our 32nd wedding anniversary. My daughter is getting married next summer, and I expect to be here as the mother of the bride. Autologous transplant 1999

• I found out that I am pregnant with my third child. Due in April, and I feel great! What a great way to celebrate my 20-year anniversary! Allogeneic transplant 1984

• I’m 34 weeks pregnant, so a lot of the problems like tiredness and heartburn are because of that. I became pregnant due to embryo transplant. I had embryos frozen before my BMT. Unrelated transplant 1996.

• My husband and I are counting down days until our precious little girl is delivered. This will be our 2nd adoption in the past 3½ years. Infertility was a result of radiation/chemo but has brought blessings to us through adoption. I know God had our children in His plans and brought them to us in an amazing way! Allogeneic transplant 1989

• I too take this survey as an annual reminder of where I have been and where my life is going. I now have a 9-month old son, and he has been the focus of this past year. My life revolves around his good health, and my own health and well-being is generally far out of mind. Allogeneic transplant 1996

Perspectives from a Distance….

• I finally retired from the California Highway Patrol after 30 years of service and the California National Guard with 22 years of service. However, during the past 25 years (post transplant), I went through GVH, pneumonia, lymphoma, skin cancer and have had hepatitis C since 1980. I know what it feels like to be in pain, to have up and down days, and can relate to all the other problems I have read about. For me, I am alive and thankful for each day. Allogeneic transplant 1979

• The actual BMT in the hospital was do-able. The recovery is the hard part. Unrelated transplant 2000

• After I received a mini-unrelated bone marrow transplant in 2002, I had pneumonia and GVHD. It was not a good year. However, during that last year, my health improved a lot. I feel good now, and I am sure I will be better this year. I am playing tennis again, and I feel great when I am on the court. Unrelated transplant 2002

• I was a difficult patient, but you persisted. Tenacity is what it is all about. Autologous transplant 1994

• Most days now I don’t even once think of my cancer unless prompted, and for the second year in a row, I had to be reminded of my BMT birthday. Allogeneic transplant 1996

• I have just passed my 9th anniversary. My husband and I remember how the Hutch made the best of a bad situation. We still remain truly grateful for that. My Labrador, Hutch, is now 8 years old. Allogeneic transplant 1995

• I’m not inclined to always see the bright side of things, but then I think, “Well, at least I do get to age, even if ungracefully.”…. And as a survivor, the LTFU staff is way above exceptional. I feel like an alumnus of the Hutch, not a patient. Allogeneic transplant 1998

• Recently, newspaper articles have appeared saying that a new term is needed for cancer patients. Apparently, someone has decided that cancer survivor is not a good word or term. I disagree emphatically. If I wasn’t a cancer survivor, then I would be a cancer victim or statistic. Thanks, please call me a survivor. It’s not a club I would have chosen to join, but in life, some things are decided for you. Unrelated transplant 2002

• I don’t feel that life is wonderful as some patients do. It’s the same as it was before transplant, but a little worse because of some residuals of the stroke I suffered a couple of weeks after transplant. Some patients say that they find a new way of looking at life. I do not, except for being somewhat damaged by the stroke. I am the same as I was before transplant. Allogeneic transplant 1990

• Well, here we are again. Filling out another LTFU form. This is a good thing. Autologous transplant 1994
I don’t think of CML anymore. And I read the comments from those who are still struggling. It hit me hard that there are so many who were not as lucky as I have been. It is to them that after 17 years post-transplant that I write this—never commented before. My heart goes out to those who struggle—I remember the fear and terror and pain—I will refocus my appreciation for my good fortune, never taking it for granted. I pray for each and every one of those not as blessed as I have been. Allogeneic transplant 1987

My heart goes out to all of those patients whose problems have not resolved themselves and who struggle for normalcy in their lives. The transplant process changes you—it has changed me. I try not to sweat the small stuff, as life is too short. Unrelated transplant 1988

When I was 9 years post-transplant, I met an 8-year old boy who was in Seattle for his transplant. Earlier this year, he was back for his 10-year check-up, and we had the opportunity to visit and continue our friendship. He just graduated high school and is going to college. It amazes me to see him further out from his transplant than I was when we first met. Allogeneic transplant 1985

During the past 4 years, I have dealt with chronic GVHD (affecting my skin, mouth, lungs and liver), pulmonary problems (BOOP), hemolytic anemia, a serious heart infection, several hospitalizations for pneumonia, an infection in my left hip joint, avascular necrosis in both hips and both shoulders, bilateral total hip replacement surgery, left shoulder replacement surgery, and open lung biopsy, and cataract surgeries. Needless to say, I also dealt with depression. My recovery has been much longer and much more difficult than I ever expected.... However, about 2 or 3 months ago, I started feeling better.... I feel like this difficult chapter of my life is coming to a close and that I can finally start on a new chapter of my life. My advice to other patients is to stay positive, deal with each day as it comes, surround yourself with people and things that you love, and don’t give up on the desire to be healthy again. Unrelated transplant 2000

