December 17, 2017 (one day before initial visit with oncology doctor)

I have come to a place in my life now where I am at peace about the chemo process. I realize not going through chemo treatments and not making lifestyle changes can very well result in an earlier personal mortality than I wish or want. With much yet to accomplish in the area of adult autism advocacy, going through the “chemo tunnel” is a must. What is the “chemo tunnel”? It’s kinda like the “tunnel” I was going through over ten years ago when I had received an official diagnosis on the autism spectrum. When I entered in one end of the “autism tunnel”, the other end was less than a pinhole. As I grew to accept myself as an autistic and learned to live as such, the other end of the tunnel became larger and larger over the course of time. One day, I crashed through the other end of the “autism tunnel” and began to see things differently in my life.

In my view, the “chemo tunnel” is both similar and different than the “autism tunnel”. In a like way, I will be going through the start of the “chemo tunnel”. The end will be four months away, but will feel like a very small pinhole at the other end. As I continue through the “chemo tunnel”, I will start seeing the end of that “tunnel” more and more. Whereas being an autistic adult (adult on the autism spectrum) has changed my life, so will my perspective on my life after completing chemo.

As well, the “chemo tunnel” is different than the “autism tunnel”. No known medical cure exists with autism, but a cure can exist with cancer (especially with colon cancer). Autism is a neurological and developmental disorder (and “invisible disability”). Autism is not physical and cannot be seen from outside a person, because autism affects people neurologically in the brain. Also, autism is not a disease like cancer is. A myth existed for many, many years that autism was a disease that needed to be eradicated. A disorder is not a disease.

In addition to chemo, a change in lifestyle habits (exercising more) and better nutrition (eating more veggies and a greater variety of them) will benefit me greatly. Fruits have never been an issue for me. However, I acknowledge that I’ve put myself on the short end of vegetables.

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Tuesday, December 26, 2017

I feel a sense or fear and have felt it for a while, even if I come across as being “fearless” to others about the upcoming first round of chemo tomorrow. I think it is ok to have a healthy sense of fear, provided that the fear doesn’t become all-consuming like a fire out of control. I went from fear to acceptance in knowing that there is no turning back now. I am going into this with full acceptance. I know what I am about to do can be a tool that prolongs my life by a good number of years.

I accept that I could breeze through chemo, but also accept that going through chemo could be potentially hard on me. I accept whatever comes my way – and will fight the good fight. I accept that changing my nutritional habits will have an effect on potentially prolonging my life. I accept that losing weight for health reasons can also have an effect of prolonging my life. I accept that doing all these things together (not just chemo) – along with prayer and positive thinking/motivation – will be instrumental in helping me through the get next four months.

What goes in as the old way of living comes out as the new way of living. What was old must die away so the new can be made and known in my life. I lay my life down – the imperfections, the shortcomings, the countless number of days when I didn’t eat well at all. I accept that eating more veggies and whole foods earlier in my life could have resulted in not needing to go through chemo in the first place. I accept full responsibility for all of my previous actions.

However, here I am, and the events of my past have led me to where I am now. I don’t see chemo as some sort of “death sentence” but a tool I need to live longer. I accept that my accumulated life experiences are different than anyone else who has gone through chemo or is going through it now. I accept that there will be a lot that I learn from these next four months of my life. I accept that I will see life with additional perspectives that I do not now.

Lastly, I accept that I am a good person and that chemo will not make me any less of a good person. Thanks.

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Friday, December 29, 2017

I am sitting here in bed, just gotten home from after a trip to the relatives (with my mask on). I ate some (with my mask off, of course). I’ve already noticed some observations from the past three days since starting chemo.

1. My appetite is nothing like it once was. I eat much smaller portions. I was offered cake this evening for dessert. Normally, I would have accepted the cake. Instead, I refused politely because man oh man it would have tasted good before chemo. But, chemo has a weird way of making things feels weird, like cake (for me, anyway). I even asked the person who made the cake if a piece could be frozen for like four months until I am don with chemo. About the sweetest I can stand are apples, oranges, and other fruits that are natural sugars. I’m not giving cancer anything it can take from me, because it has taken enough as is. Realistically for me, I cannot see myself having anything like pies, cakes, ice cream (the aspartame/Ace-K stuff was sickening to me long before cancer came rearing its head to me). Maybe it is not such a bad idea that pies and such are appetizing to me. Otherwise, I’d be like salivating for it. And there’s no salivation for me ☺. This is actually a blessing in itself, given my propensity for sweets.
2. In three short days since starting chemo, I feel more tired. When family get-togethers took place, I would be up generally up to 11ish at night with no problems. Going through chemo is like going through the physics of time compression. Why so? Because everything seems so strung out that it has slowed down. Not that I am complaining or anything. I could not make it much past 90 minutes and didn’t make it until 8 tonight. On a better note, I have steadfastly refused to isolate myself from everyone and will continue to do so as I go through through all eight rounds of chemo. Does that mean I’m going to put myself in harm’s way if I have a low cell count to the point where I will hurt myself further and my cancer treatment takes much longer to be effective than it would be otherwise? Of course not. I don’t know of anyone in his/her right mind that would do something like that. I slept a lot today, so yea me!
3. I refuse to isolate myself from everyone else. I understand that isolation is a challenge we face in going through chemo. I have kept in contact with the colon cancer group online. I have kept in touch with my autism nonprofit group locally. I am fortunate to have a large support system – locally, regionally, and online. I am grateful and thankful for the cards and well-wishes I have received from others. On the flip side, I feel for anyone who is going through chemo and/or radiation alone without any kind of support base. I have been there as well and understand the struggles and challenges that accompany it. My heart goes out to anyone going through this alone.

