Thoughts and Comments from Patients—2005

The Best of Times….

- We are still around to hug each other every day and we make each day count by making it joyful and fun and not living in the past. Allogeneic transplant 1992

- I am a full-time police officer...with no restrictions. Since my transplant my children have given me 3 grandchildren which I enjoy every day. Life is good! Allogeneic transplant 1998

- I feel better than I have in over 4 years when I was first diagnosed with non-Hodgkins lymphoma. I am 76 years old now and can’t dance all night like I used to at age 18. P.S. I exercise daily by walking 1-2 miles and eat lots of fruits and vegetables. Autologous transplant 2005

- I graduate from medical school...in May...and start internal medicine residency...in June. If all goes according to plan, I’ll do a heme-oncology fellowship following residency. Allogeneic transplant 1983

- I will always remember the time I was to begin, a friend I made at the Hutch was getting ready to fly home after a month in the hospital. She told me, “you can do this.” When things get difficult in life I repeat those words to myself and think, “yes, I can.” Autologous transplant 1997

- I’m still riding racehorses for a living and doing well. I won five races in one night a couple of weeks ago... Thanks for everything and have a good ride. Allogeneic transplant 1978

- Last year I participated in the Relay for Life. It was a turning point for me. Up to that point I was ashamed of having been sick and so weak. But when my caregivers and I did the survivors' first lap and thousands of people clapped and cheered, I realized that I am proud of having survived...of being so strong. Allogeneic transplant 1998

- My life is very full and busy. We still are on our family farm, have finished (well almost) building our home, a lot of work, but rewarding. I learned how to use many different power tools and still have all my fingers. Allogeneic transplant 1978

- My son continues to be his “old” self. He is completing his sophomore year at the University of Arkansas with a GPA of 3.57. He runs 4 miles daily, lifts weights, eats like a pig and enjoys a normal life for a 21 year-old – except – never a day passes that he doesn’t thank God, his Hutch family, patients and scientists past and present for giving him a second chance. Allogeneic transplant 2000

- I’ve been feeling very well, and my energy and self-confidence has increased massively since being off of the medicines and treatments. Allogeneic transplant 2000

The Worst of Times….

- I am disappointed with my quality of life after my BMT autologous June 2003. I know I will have to decide on another BMT when my myeloma comes back and I am not real sure that I will go through that again without a more positive post-transplant outlook. I can’t work like I want to, my family life and social life is significantly affected and I feel like an outcast and not part of the group. I can’t lead the family anymore and I don’t provide for the family as I used to before cancer and the BMT. Our financial situation is not good and that affects me being that 3 of our children are in college and we have to plan for the family’s future when the myeloma resurfaces and I get real sick again and go on treatment (maybe). Autologous transplant 2003

- I am glad I had the stem cell transplant, but did not have a clue that 2 years later I would still be so disabled. I thought I would sail right through it and return to work and all normal activities within 6 months. It now appears I am permanently disabled and will never return to work or my once normal activities and quality of life. Allogeneic transplant 2003

- I am still on lots of medications due to chronic GVHD. At 31 years old I am living in this purgatory-like state. I had to move back in with my parents, I cannot work anymore, and finding “others” like me is nearly impossible. Most friends and family just don’t get it. Allogeneic transplant 2004
The side effects of transplant have been fixable however it has changed our son. The adrenal insufficiency is awful; the cataracts are tolerable and annoying for him. He is not doing what peers his age are doing—sports, driving, etc. After 9 years from transplant, having to do shots and pills is a constant reminder of health issues. Allogeneic transplant 1996

There’s no way I would do this again. I continue to be in remission, however the GVH issues make my life miserable 24-7. My children have benefited from my surviving the past 2 years, however, NO ONE, not even other cancer patients can comprehend the chronic GVH issues which never get better. As I said last year, the cure is worse than the cancer. At least death would take away the suffering and after enough suffering, I am not at all afraid of death. Each day I ask God to take me. Allogeneic transplant 2003

Would really like to have my life back. The last 3 yrs. have been unreal. My body has been through hell and looks it. My mind seems to have taken a very long nap. Can’t remember things, words to songs, people’s names, dates, times, even something I just watched or was told. Can’t make decisions – going to the store is a nightmare. The feeling of being totally lost is overwhelming. Spelling is bad too. May not get to drive my school bus again come September, so then I have deal with being unemployed. Autologous transplant 2004

The “New Normal”