For those who have fear of relapse, I want to encourage you. Cancer is not a death sentence. My first bout with Hodgkin Disease was in 1992, and my first relapse not 2 years later when I had my transplant. I relapsed again almost 3 years later, and again 3 years ago.... After going through the adventures of Hodgkin Disease 4 times, I’m thankful to have each day and beg people to ask me how old I am on my birthday each year. I’ll be a splendid 38 in October. Joy to all those relapers out there or those who fear it. Autologous transplant 1995

What has helped me the most to get past the difficulties of transplant and subsequent illnesses is to surround myself with positive minded people and have a sense of humor. I choose to look on the bright side and be grateful for whatever time I might have left and not dwell on the negative. I really believe it has made a difference in the quality of my life. Allogeneic transplant 1988

Compliments, Complaints and Suggestions....

I do believe that a little more attention needs to be paid to the male sexual issues post transplant. FH people seem a little shy about discussing the issues. Allogeneic transplant 1992

The emotional recovery takes years longer than the physical recovery. Programs are needed to help long-term survivors emotionally recover. Psychologists without BMT experience just don’t get it. I hope FHCRC can develop programs and training seminars for mental health professionals. Unrelated transplant 1996

I think it is very important for emotion to be better treated in regards to follow-up care.... I love that you helped me to survive my illness and tried to give me back my old life, but I think more has to be done in stabilizing the mind after such a whirlwind experience as your transplant patients endure. Unrelated transplant 2003

A constant turnover of transplant team personnel, PA’s and RN’s that knew nothing of my case and opened the patient file for the first time in exam room was very frustrating. Autologous transplant 2003

I would have preferred a single attending physician throughout the SCT process instead of having someone new each month. Allogeneic transplant 2004

My suggestion is you should/could do a better job at discharge informing patients as to what to expect. Major issues for me have been dry eye and AVN, neither of which was on my radar screen. Allogeneic transplant 1991
• You should focus on after-care when the patient goes home, relating to female menopause as it affects moods, energy and sexual dysfunction; and grief counseling for loss of fertility. This is so important. It is crucial to have this kind of support at home. I wished I had it. Maybe I wouldn’t have had several years of frustration and stress to my life. Autologous transplant 1996

• Need to tell (remind) patients for how long of a period they should avoid the sun. I was nearing my one-year anniversary, taking no meds, feeling normal, then POW! Rash and GVHD…. When you feel good for so long, it’s easy to slip like I did. Now I’m back on the pill train. Allogeneic transplant 2003

• The Hutch was very up front on the repercussions of the stem cell transplant program. One thing I wish they had addressed earlier is the length of rehabilitation, which I see has come out in a study showing a lot longer period of adjustment than had been thought. This would not have affected my decision to go through with the treatment though. Allogeneic transplant 2000

• One of the most helpful activities before coming home was the visits I had with the physical therapist, Andrea. She gave us a good program of exercises to use here at home, which has helped me build strength and helped my sense of well-being. Unrelated transplant 2004

• Because of a back problem, I saw Andrea in physical therapy. One session, we covered cardio and exercise needs over the long term. I highly recommend that every patient have this opportunity. It definitely changed the way I’ve approached my lifestyle choices, since I’ve been home. Allogeneic transplant 2004

About the Questionnaire....

• I really don’t see how anyone who isn’t married to a Dr. or R.N. like I am, and wasn’t accompanied by the spouse during treatment, could have done this in 30 – 45 minutes. I am, and it still took me 56 minutes. Unrelated transplant 1994

• The numbers rock. It’s a little hard to assess them because we don’t have the base numbers, but still, they’re interesting. Allogeneic transplant 1997

• Reading about other people who’ve relapsed or aren’t doing so great makes me feel at once very sorry for them, and also like I’m not alone. Autologous transplant 2003

• I am constantly blessed with life. However, thoughts of all the problems combine and make a “what’s next” worry. These questions remind me too much of the negative. Allogeneic transplant 1994

• I welcome your questionnaires—but please don’t send all the comments from others. Autologous transplant 1996

• Thank you for the “Thoughts and Comments from Patients.” It is nice to hear from people who are doing well. It is sad to hear about those who are not. But mostly it is comforting to know my trials and tribulations, my health issues, both good and bad, are not unique. I do not travel this path alone. Autologous transplant 1991