We will make it through this. My best years are in front of me. No matter how I may feel on a particular day with chemo or its side effects, my mantra has become what it was like with autism – my best years are in front of me. Nothing can stop me but me. Not death. Not anything else. It’s all about legacy.

January 11, 2018

 I was unable to get much sleep last night from not getting much sleep. This was due in part to resting all day yesterday when I got back from chemo. Then, having the use the restroom a few times from the 5FU going through my system. Side effects have been minimal once again to this point – a tinge of nausea that the cinnamon rolls solved. I still have the gingerbread as the cinnamon rolls mysteriously disappeared – save for two rolls that my stepson and wife ate. Also, I felt a tinge of neuropathy, as cold objects do not respond well to me. I would touch it without gloves (I forgot to wear them) and feel the nerves at the end of my fingers. However, soon thereafter, it would go away. Then, I would touch another cold object and the neuropathy appeared. But within seconds again, it was gone. I got smart and actually asked my grandson, Quinn, for assistance from the refrigerator. I touched cold water accidentally and felt the nerves. Within seconds again, it was gone. If that particular side effect remains that way, I can live with it. Just remember the gloves…the gloves.

 Diarrhea hasn’t been an issue this time. Not going into the details because that would be too much information. Except I will say this. I was proud of myself when I looked and the opposite of diarrhea came out of me. I summoned my wife and told her what happened. Told her it might be a small victory, but a victory for what I went through in Round 1 with diarrhea. She feels it has more to do with my change in diet. I think this is true, because of all the times in the past when I would go eat fast food and greasy items (yes, those Sonic onion rings, I miss you guys and all, but given what I’m going through right now…it is like rain rain go away, come again some other day). Actually, if there was a way to have Sonic onion rings be baked onion rings, I would be all over that…but in total moderation when I got past recovery from each chemo round.

 Although I promised myself that I would put the autism advocacy stuff aside, it doesn’t strain my body of strength or energy or tax my mind. So, I allow myself to do it, just on the bed so I can relax and with reduced amount of time devoted to it while in recovery after chemo. Nice thing about something like autism advocacy work is that I am not restricted to the 10-pound limit I can carry because the only thing I have with me if going someplace is my laptop. But, here at home, I am not carrying anything, so there. It’s like eating all these cinnamon rolls (so the great mystery is solved) because there’s only 1/2 teaspoon of sugar total for the 8 rolls. For the mathematically declined, that comes out to 2 grams total of sugar or 1/4 gram of sugar per cinnamon roll. 1/4 gram of sugar. 1/4 gram of sugar. Combine that with the cinnamon in the recipe, I don’t miss the extra sugar at all. Tastes sweet enough for me. My wife approved of the cinnamon roll she ate, so this will go into the rotation of foods I make when I go into remission.

Cancer is a bad thing, truly bad thing, extremely bad thing in our society. To me, going through chemo and living with cancer is a blessing in itself. A hidden blessing. If I was not diagnosed with cancer in the first place, I would still be doing the fast food thing. I wouldn’t have known about the Southwestern Soup (which everyone loved), the Easy Cinnamon Rolls (which my wife and stepson loved), etc. I would not have realized just how good great food like this is, instead of going to a grocery store and getting a roll of cinnamon rolls with all that extra sugar and glaze on the top of them with all that processed sugar. I wouldn’t have seen the great recipes in the Betty Crocker Breast Cancer (cancer is cancer) and Holly Cregg cookbooks. When I get through my last round of chemo and go into remission, yeah I will be celebrating that I made it into remission. But, I will be celebrating even more that I found great recipes and food from both of these cookbooks that I can continue making. Not only to help protect my body in what I fought for and was victorious over cancer, but to experiment with more foods involving cancer prevention afterward. I will not go as far as saying that cooking is a special interest (borrowing a term from my autism community) of mine but a good, general interest to have.

When I get through Round 2 of chemo and recovery, I’m coming to get you again when Round 3 starts. There is no stopping me now, and there is no place for you to run and hide, cancer. It is like the Terminator series – hasta la vista, baby.