After reading anecdotal comments included in this package I feel I would be remiss without a comment or two. The phrase “new normal” stood out to me as an accurate description of my current state. My short and long-term memory still blows, carbonation is no longer my friend (see you, Beer!) and I can gain ten pounds just thinking about pizza. But don’t get me wrong, I ain’t bitchin’, I’m just sayin’. Thanx again. Autologous transplant 2003

Before my cancer, I could teach (my occupation/career), coach sports, garden, cook and socialize. Now I go to work, come home and take a nap and then make dinner – maybe. I would like to exercise but cannot muster up the energy or the will. Allogeneic transplant 2003

Getting used to the ups and downs has been trickier than I expected. Recovery looks less like the smooth slope upward that I had been prepared for (in my mind). Rather, it is a jagged/bumpy slope upward. Allogeneic transplant 2005

I expected to be able to return to normal after the transplant. I retired from work as I lack the strength required to do my regular work. I can’t do many of the things I used to do. I tire easily and have to rest a lot. I seem to be able to do one thing at a time, no multi-tasking like I was famous for. Normal has taken on a new meaning. Autologous transplant 2004

I feel very hopeful about my future, welcome every new day for the precious gift it is, and appreciate my family, friends and medical support teams more than ever! No, I am not back to my pre-AML diagnosis self and don’t know if I ever will be, but that is okay. For each thing I struggle with (fatigue, neuropathy in my feet, “foggy brain” from the meds.), other positives have popped up. I try to balance each day by focusing on mind, body and spirit. Thank you for giving me a new lease on life! Autologous transplant 2005

It is very hard to be 6 yrs. out of BMT and look “normal” yet have challenges that no one can understand. I am VERY thankful to receive the comments because that seems to be the only affirmation that BMTs have long-term effects… for all my challenges – I find the silver lining but I guess it is frustrating that nobody realizes what a struggle each day is. Autologeneic transplant 1999

My health is as good as can be expected. Everything the docs told me to expect is gradually becoming true, i.e. stiff joints, (I am rapidly approaching 50, so a lot of this is probably age-related), dwindling vision, some skin irritations (cold sores I never used to get pre-cancer), swelling of the ankles and feet to name a few. I lived through cancer (thanks to you folks) and shortly after, my then-wife divorced me and has taken me to the cleaners, so, with no medical insurance, hugely in debt (I didn’t work for 2-1/2 years) and having to start over again, with less than nothing, it has taken a giant mental endeavor to maintain a positive attitude, but I am, and I will be damned if I am going to live through cancer and die of divorce. HAA! Autologeneic transplant 2002

Recovery has been about a thousand times more difficult than I ever imagined. But I am so happy to be alive and my life, while difficult, is full of blessings and joy. Autologous transplant 2004
• My battle has been going on for 5 years now including surgeries, chronic GVHD, job loss, hobby loss, mental anguish and guilt. It’s tough to communicate one’s limits without sounding like you’re soliciting pity. I feel I appear to be a malingerer to others when in reality my recovery and survival following two transplants took enormous courage and determination to get back this far. Allogeneic transplant 2002

• We live near Hood Canal so we go boating and we have a small 5th wheel trailer that we use for camping... I still have a lot of side-effect problems, but I look forward to each day. Unless it’s raining. Autologous transplant 1996

• I can tell I will never have my old body back again, but without the transplant I would have no body at all by now. I was on my second recurrence of AML when I got my transplant. The transplant has allowed me to have at least two more years with my young daughters – and hopefully many more to come. I have been able to return to part-time work as an ophthalmologist helping other people with their health problems.

Some Expressions of Gratitude....(among many)

• After transplant I went back to school and completed my Bachelor’s degree in Psychology. Have been able to work with pregnant women and children and can say that my experience has been an inspiration to others. I thank all of the nurses who took care of me and my family and all the doctors and staff at FHCRC. It has been 9 yrs. and (I) look forward to make it many more. Allogeneic transplant 1996

• When I was first diagnosed in September of 1990, I saw Dr. Thompson at UW hospital. Working with him was Dr. Benyunes. Although I was no longer under his care during my transplant hospitalization, he came to visit me. When we first met, I told him that I just wanted to get my girls raised. He told me I would live to be a grandmother. I have 3 wonderful grandchildren. I haven’t been able to find this kind doctor to tell him how much his words and visits meant to me. Allogeneic transplant 1991

• Hope to get an “all clear” at my 1-year checkup. I miss yard work and salad bars. THANKS. Allogeneic transplant 2004