• Re: Comments Section. Again, God bless for this section. I ask my family and friends to read it as well, and I will send copies to my primary care doc and my counselor. I need to quit beating myself up for not being able to do that which is physically impossible—“pull myself up by my bootstraps.” Sheer will power isn’t winning the fatigue battle, so I need to learn to use that energy on something more positive. It is also helpful to hear that it does take years for some of us to recover some energy, that memory and concentration problems are common, and that others feel like they have P.T.S. disorder. I feel that it isn’t so much related to the BMT or SCT procedures but more to that life and death struggle, the fear, etc. that naturally occurs with a life-threatening illness. Allogeneic transplant 2001

• The patient’s thoughts and comments floored me. So many problems and questions I have over the years either went unanswered or the doctors (not just in Seattle) were confused over. I became very depressed, and Thanksgiving weekend, I (accidentally) over-dosed on sleeping pills and muscle relaxants. I was hospitalized and unconscious for at least 6 hours. It took months to realize that I was not alone anymore with my health issues and concerns. Finally, I decided to “try harder” at living a good life, and in July, I turned a huge corner. My life, my marriage, all fell into place. I finally felt happy and put the transplant behind me. I hardly think about it now. I looked forward to this year’s questionnaire, not only because it’s my 10-year anniversary (my husband calls it my re-birthday), but because I am at peace. I know I’m going to live now. Allogeneic transplant 1994
I really benefited by reading the wonderfully frank and honest comments sent in by the other LTFU patients. I felt so validated by reading about other folks dealing with “chemo-brain”—the array of cognitive and memory problems, and the fatigue factor. Thank you for taking the large amount of time it must have taken to edit and compile those 12 pages. Reading the comments out loud to my husband/care-giver was re-affirming for both of us. Unrelated transplant 1998

I do think the comments package should be given to patients considering transplant. I believe it would be beneficial to patient’s knowledge of what to expect, because a lot is left out. Allogeneic transplant 2003

Giving Back....

I am president of a non-profit organization to help cancer patients with financial aid. So happy to be able to give back! Unrelated transplant 1998

I am involved with cancer support at our church, have spoken at a bone marrow donor drive to benefit our local football coach who has leukemia, and feel that I have found my mission in life. I want to be the person who can show the great outcome that people can expect and keep their hopes up. I say, “Look at me. This will be you soon!” Unrelated transplant 1990

I have tried to take what I learned from my sabbatical with you and apply it to other areas of my life. It has led me to participate in the Anderson Network, a patient support organization affiliated with the MD Anderson Cancer Center here in Houston, Texas. I have served on its telephone committee for 14 years, its Steering Committee the last 6 years and served as its Chair in 2000. I am now serving on the Patient Advocacy Committee of the National Marrow Donor Program and have worked closely with its local affiliate. The spirit of giving and hope that surrounded me at Fred Hutch is alive and well in me now and is constantly being extended to others. Allogeneic transplant 1989

I am proud to say that for my 10th anniversary, I am graduating my first class of 19 guitar students in a volunteer program called Guitars Not Guns. Free guitar lessons and free guitars for underprivileged youth-at-risk and foster children. Unrelated transplant 1994

Within the last year, I have begun to focus my business on financial planning for seniors. In my seminars, I make reference to the bone marrow transplant and the fact that although age-wise I am one of the very first of the baby boomers; the BMT resulted in a “battle field promotion” to the senior generation. I am somewhat more conservative, but more importantly, I am hugely more compassionate and empathetic. Much personal and spiritual growth came from the experience. The problems I have had along the way have ranked as somewhat minor nuisances in comparison to great growth. I wouldn’t wish it on anyone, but I tell people that are facing BMT that it will be one of the great and pivotal experiences of their lives, if they face it in the right spirit and with the right attitudes. The risks are great, the rewards can be greater. Unrelated transplant 1997

I thought I would let you know that my wife is donating her marrow to an unrelated 22-year old patient. We are excited to be able to give back, considering how blessed we are. Unrelated transplant 1997

A Final Thought....

I would like to see a survey for caregivers. Since 2001, my life has consisted solely of concentrating on my husband’s health and caring for him. The process of caring for a loved one with leukemia, which requires a bone marrow transplant, is all-consuming. I have only recently begun to grieve the losses we have experienced along the way.... It has been two years since my husband’s transplant, and I am thankful that he is alive and with me. It has been difficult to get back to the “normal” we once knew. There is a “new normal” for us, which includes regular doctor visits, some limitations of activity due to fatigue and restrictions related to immunosuppression, daily medication, and the reality that we will not be able to bear children “the old fashioned way.” The “new normal” also includes experiencing the blessing of life as we have never known it before. We have our priorities in order, and we look at life differently, which is a good thing. We also have the opportunity to help others who are going through similar situations. There are people all around us who are hurting, and we have been able to help them through the sharing of experiences. Allogeneic transplant caregiver 2002