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January 12, 2018

Good morning. I write this today, knowing that within a couple of more days I will feel like myself after Round 2 of chemo. My wife theorized that I had a lot of the fear of the unknown about what was going to happen in the chemo process for Round 1 and that is the reason I was never heard from during so much of my recovery time in Round 1. I think there’s something to be said about fear and the unknown, and that the effect that can have on someone. I am no less human for dealing with fear and the unknown. I am grateful and thankful for getting dealing with the fear and unknown of the chemo process. I had never been through chemo before in my life. I didn’t know what to expect. But, I followed the process (I am a process type of person who thinks a lot) of going through chemo and recovery and did not veer from that one iota. I am someone who believes much in the Benjamin Franklin way of making decisions. Weigh the pros and cons and then determine the course of action based on a lot of things – plus prayer helps greatly, too.

So, going into Round 2, I did not have the fear of the unknown. I knew from Round 1 what side effects I went faced. Round 2 was slightly more tingling of ends of fingers and toes, but not anywhere close to screaming bloody murder at murder or to curse the world away (just kidding, I would not think of doing something like that anyway). I listened to a lot of smooth jazz music (which is what I listen to anyway) in the past couple of days during recovery, which I found helped me. I think people should listen to the kind of music they feel will help them. I can not subscribe to the idea of listening to heavy metal music or hard rock music or something with an extremely powerful beat or major guitar rift while going through chemo and recovery. I can only imagine cancer cells jumping up and down on a stage inside of a person’s body going through chemo and such to Motley Cue, Ratt, Quiet Riot, etc. Ummm… no. Next.

I have been feeling a lot more alert, though somewhat fatigued, as I recover from Round 2. Can’t wait to see what a couple of days from now will be like. I am planning to make French toast over the weekend for the grandkids and all. They like my cooking. Seems like no matter what I make they love my cooking. I guess it is one of those things when you can appease a 7-year old, 11-year old, and 14-year old with food that they WILL ACTUALLY EAT that it is worth it after all. On the other hand, that window cleaner with ammonia affects what I am going through with the 5FU. I do not know what anyone else’s experience was like being around ammonia while having 5FU. Thought I would be going through nausea, until I got away from the stuff and then feelings of nausea went away quickly. So, I don’t recommend using window cleaner with ammonia when going through chemo and recovery.

I have been doing autism advocacy work to a limited degree the past couple of days while going chemo and recovery, which is something I learned from Round 1. I think it is important to get back to doing `something you are passionate about or doing something that you enjoy, provided it is not something that will wear you out and tax your body. I am grateful and thankful for the support I have received from many different people and organizations. I am part of the Chattahooligans, the supporters club of the local Chattanooga Football Club soccer team. These guys have been amazingly supportive of what I am going through with cancer and chemo. They all want me to come back as quickly as possible to help lead the team onto a successful season. The autism community in the Southeast has been very supportive in terms of wanting me to get back to strength in the second half of this year.

If you are reading this and you do not have a local support system, please know this online support group is here to support you. I may have only been involved with this group for a short period of time since right before I started Round 1. But, I will assure anyone that an online support group has immensely strong value and assistance for anyone going through what you or I are going through right now. With the thousands of people who access this group, there should be someone who can relate to your situation. I am grateful for this support group and what how it has helped me during this time so far and in the time to come (even when I am done with my rounds of chemo and ring the bell at the very end after my tank is removed from me for the last time).

You can do this! We can do this!

January 13, 2018

Good morning. I am feeling better than I have the past couple of days. Surprisingly, I have not had to deal with any level of constipation in Round 2. Not sure what I was doing right or whatever, but I am hopeful that continues in the Rounds ahead of me. I feel good at this point that I will be more like myself on Monday (basically the same as Round 1). I am grateful and thankful I followed the directions of the oncology nurses and oncologist to this point. This morning, I chose to do something a little different. I was going to make an omelette with the leftover onions, mushrooms, and peppers (all excellent veggies when going through cancer recovery) I had from the previous couple of days.

Instead, my wife had an even better suggestion. Why not make a frittata and add a half a leftover baked potato (another excellent veggie) from last nights meal? So, I cubed the half potato and added that along with the rest of the veggies and mushrooms into a frying pan with cooking spray on it. Let that go for a couple of minutes. Then added approximately a dozen eggs into the frying pan with the veggies and all. About 20 minutes or so later on medium low heat (and covering the pan the entire time), it was done (with a nice brownish look to it on the bottom of the frittata). Wife loved the frittata and suggested it should go in with the rotation of foods I have been making this Round. I have this suspicion that I will have a full two-week repertoire of foods I will be making by the end of the 8 rounds that I will be carrying forward into the rest of my life (of course, adding other entrees along the way).

Take that, cancer! You might have invaded my body without letting me know about it. However, I refuse to allow you to control my life and put me into a spirit of fear. Cause that fear is gone. As far as I am concerned, you are like the uninvited guest who has decided to claim residence in my body because you thought it might be a good idea to rob things from my body so it could not function. But, I got a surprise for you, cancer. These foods I have made from the cookbooks – I will continue to make them. Along with all the support I continue to receive and prayers and everything else after I go through the 8 rounds of chemo, I am going do everything very much possible to ensure you do not come back and such. I understand that there are no guarantees of this. But for me and my body, you will have a very tough fight on your hands. Yes, I know. So many different kinds of foods are not your friends. You would be just as much wishing I did not consume them because of what they would do to you. But guess what? You don’t have a choice in the matter anymore, now that I have been educating myself about cancer and learning what makes creeps like you go bye bye – never to see you again.