• I am now 67 years old (I can hardly believe it – I feel young inside) and am having some of the problems of aging... I no longer scrub floors on my knees or take long walks but I have a lovely cleaning woman and lots of friends in and out of church. My husband has always been a saint. I you don’t believe me – ask him. Allogeneic transplant 1974

• I don’t even know what to say to you guys. Thanks isn’t enough. There aren’t words. I guess all I can do is enjoy what I have. Sixteen years have gone by and each one is faster than the other. I just went to dinner tonight with my parents, sister, and fiancé to celebrate. Thank God, thank my donor (my little bro.) and thank you! Allogeneic transplant 1989

• I work full-time as a nurse anesthetist...I also play hard: skiing, in-line skating, swimming, biking, weight lifting and riding my Harley. Thank you, thank, thank you... Allogeneic transplant 1989

• I would...like to say thanks for the dedicated professionals who took me through the process 25 years ago. Dr. Doney and all the team. Now I look back and sometimes it seems like a really bad dream. Praise God! Autologous transplant 1980

• My blast crisis gave me a stroke that paralyzed my entire left side – I’m fully recovered from that. Who wouldn’t choose life, even with some problems, when faced with the ultimate conclusion of AML? I’m glad I did, and thanks to the doctors, nurses and researchers at FHCRC, my donor, and my wife and caregiver, I hope to resume climbing mountains this year! Allogeneic transplant 1994

• My caregiver is probably the most responsible person for my progress and excellent health. If not for her constant vigilance I would not have survived. Allogeneic transplant 1998

• Myself and my family celebrated “The Hutch’s” 30th Reunion on July 29-31st. It was a wonderful weekend and very emotional for me being back there. I kept thanking God for allowing me to still be here with my family along with my endless gratitude for the staff at “The Hutch.” The highlight for me was shaking hands with Dr. Thomas and his beautiful wife and thanking him for pioneering BMT. Allogeneic transplant 1996

• Thank you. I have just doubled my life span! I was 21 when I had my BMT and I just celebrated my 21st anniversary. I am in great health and ran my first marathon last year to celebrate my 20th anniversary. Thank you for all that you do at the Hutch. Allogeneic transplant 1984
• Thanks to Kerry the nutritionist I have become the chef in our house. The wife and kids are grateful. Allogeneic transplant 2002

• Things would have to be extremely, extremely bad for me to choose death than any kind of life at all! Thanks for everything... Autologous transplant 1994

• My BMT has been a blessing in my life because it has really made me cherish my life. I was very lucky to have had a smooth recovery, and I now take much better care of myself than I would have if I hadn’t been ill. Thank you for all you have given me. Allogeneic transplant 1984

Exercise!....

• Although the progress is slow but I can definitely feel the improvement from year to year. Part of the problem is that I didn’t exercise regularly. Autologous transplant 2001

• At the advice of my doctor, I began routinely exercising and working out w/weights beginning at the end of May. I think this has definitely helped my energy level and my overall well-being. Allogeneic transplant 2005

• I have lost a lot of muscle strength and endurance during the last 2 yrs. that I have been on Prednisone. I am now off Prednisone and feeling a little apprehensive about possible return of chronic GVHD. I am trying to exercise more (walking, golf, lifting weights) to restore some muscle tone. Allogeneic transplant 2001

• I work out 50 minutes four days a week. I have started a series of stretching for golf. My average golf score has improved and I shoot around 85. I play golf a couple of times per week. Autologous transplant 2003

• I’m 6 months post-transplant and feeling better and stronger everyday. I started a very rigid physical therapy regimen on March 1,’ 05 and it has made a TREMENDOUS difference in my endurance, strength and mental well-being. I would recommend it highly to any post-transplant patient that is on Prednisone or other steroids. Allogeneic transplant 2004

• My new goal is to swim 50 laps on my 50th birthday, volunteer overseas in medical missions, and to finish raising my children. Autologous transplant 1994

• I am approaching my 50th birthday, having put a 21-speed road bike on layaway, and purchasing a new pair of downhill ski boots, with all intent to use both with joy and exuberance! Allogeneic transplant 2002

Memory and Strategies for Coping....