When I get done when chemo and begin going into remission, I plan on enjoying the rest of my life as cancer-free as possible. Cause you know what? When my time comes one day, cancer, I want you to know that you did not have any say how I lived my life after chemo.

January 15, 2018

Had a good weekend, which would have been better if I was not on the anti-nausea meds. But, I will take being on anti-nausea meds if it means that I do not feel sick consistently until when the next round of chemo starts. When I woke up this morning, I felt like I did before chemo started in Round 1. There is something to be said about being done with anti-nausea meds for each round. I met with my oncologist this morning. A couple of things to share with you. If you are reading this and starting Round 1 of chemo, you might want to keep this in mind before starting Round 2. If you are doing Round 2 or beyond and have not considered this idea yet, you may want to do so. This all involves diarrhea issues.

If you find out after Round 1 or whatever when diarrhea has been starting, my oncologist recommends using Imodium AD not on the day of chemo (for fear of stopping up the pipes from doing their thing), but the day before diarrhea is noticeable. Your chemo day may be different than mine, but follow me here. My chemo day is Wednesday. The oncologist highly recommended for me to take Immodium AD first thing on Thursday, even before the anti-nausea med. To take 2 Immodium AD tablets that morning. Then after every time diarrhea occurs, take another Immodium AD tablet. In addition, diarrhea can cause dehydration because of water loss that occurs with dehydration. That is why the oncologist recommended early on right before I started Round 1 to drink 8-10 cups per day. That comes out to roughly 64-80 ounces of water. That may be a lot, if you’re not used to drinking that much water. However, it could make a world of difference by keeping hydrated. I go a minimum of 8 cups of water a day (10 is too much for me). This way, when I have diarrhea, I drink water afterward to hydrate myself.

A hydrated self is good. You want to be sure you are hydrated. Think about those times before you started chemo and felt dehydrated from not drinking water, etc. I am sure those days were not good at all. As important as it to be hydrated daily, it is even more important when going through chemo. You do not want your body screaming at you of its water needs. When you are not feeling good going through chemo and recovery, you want to be sure that you are keeping up with water intake. Before you entered your local Infusion Center, perhaps you were given a plastic (or other) water bottle. Remember what I shared earlier about wearing rubber bands? If you are new to my articles and are wondering why wear rubber bands, here is why. When you are sick, the last thing you need is a lot on your mind. On chemo and recovery days, you want to make things as simple for yourself as possible.

Thus, the rubber bands. My suggestion is to put 8 to 10 rubber bands on one of your wrists. When you are done drinking a cup (8 ounces) of water, you take one of the rubber bands and move it to the other wrist. While the rubber bands may look colorful in a decorative way, using rubber bands to help with knowing how much water you drank is key. If you have not tried it yet, I ask you to consider it now or before your next round of chemo.

My oncologist said that my bloodwork after Round 2 is in the acceptable ranges. Noticed that the red blood cell levels are close to the low end of the acceptable range. While I do not plan on eating 8 hamburgers a day as my oncologist joked about me considering, I plan on increasing my level of iron in my blood to help with red blood cell development in preparation for Round 3 chemo. My wife thinks I should eat liver. The last time I tried liver, it was not a good situation for me. She suggested I try it with ketchup. We will see. I am not someone who is going to readily start eating other foods. Now, if my red blood cell count is low and liver is the only thing that will keep my red blood cell counts up and all, by all means, I will eat liver. Not my preference and such, however.

Platelet counts look good and in the middle of the range. This afternoon, I went to the local Earthfare grocery in the city. For anyone not familiar with Earthfare, I would put it on par with the Whole Foods grocery chain and Trader Joe’s grocery chain – due to products with no GMO (genetically modified organisms), no artificial preservatives, etc. Not someplace I can go on an everyday or weekly basis even before starting chemo. But for the purposes of preparing for each following round of chemo in advance, I will consider going to Earthfare, Whole Foods, etc. during my cancer treatments. I bought a box of gingersnap cookies there this afternoon, which will be used for Round 3 the middle and end of next week (when the nausea feelings return).

Oncologist was happy to know that my experiences with the cold have disappeared after Round 2. Feeling started to amplify the two days after chemo during recovery, then started going away over the weekend. Don’t have them now. Oncologist mentioned there was three stages with the ends of hands and toes. First stage is what I experienced. The was something about a second stage, I forgot. Then the third stage being the pain that other support group members have mentioned in their posts. He said that I would not be able to continue my chemo treatments if I ever got to the third stage. I experienced a water pill bulge in my throat below my chin that made things a little difficult to swallow. That bulge has disappeared, according to my life. Oncologist said that most cancer patients experience that in their legs and not the throat area from his experience.