• I am beginning to think my mind is affected for memory. I forget where I put things – glasses, keys, purse, etc. It is driving me crazy. I tell friends the same thing several times – they say “You told me that” – so embarrassing! Allogeneic transplant 1997

• I struggle with memory loss and the ability to organize my thoughts and my surroundings. I feel like “Dory” the Blue Tang on “Finding Nemo” that has major short-term memory loss (my son’s classmates from Kindergarten called me Don due to my frequent forgetfulness of what I was doing/where I was going!) “Keep Swimmin, Keep Swimmin, Keep Swimmin” is my mantra. Allogeneic transplant 1998

• I suffered from fatigue and memory loss. I attribute this to the medications I was taking for chronic GVHD. Once off the Prednisone and Cyclosporine, I began to feel so much better...after the transplant, I do crossword puzzles. This helps my handwriting and my memory. Allogeneic transplant 2003

• My concentration level is terrible. Many times, I lose what I am thinking about and can’t finish my thoughts or expressions. I will think of something I need and I will get up to go get it and the thought will immediately go away and I can’t remember what I am doing. I must make continual notes to remind me of what to do daily or I will just forget. During the last few months, I feel dum dum sometimes. I just feel stupid. I will do things like leave the oven door open while cooking. Go to the store and buy half of what I need. Just dumb things that I never did before. Like chemo brain. I have heard this term but now I understand what it means. Allogeneic transplant 2001
• The most difficult after-effect of the bone marrow transplant is the loss of memory and brain sharpness. My short-term memory is horrible whereas I used to be able to recall names and faces quickly. I also become very distracted easily and forget things very easily. I have become confused and can’t seem to understand or retain information like I used to. It is very frustrating to me and others as well. Allogeneic transplant 2004

• I have ongoing memory difficulties but try to deal with them the best that I can. I do get very frustrated when I check and re-check myself, especially at work. I am a medical biller and I find myself going over my work to make sure I enter the correct ID #’s and CPT and ICD-9 codes. Allogeneic transplant 1988

Financial and Billing Problems....

• Finance and billing has been a nightmare. Problems with billing codes, determining what is in the case note, and more. Seem to have serious systemic flaws. Caused constantly recurring stress. Many phone calls not returned. Allogeneic transplant 2005

• However, your billing department is a shocking contrast. Over the last 18 months, I have called 19 times trying to get a charge for Oct. ’03 billed properly to my insurance. I have faxed the EOB from my primary and secondary insurance twice. I paid a co-pay by check which your department has no record of – I had to request a copy of the cancelled check from my bank. When I finally thought I was making progress, they told me the person I had been dealing with no longer worked there and I had to start all over with the faxes, etc. It has been very frustrating and is still not resolved. Allogeneic transplant 1996

• P.S. I am pleased to learn that you are addressing billing concerns. Last October/November, I received a phone call from your business officer informing me that I had overpaid (on) a check for $110-$130 - was forthcoming. Still no check. Allogeneic transplant 2003

• The billing process has been and still is a complete nightmare! None of the facilities will cooperate with insurance requests for information (even though I signed releases). We have tried to work out payment plans, but too much change in personnel, or some reason, we have been sent to collection instead. It has affected our credit rating and left me very nervous about getting adverse phone calls and mail. Would appreciate cooperation! Allogeneic transplant 2003

• The only problem we incurred was with your billing at the SCCA and the physicians billing. Allogeneic transplant 2005

• We have had billing problems as well. One computer and operator doesn’t have the same information as others. You have problems you should not have such as the loss of the name of the secondary insurer or they fail to bill them. The most frustrating thing is they argue with you when you tell them you have complete coverage. They say that is impossible!!!! There have been charges for procedures that I did not have. Allogeneic transplant 2002

• We are still paying out of our pocket for each prescription. By the end of the month it is food or medicine. We try to stockpile sale items to eat and thus far we have made it work. Sometimes I have to take 1 pill a day instead of 2. Autologous transplant 2002

• I wish I didn’t have to work...so that we could enjoy what time I have left. ...due to multiple health issues in our family... we both need to work to keep our health insurance. There is no way that we could afford my treatments and the medicines I need to stay alive and keep my cancer controlled without our insurance. Autologous transplant 1998

• The week before I left Seattle (I read that) a dog got a stem cell transplant for $45,000. I should have gone to a vet! Allogeneic transplant 2005

Other Problems....