I am putting aside thinking of Round 3 until Monday of next week, and will use this time to enjoy the many blessings I have in my life from making it through the first two rounds of chemo. Really though, there are no Ancient Chinese Secrets (Calgon saying) about getting through chemo. I think it is all about preparation before each round of chemo, in addition to what each person’s physical and mental makeup was before starting chemo. I feel that there is increased risk for people who have been diagnosed later in life than me (I was 50 when diagnosed), but we are all at risk with chemo drugs anyway. However, to counter that, it is also about following the directions of the oncologist and doing the very best you can through each round of chemo. As always, prayers and positive energy from others help, too.

As others have suggested in the group, always let your oncologist know what is happening with side effects (which is what I did at the oncologist appointment today). My next appointment is with the oncologist is four weeks from today, after Rounds 3 and 4.

Again, going to chill and take it easy and let my body recover some more (although I am back to my normal self again) and just enjoy each and every day until Round 3. Then, I will go into Round 3 like I did with Rounds 1 and 2.

January 21, 2018

Time for Round 3 of chemo to start on Wednesday. I found it very beneficial for me to not even think about colon cancer or what I am going through once I get past recovery from a recent round until Sunday of - chemo week. On one hand, it takes my mind off of me and the things I am going through and allows me to enjoy other things in my life like adult autism advocacy work and much more. On the other hand, I am not sharing much at all with this group about what is taking place. When things are going well after recovery from a previous round, I am unsure what to post about why I am feeling well and such.

While my grandson, Quinn, was away this weekend on a youth group weekend event called Resurrection, he chose to buy me this one sword. I thought it looked – hokey - and all for the $12.00 he paid for it. Then, he went into his reasoning for buying it. He was like - Scott, I wanted you to have this, because of the battles you face with your cancer journey. I want you to fight cancer and beat it. Swell kid. I thanked him for the sword and have it hanging between both boards with the cards on them. I’ll post the picture in a followup. You know, teenagers go through that time in their lives when parents and grandparents and others wonder what will become of them because of their sometimes ill-advised actions (Quinn is no different). I think the teenage years are a time of inconsistency, but you love them anyway.

If you remember from a post a couple of weeks about the cinnamon roll recipe I posted, I had bought a canister of crescent rolls (and thought they were biscuits). I got wise this time and bought THREE canisters of biscuits. Since I made the promise to my wife, April, that I would make a 10-count of cinnamon rolls, I get to have the rest of the rolls for myself (yay rah!). Can not beat that. Also, tomorrow (Monday) will be my cooking prep day as I prepare for Round 3 chemo on Wednesday. The cinnamon rolls got me through safely last time when I was having tinges of nausea. This time around, I will have twice as many cinnamon rolls. Something sweet enough to control nausea, but not so sweet that it is not a good situation for me at all.

I’ll make another batch of Southwestern Soup again for Wednesday. When I had it the last time on first day of chemo, it was really good. By the way, I heard that elderberry syrup is good for increasing the immune system. So, what my wife did was to go the local online farmers market that sells elderberry syrup (then delivers goods on Wednesdays). I took two spoonfuls of the syrup tonight. Not a big fan of elderberry stuff in general, but am a big fan of elderberry syrup especially if it can affect my immune system positively in a large way. I took it tonight, so I can openly admit to giving this a chance to see what happens. After hearing peoples comments about iron supplements (and a lot of people gave different options that worked for them), I chose to go with the Slow FE because I think it will work best for me. I will try that first and then evaluate.

Recap from Round 2:

Commentators – Going into Round 2, Scott looked like he had cancer running around the ring. Scott took the first round, 10-8. Side effects of cancer were a little worse in different ways than in Round 1. However, by the following Monday, he was back to himself and fought brilliantly against cancer. He was more like himself as he was in Round 2. Due to the various side effects that showed up in Round 2 that did not show up in Round 1, we are giving Round 2 to Scott by a score of 10-9. Total score after two rounds, 20-17, Scott. Key to Round 3 for Scott is to continue to do the same things he did in the first two rounds, plus be more prepared organizationally. This will go a long way in Scotts fight against cancer via rounds of chemo and recovery, then remission. Scott has done a great job with resting in bed as much as he has between Wednesday to the following Sunday (5 days), which has allowed him to recover as he has. Scott just needs to keep doing this and be ready to report any increased side effects from the first two rounds and any new side effects. One big factor in his corner is his amazingly positive attitude that he keeps during these times, when chemo wants to keep him down. Even so, he still is amazingly positive. He does not let things like this keep him down at all. He knows what is at stake – another potential 30 years or so in his life. He understands nothing is a given, but he takes what he can.

Tuesday, January 23, 2018

Good morning, everyone. The morning before Round 3 of chemo starts. I am ready to go. Bring it on! All this and I have a sick granddaughter who spend the night on my wife’s and my room last night. I was like, can not have this when I am going through chemo. One thing my wife says about me when each round approaches is that I get something called – self-absorbed into myself. I have tried to understand what this self-absorption is, even after she explained it to me. Either I have a thick skull, or I have a lack of understanding what self-absorption is. Sounds to me that chemo weeks are more about self-preservation (yeah, I think that is what she is trying to get at about me). I see nothing wrong about self-preservation from the standpoint of preserving my own energy during chemo and recovery so I can be like myself before chemo. No shame in that at all.