• One of the biggest problems I face shows no sign of improvement – dealing with our failed dysfunctional health care non-system. My biggest challenge finding a primary care MD not just knowledgeable about BMT/cancer survival issues, but willing and able to work with me to manage the various issues and specialists, and help me make a health game plan. Allogeneic transplant 1998
As I read through the comments, I almost get chills as it brings back bittersweet memories of my times in Seattle. It also makes me a bit scared when I read comments of long-term issues. I too received Hep C during my fight for life in 1989. I am blessed to be able to say that the virus is dormant and not creating any problems in my life. I do stay in yearly contact with my gastroenterology doctor. Allogeneic transplant 1989

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

I was 70 when I received my non-myeloablative transplant. I am now 72 – doing well… One problem that plagues me is GVHD of my fingernails. They are a sight to behold; it appears little stubs of nails are fusing to the skin/quick. Only one nail is normal. Allogeneic transplant 2003

I’d like to be able to laugh more. Is there a pill for that? Allogeneic transplant 1994

I’ll write more when my writing stops being so shaky. Allogeneic transplant 2005

My biggest problem is lung deficiency, bronchiolitis obliterans. This untreatable disease needs more research and funding. It affects me every day and everything that I try to do. Allogeneic transplant 1998

My main problem is between the ears and under my hair. My mental/emotional state keeps me in a world of isolation. I forgot how to socialize. I keep trying but I just don’t seem to connect anymore. I used to be quite social but the last several years have been stressful and it’s like my personality has changed – unintentionally. I’m working on it though. I’m not hopeless. Autologous transplant 2004

My primary physician, who helped me through my diagnosis and treatment plans with oncologists and Fred Hutch, retired this year. It wasn’t easy finding another doctor…who would take me. Allogeneic transplant 1994

The problem that troubles me most has been my inability to put cancer behind me and move on. No matter how small or large the issue, you find yourself always considering the illness and letting it influence your decision. I look forward to the day when cancer no longer runs my life. Autologous transplant 2004

Emotionally, my recovery continues. I tried therapy but she (the therapist) had no clue. I even bought her books about BMT and leukemia (“Survivor, Time on Five”) but doubt she ever read them. So my self-diagnosis is depression. Perhaps it’s survivor guilt if there is such a thing. But I am here and try to help others who have been newly diagnosed with leukemia and need a BMT. I hope that Hutch will study, develop and implement programs that focus on the long-term emotional health of survivors. In many ways, I think regaining emotional health is the final stage of recovery and the most difficult. Allogeneic transplant 1996

Pediatrics….

My son is almost off the Prednisone, has finished first grade as an honor student, no signs of learning disabilities, thank God! Very sharp memory (better than mine). He is a good leader and helper. Spends many hours helping children with cancer with schoolwork at the hospital. He is taking karate and he is a cub scout. Allogeneic transplant 2002

The biggest, hardest thing for my daughter is what she “cannot” do that everyone else can. She feels well enough to participate, but because of her delicate immune system, she must sit out. This is hard for a 10 year-old. Allogeneic transplant 2004

I always fill this out for my son (now 19) as he has moved on from illness and says he just doesn’t worry about it anymore! His health is remarkably good 4 yrs. post-transplant. His outlook on life is very positive. He goes to college (full-time) and works 32 hrs./week! He gets sick less often than the rest of us. As his mom and caregiver during his transplant, I am sure I think more and worry about him a lot more than he worries about himself. I don’t suppose that will ever change. My son is a great guy – very kind, nice, and responsible in all areas of life. We are very proud of him! Allogeneic transplant 2001

My daughter is such a happy, fun-loving, joy-filled little 2 yr. old. She is extremely intelligent and has not been affected with her ability to learn. Everyone always comments on how incredibly bright and intelligent she is. Very often strangers that don’t know what she’s been through. She is funny, caring, loving, fearless, strong, courageous! She is our amazing miracle! Allogeneic transplant 2005
As a caregiver, I am exhausted, after 2 years on this roller coaster. I will always be grateful, though, for the chance my daughter had at a normal life. I just wish it had turned out differently for her. Allogeneic transplant 2003

Children....

God blessed me this year with two healthy babies...I delivered them without any major complications – just a blood transfusion for me. They are 6 months old now and continue to amaze me every day. I left my teaching position to stay at home and raise them. I love my “new job” and would never do anything else. Autologous transplant 1992

I would like to see more attention given to (female) sexuality after transplant. Not only has my sex life changed drastically, but I am still grieving the obliteration of my ovaries, and still get angry when I think about how flippantly the obstetrics nurse was in discussing the imminent obliteration. Allogeneic transplant 2003

I’m filling out this survey 38 weeks pregnant, at the age of 38, with a due date 5 days before my 16th BMT anniversary – having conceived naturally on “the first try” a few months into my marriage! I cannot thank the Hutch enough for my “second chance.” Allogeneic transplant 1989

Like many of your patients, we were not able to have more children. As the well-known saying goes: “When God closes a door, He opens a window.” In our case an angel flew through the window. In 1987 my wife and I adopted a baby girl from Korea. I can’t imagine our lives without her, so I can’t imagine why I would regret anything that happened to me that led us to adopting her. Autologous transplant 1980

We just got back from the reunion. It was a weekend well spent. It was wonderful to see so many people who know what it was like to go through a BMT. Also to talk to many who had transplants as children and to see them all grown-up now. Many with their own children. Allogeneic transplant 1990

I used to wonder often at why I was given the strength to survive this ordeal and this year for the first time I have begun to understand. I became the proud father of twin boys...Today,....our once-tiny little preemies are almost eleven months old and doing spectacular...I realize that my life might not be perfect nor that I will ever be free from GVHD, the muscle cramps which at times become almost (disabling), or loss of memory, but that’s all right with me. I am blessed with a wonderful family, great friends, and a second chance. Allogeneic transplant 1989

FH needs to do a better job at addressing premature menopause in younger women and that should include counseling. I think I am finally over the sorrow of not being able to have children...having a close relationship with my niece (5 yrs. old) and nephew (3 yrs. old) has really helped. But it was a struggle dealing with my feelings and had a significant impact on my personal relationships (or lack of). Allogeneic transplant 1992

Perspectives from a Distance....

I believe I’m going to grow up to be an old man and I invite everyone at FHCRC to my retirement party April 16, 2021... Allogeneic transplant 1984

I still see my BMT in 1994 as a very expensive E-ticket ride. If you visited Disneyland in the early days, the tickets for the rides ranged from A-E. The E tickets were the most expensive, could make you sicker than a dog and scared you half to death. But they were the best. That, in a nutshell, is Fred Hutch. Autologous transplant 1994

As I have passed the 26-years mark, I realize more and more that some minor ailments or stiff joints I have are more likely caused by aging than the BMT trauma. It’s so good to be old! Allogeneic transplant 1979

At 73 I look at the obits in the local paper every day – if I can’t find my name I know it’s going to be another great day. Autologous transplant 1990

Having been published in your comments the last 3 yrs. I am feeling the pressure!...In my case, the bone marrow transplant was both a spiritual adventure, and a landmark, in my life. Often I still classify things as “before bone marrow transplant,” and after. In May I turned 8, and 59. In many ways I am starting over this year. All of these things seem to be working together to produce positive change in our lives. Allogeneic transplant 1997
I am so glad I read the comments section included in the questionnaire. Nine years ago, a CML diagnosis made me adjust my priorities in life and helped me to understand those precious moments that are so important in life. Today, nine years after my transplant I once again find myself on the same relentless quest of long working hours to try and make my family wealthier... I had to take a Friday off this week to do some father time because my wife will be out of town on work. Normally, I would try to make up that 10 hours on Tuesday (my normal day off) so that I do not lose the pay. This Tuesday though, after being reminded of what a gift this time I have been given is by the comments of others, I am going to take that time and reflect on these last 9 years and how truly fortunate I am to have had them. Allogeneic transplant 1996

I continue to be incredulous and grateful about the gift of good health I have received. When I had a reoccurrence of graft vs. host disease this year I was initially angry, but a look at how far I’ve come since diagnosis 3 years ago and keeping the big picture perspective brings my attitude back in line. I am so happy to be sharing my life with my family and young children. Allogeneic transplant 2003

I don’t think about my experience a lot I just try to live each day the fullest I can. When people ask me about my experience I tell them this - “They bring you as close to death as possible and bring you slowly back to life.” One person’s comments were so resonating with me. It is hard to explain to someone else what you went through. Thank you Fred Hutch for helping me re-celebrate life! Autologous transplant 1999

I feel completely back to normal. It’s as if it was all a bad dream. Allogeneic transplant 1997

I tell everyone that I meet that cancer was the worst thing that ever happened to me and the best thing that ever happened to me. My BMT was a grueling physical and emotional experience from which I will never fully recover. But my cancer experience opened up a whole new world for me. My pre-cancer life was shallow and self-focused. My post-cancer life is rich in new relationships, attitudes, experiences, and spirituality. Allogeneic transplant 1996

I was diagnosed with non-Hodgkins lymphoma in 1989 and was told there was no cure. Since then we have been planning for my death. Now we are planning for my life. Allogeneic transplant 2004