But self-absorption or whatever she called it? Sounds more like a paper towel absorbing itself of liquid. That does not sound good at all, and makes me think that self-absorption only has one function for people going through colon cancer. I disagree with that idea, because I still make eggs for myself on mornings that I have the tank with me (and will be doing so again later this week). I do other things too, but on a more limited basis. So how does that make me this idea of being – self-absorbed? Sure, I will ask my wife or my grandson or whoever for help opening things, especially when cold., when going through chemo and recovery. I see no shame in that, either. It is one thing if someone does not have help available and needs to do that on his/her own. But in doing so when help is available? I rest my case.

Maybe another thing that chemo and cancer has been teaching me during this time is about the need of rest. I have been resting well during chemo. I will be on my bed the entire time almost, either sleeping, relaxing, or sitting on my bun just typing something into my laptop like this (while listening to my smooth jazz). These activities rejuvenate me during chemo/recovery days because they do not wear me out. I think of it like my iPhone being on restricted power because the light on my screen is dimmed. That is what going through chemo/recovery feels like on those days. I can still answer emails, but they cannot require responses that require a lot of thought. I prefer to keep my mind as dimmed as possible on those days to conserve as much energy as possible to fight cancer with 5FU, etc. No one will ever hear me of me being like the guy who loves to bungee jump.

As much as I am here to support those who are new to colon cancer (cause I was just there a couple of months ago), my hat goes off to those in this group who are going through relapse and are fighting cancer a second time, third time, etc. My prayers and thoughts are with you and your families during this time, especially. I feel it is up to each individual on what to do when relapse occurs on what works best for him or her. I hope to never cross that bridge after going through chemo for my current cancer situation, but will deal with things as they happen.

Lastly, I was talking with a friend of mine who is a senior pastor of a congregation where the GCA Centre for Adult Autism office is in the back room of the congregation. Her husband had pancreatic cancer and turned out that his time came sooner than expected a few years ago. So, she and I and her secretary were all talking. They wanted to know why I carry the positive attitude like I do and why I carry it into each round of chemo. I said to both of them that there are two ways that people can react to a major life event (including cancer). The first way is playing the – woe is me game. This game involves wanting people to feel sorry for a persons situation so much to the degree that it swallows other people into that persons vaccum of pity. I did that when I was diagnosed on the autism spectrum over ten years ago. Also, I made a promise I would never do anything like that again for as long as I lived.

So, when the surgeon who took out two feet of my colon and resectioned the rest of it to that area of my body, I felt relief. Then, when he diagnosed me as Stage 3b and told me what would to come with chemo, I told myself that I would go into whatever would come with an immense positive attitude. Because you see, there is the woe is me game. The second way is playing the positive attitude game. This game involves taking things as they come, making the most of it, and doing so with a positive attitude. You realize and accept that relapse could be possible down the road, but you look at the cancer situation as a distinct possibility that you could go on living another 30 years or so and relapse does not occur at all. Given that this is the first time I am going through chemo, I am looking at this as let us do what we can, make the most of it, use this cancer experience as a learning and teaching opportunity to educate others and in my own life to influence others, and go from there.

I do not take the rest of my life for granted, no matter how many years I have left after going through chemo. One day at a time, one round at a time is my motto. I am grateful and thankful for each day I have on this planet.

May you have a great day today!

Monday, January 29, 2018

Good evening. I have long moved past the events that took place for me at the local Infusion Center on Wednesday last week. I am ready to - butt heads – with cancer again on Wednesday this week. The suspended week came at a good time for me, as the week allowed me to heal up from the first two rounds. I was glad to see the potential take place in my life of what could be after all 8 rounds of chemo are done. Granted, having vivid dreams one right after another about people from my past coming back to do weird things to me was something else. It was just weird to say the least. One person from my past said hi to me, only for someone to hit the back of my vehicle. Another person from my past – totally unrelated – tried to harm me seriously in another dream. And so on and so on. Was the kind of thing people just do not experience on an everyday basis (that is, unless of course someone decided to make bets with a bookie and did not pay the bookie off then that is for another time for that individual).

My wife suggested that these dreams were related totally what was going on with cancer and my cancer journey. The interesting thing about this is that I bounced back up after every dream in the dreams and went on to fight another day. I am not surprised at all about this because this is the kind of person I am. I can assure anyone that I will have the last of cancer before cancer has the last of me. Cancer is going down, down, down. I’s gonna get ya, cause you can hide, you can run, you can do whatever you think you can, but in the end, I’s gonna get you and get you good. In addition to the many things that I will be putting back on my plate after I go into remission, I just added something else as well (amazing how that works). So, I am feeling great about where things are going after ringing the bell sometime in April.