In retrospect, I am now quite certain that the best way to convey an understanding of my limitations is to imagine that I have been somehow prematurely aged 10 or 20 years beyond my chronological age due to the cumulative effect of the disease(s) and all of the systemic treatments I received over 7 or 8 years. Autologous transplant 1991

It is 9 years since my stem cell transplant. Even after these 9 years I feel the “Big C” hangs over my head. These thoughts do not consume me, but are still not erased from my mind. The joy in my life is my 2-1/2 year-old granddaughter. I feel blessed and thankful for my life, and for treasured memories I have had the time to make. Autologous transplant 1996

This has been five years that I wouldn’t wish on my worst enemy, but, strangely enough, wouldn’t trade for the world. The experience has had a huge impact on my outlook on life – I cherish every day! Being on the “right side of the grass” is something I am truly grateful for. I know that God has something else planned for me down the road. All I have to do is look for the opportunities and live life to the fullest. Allogeneic transplant 2000

Compliments, Complaints and Suggestions....

I agree that caregivers would benefit from a survey focusing on the issues caregivers face. I know caregivers go through a roller coaster of emotions and are often overlooked. Autologous transplant 1995

I’d...recommend putting in a couple of treadmills, exercise bikes and a universal gym at Pete Gross House for patients and caregivers. I have never encountered an organization as large and complex as the SCCA/FH where everyone from receptionists and administrative personnel to doctors and medical staff were so uniformly positive, encouraging, and “on message” in pursuit of excellence in patient care. Autologous transplant 2004

In your Newsletters please give more references to internet sites such as ACOR-GVHD support groups (http://listserv.acor.org/archives/gvhd.html). This has helped me most in being in on cutting edge of treatment options for my GVHD issues. Oregon Leukemia-Lymphoma Society has a “Buddy system” for all BMT, SCT pts. They match-up patients with similar ages, diagnoses, and mini vs. full transplants to follow throughout whole transplant process. I wish the Hutch would do that. I am a mentor for 4 patients now, and it’s very rewarding. Autologous transplant 2002
I am concerned about the growth I see happening at the Hutch. I don’t think the staffing has kept up with the growth. I should not have to schedule an appointment SIX MONTHS in advance. I should be able to call and talk to a person and not have to wait two days for somebody to call me back. Also, I’ve been quite frustrated with the billing department and their practices. When I called to ask what a certain charge was for, they said “we don’t know, we’re only the billing department.” Allogeneic transplant 1998

I have talked to two people who need transplants and I wholeheartedly recommended they come to Seattle. One of them told me I sounded as if I was describing a vacation rather than medical treatment. Allogeneic transplant 2003

My first couple of weeks upon discharge from UW were very difficult in managing the meds and the pump! I would have liked to spend a week managing my own pills and pump. Being on a self-med program would’ve been extremely helpful. Allogeneic transplant 2004

My husband says that SCCA is a fire fighting crew that puts out fires, but does not rebuild the house. That task is left to the patient and her doctor. LTFU needs more staffing. Everyone I talked to was knowledgeable and helpful, but it often took several days for them to get back to me and talking to a different person who didn’t know my history left me again with feelings of abandonment. Ideally every patient should be assigned to a designated contact. Working with Judy Campbell has truly made a difference in my recovery. Also communication with the local physicians needs some work. Allogeneic transplant 2005

My only complaint continues to be my very thin hair (coverage as well as hair thickness itself). However, I just went off Femara 3 months ago and I believe I’m getting some hair back. Patients should know that hair loss is more common with this drug than is indicated in the information in the drug side effects listing. Autologous transplant 1999

Our stay in Seattle was kind of like a mini-vacation. We only did the things you all provide that were free but just enjoyed walking around and see a part of the country we would have never had the chance to see otherwise. Your culture is different and it was a pleasure to see how others live and handle things. Allogeneic transplant 2003

About the Questionnaire…. 

I always dread receiving the questionnaire, but after reading it I am so grateful to have it. The memories and experiences at the Hutch are always around – especially on the subconscious level. Facing these memories with this questionnaire is very emotional and cleansing. Reading about others who have the same problems is very comforting (especially when I haven’t really recognized these symptoms myself). Please, keep up the good work. Allogeneic transplant 1994

P.S. Wow—these questionnaires have sure come a long way in 18 years (remember the sliding-scale of pain?) Allogeneic transplant 1987

FHCRC continues to treat me by providing this chance to vent. See attached. Allogeneic transplant 1984

Thank you for sending the summaries of patients’ comments from last year. I feel much more positive about the slow pace (to me) of my recovery and the constant new problems that keep popping up. I really expected to feel much better by the one-year mark. Now I know this will be a long process. Allogeneic transplant 2003

There are (3) constants in the universe; death, taxes and the LTFU Questionnaire. Every year, just like clockwork, the annual questionnaire arrives. The postal delivery people must cringe in despair when they see the sheer bulk and weight of this massive request for personal data. I am writing this in jest of course. Even though it has been over 33 years since those eventful days occurred over the spring and summer of 1972, I remember most details of the experience (with the exception of some names). And yes, I do still raid the refrigerator in the middle of the night just as I did during my post-transplant days. Life is good. Allogeneic transplant 1972

This questionnaire is great. But what I like most is seeing the tally after you compile. It makes me realize that the things I’m going through and feeling are somewhat “normal” for transplantees. After transplant, there is a whole new definition of normal – and the survey results help me sort out that definition. My new mantra – Life is a gift…Live in the Present. Allogeneic transplant 2002
I would like to know why it is that all the people in the Comment Section are from transplant survivors? How come I had “ATG” treatments and yet no one else has had any types of treatments? Could I have had a transplant and never been told by my parents? Or did the “ATG” stuff take care of it without a transplant? ATG treatment 1981

Giving Back....

I have come into contact with many people who have leukemia and some who have had transplants. I feel it is important to be a source of hope to those individuals in a “Look at me” kind of way. Allogeneic transplant 1990

I was able to raise over $8000 this summer for the Leukemia/Lymphoma Society as I participated in a 100-mile bike ride around Lake Tahoe. I am a better fundraiser than a cyclist I must confess. At mile 53 I was involved in a four-rider pile-up that left me with a pelvis broken in two places and a cracked sacrum. The good news is that my bones are strong and that I healed quickly. From now on I will look for LLS fundraising events that involve tennis or ping pong and perhaps shuffle board. Allogeneic transplant 1995

Living through cancer and BMT reminds me of a documentary I watched about a hiker dismembering a limb to survive. I believe survivors are courageous people who can positively influence other lives. Kind words, touches and support from those who have experienced the most severe adversities of life can be very uplifting to others. Do not underestimate your willpower and capabilities. Allogeneic transplant 1992

My cousin’s husband has just been diagnosed with multiple myeloma and will have a transplant in April. They are grateful to have me as a source of hope and experience. I am blessed to be able to share my positive survivorship with them. Autologous transplant 1991

My doctor has never seen or heard of (anyone) that’s still alive and cured for 8 years this December. After relapsing 3 times, I’m biography material. I plan on writing a book soon to help others cope and give them inspiration. Autologous transplant 1993

The questionnaire is an annual reminder of the spectrum of post-transplant life. My wife and I are on one end through miracles. After many anxious months post-transplant I emerged whole without apparent sequelae. In returning to medical practice I have new empathy for patients and their caregivers. We are blessed and better appreciate the anxieties, uncertainties and struggles. I am returning the support to others undergoing chemotherapy as I DO understand thanks to all at the Hutch. Allogeneic transplant 2002

Final Thoughts....

Every year, I am happy to see another LTFU Questionnaire—I know another anniversary has come and gone. Unfortunately, it also reminds me of the pain endured and all the friends lost, because I was the “lucky” one. Afterwards, I didn’t feel so lucky. It took many years passing just to feel normal....I suppose I am lucky that the memory of my transplant is a blur—not so for my family, who never left me. I never ask them of their memories. I have no children, and I do not mourn. The sacrifices that we made to save my life were necessary, and I have no regrets. Sure, I have serious health issues now. I have to take handfuls of prescriptions. I wonder how long I will live, and I have no medical coverage—but I know my transplant made me a better person, stronger, and I look at the world in a different perspective. Post-transplant, I am a person that loves life and is no longer afraid of the future. I may not live forever, but I thank the Hutch for giving me the opportunity to really live and now have the ability to love myself and life unconditionally. Here I am at almost 40, and I feel better than I did at 19. Imagine that! Allogeneic transplant 1987

No one who has never undergone the BMT experience, including spouses, can ever understand or grasp its full extent, both physical and emotional, long-term or short-term. I feel that the BMT experience has caused me to grow immensely, both emotional and spiritually. This despite the problems with focus and concentration and multiple physical ailments. I feel liberated from petty jealousies and life problems that are important to others. I am no longer afraid of dying. Although I feel much more self-reliant, paradoxically I am also lonely in that I cannot share what I have experienced with anyone who has not been through the same experience. Allogeneic transplant 1999