Making my cinnamon rolls tomorrow (cause well the stepson was in the house all day and would not do much of anything). After having a conversation with my wife about how I should not allow my stepson to dictate what I prepare for the next round of chemo, I will do just that – go on with making the cinnamon rolls. I do not know the side effects that will result from round 3. If I had to guestimate (which is about the extent of it), I would venture to guess a lot of the same things in the first two rounds. Nausea, diarrhea, cold sensitivities, etc. The usual culprits and suspects. I put off the Slow FE but will take care of that tomorrow in addition to anything else I need to buy tomorrow. I ended up getting two bags of non-GMO pretzels the early part of last week when I thought Round 3 would be Wednesday last week. I still have both bags for this go around and look forward to mowin’ on some of my favorite snacks.

My wife told me she was making gingerbread cookies, which I think will turn out to be better than the pan of gingerbread I made. Turns out that eating a 3 inch by 3 inch square did not do much for me. If I have gingerbread COOKIES, then I can have cookies for breakfast the second half of this week. While I will be suffering from 5FU and the anti-nausea pills over the course of this upcoming weekend, the gingerbread cookies will hopefully taste better than the pan of gingerbread. Then again, maybe I will have some ginger ale with the gingerbread cookies.

I can tell I have added some weight on during the offweek of chemo I did not plan on anticipating. This is not from the effects of chemo but rather from a healthy appetite for the time being (before I go back on chemo and anti-nausea drugs and do not feel like eating remotely close to what I ate tonight). No regrets though. For what chemo does not do in terms of taking off weight during the next 6 rounds, Weight Watchers can take care of the rest of it when I am ready to go back to WW meetings later this year. Given all this, I feel no shame if I added back on a few pounds between last week and this week, because going through chemo and not wanting to eat as much will take those pounds right back off of me. No shame, since I made the meal this evening and was glad to know my culinary skills have not evaporated in the light of chemo.

The scorecard of my Round 3 will be announced in about two weeks, when I have gone through that round of chemo and recovered from it. Safe journeys, everyone!

Wednesday, January 31, 2018

Round 3 of chemo went off without any hitches this time, which made me very happy (I have a smile on my face as I type this). I am back at home on my bed with the 5FU tank. I am not big on giving nicknames to much of anything. I do not have a nickname for many things, and that includes my car. Maybe I see much of life as being utilitarian in nature or something that giving a nickname to just anything seems not something sensible. For my, April, yes. For my grandkids, yes. For the two kittens, yes. But for a car, a pump distributing 5FU in my port to kill cancer cells and all that – nah. I will be done with the pump in just over two months. Then, I will not remember anything more of the pump except in being thankful and grateful it did what it needed to do to get me on the road to remission. That is fine if people want to give their pumps a nickname. If I am going to give the pump a nickname, I will call it something like Rocky Balboa’s training/sparring partner. And as for the car, well, I am grateful and thankful it takes me where I need to go in good form.

I started to feel something related to cold sensitivities, etc. just before I left the local Infusion Center with regard to swallowing. Nothing major at this time, just a little minor here and there. Will monitor this to see what happens in the next four days or so, and then go from there. I have been following on a couple of colon cancer FB groups about various individuals and the experiences they face in their challenges against cancer. As much as people feel inspired by what I have written (and thanks for the comments), I return to same to everyone who have been brave and have put himself/herself out there. I get it that people have mentioned to me about how brave I must have been when it came to self-advocating for myself from an autism standpoint. I just got an email this morning from an autism foundation in my state who wants to know if I can speak with them because of all these young individuals who are on the autism spectrum and have had no access whatsoever to someone like me talking with them and possibly serving as a mentor later this year when I have gone into remission. To me, it has long been about putting myself out there and pushing my comfort zone as far out as I can. But I am used to it.

Likewise, I see strong similarities with my cancer journey, too. While many people may choose to not share anything because of it being a private journey, I respect that very much. I feel people should do whatever it is with their cancer journeys that they do. I have chosen to make my public through blogs, etc. because I want to share my story with others (like I have with autism). I want others who are going through a cancer journey for the first time to see what my journey is like (although my experience is that – only one experience and not the experience of anyone else). My story has been about hope and opportunity, and that is the story that I wish to convey in the autism and cancer communities.

I feel very thankful, grateful, and blessed today. More than I did in Rounds 1 and 2. Not sure why, because I should just as thankful and grateful after each round of chemo. Maybe I am just settled into each round and have a good idea of what to expect now when I am at the Infusion Center. While I am respectful of the cancer journey with each individual reading this, I want to share what I am thankful and grateful with you.

1. I am grateful and thankful to make it through Round 3 without a hitch and feel very good (knowing what is about to take place over the next few days, starting tomorrow)
2. I am grateful and thankful that my pump will be removed on Friday this week, like it has been removed on the Fridays after each round of chemo.
3. I am grateful and thankful that I will have 3 three less rounds of chemo and only 5 more rounds to go
4. I am grateful and thankful to my oncology doctor and to the oncology nurses for the care they have provided me
5. I am thankful and grateful for this online support group, as well as the in-person support group I attend monthly while going through remission
6. I am grateful and thankful for all the experiences that people share about their cancer journeys, regardless if it is preparing for Round 1 or someplace during a round of chemo or the individual who is going into remission or the person who may be going through chemo or radiation a second or more time. I learn from the journeys of all and appreciate them greatly.
7. I am grateful and thankful that I have been choosing to give myself as much rest as possible, especially on chemo and recovery days and in doing a better job of listening to my body and how it is feeling. I am grateful and thankful that I am taking my cancer journey seriously.
8. I am grateful and thankful for the sense of humor I have been able to use as I go through the rounds of chemo and have a positive attitude during this journey
9. Since I wish to be respectful of various religions, spiritualties, and whatnot that individuals in this group may or may not practice, I will just say that I am grateful and thankful for a power and force much greater out there for me that has been a guide for me during this my cancer journey.
10. I am grateful and thankful for everyone who is waiting for me to get through all rounds of chemo then go into remission to ask for my adult autism advocacy assistance in the second half of the year, and for being patient waiting for me in the process

No matter what our challenges may be in life (e.g. a cancer journey or other things), cultivating a spirit of thankfulness and gratefulness can often go a long way in helping someone deal with a challenge. That was true when I was diagnosed on the autism spectrum (where there is no known medical cure, unlike cancer) and in other distinct times in my life.

Have a great day – Scott

February 2, 2018

Good morning. This round of chemo has been a tremendous blessing in disguise. I keep going back to where I was told by the oncology nurses that going through chemo in Round 3 would be like being hit by a ton of bricks and such. I have not felt as such. Sure, I felt the cold sensitivities some (I made sure that my grandkids got things out of the fridge and I will continue following that in the rounds to come). But nothing this round with regard to diarrhea or feeling stopped up inside of me (the c word) that no stools would result. A tinge of nausea – yes – and that is what the cinnamon rolls were for to help combat that and has been very effective in helping me. My wife, April, I must be some modern marvel miracle, but I stopped her short of that. I do not feel I am a miracle although I have healed fast from that accidents and such. I have had a strong immune system. I admit those things. But to call me a modern marvel miracle for something like this? Maybe I will leave that to Dr. Oz (by the way, days after I baked the cinnamon rolls they still smell good this morning) or other medical professionals.

I have a hard time explaining the above and how this is the best I felt after going through the first three rounds of chemo. I cannot explain how I slept soundly for seven hours straight last night on top of the about six hours the night before – when in the first two rounds I struggled to sleep in a couple hour increments when having the 5FU tank attached to my port. I sleep pretty well without the tank before I started chemo, and for something like last night to sleep seven hours straight? I know some people will read this and say, nah, no way, can not be. I have a hard time sleeping seven hours straight even before I started chemo. Like, I say, I have no answers to why I have had not had the nearly the challenges this round when I had more of them in the first two rounds.

One thing that April suggested to me was taking anti-diarrhea tablets the first full day after I come back from having the 5FU tank installed. This was after Rounds 1 and 2, when the bathroom became my newest friend and I would often be in there doing what I needed to do to with diarrhea. But after round 2, I visited the oncologist who suggested it and then April suggested to me. Or what it April suggested it first and then the oncologist? I really do not know and care not to think who said what first, otherwise this becomes like one of Dante’s comedies or something. Anyway, someone suggested that I take anti-diarrhea tablets the first morning after I have the 5FU tank installed into my port – then follow the directions accordingly if more diarrhea episodes take place.

If you are reading this and thinking, this sounds like a great idea and if it can work for Scott maybe it can work for me, you might want to consider talking with your oncologist first. Like others have said in this group, an experience one person will have with going with the various rounds of chemo and radiation will be different than other people. My experience may be different than many others with the discovery I made about taking anti-diarrhea tablets. All I can say is this from my own personal experience – my butt is thanking me for not having to take it after me to the restroom as much as I did in Rounds 1 and 2. A sore butt is a tired butt and at times a painful butt that needs to be cooled off by sitting down. I am glad that has not been my fate on Round 3. **Note: Do not follow my advice on what I am doing. Check with your oncologist first to see if what if what I am doing is something you should consider doing. I can imagine it would be easy to look at someone at myself who is having success in Round 3 and think to yourself that you should be doing this.** Should you choose to do what I am doing in Round 3 and your results are far from my results, then my disclaimer is that I am not at fault for what you chose to do without consulting your oncologist. Fair enough.

I will stop here and look forward to getting the pump removed from my port in about 2 hours or so. Have a great day!

Thursday, February 8, 2018

Good morning. It has been a most interesting week with the effects of 5FU (sometimes, admittedly, I want to take the 5 off of that and shout expletives like I did yesterday morning by telling cancer where it can go). Been one week since I was given 5FU at the Infusion Center and started feeling mouth sores (or what will soon be mouth sores, I am sure) for the first time after three rounds. They are irritating but not impossible to live with at all. I am thinking of this as The Process of going through the eight rounds of chemo and realizing the possibilities of how many more years I could have to live. I mean, after all, if someone reported in the informal survey I conducted on colon cancer patients and survivors of going cancer free for at least 30 years, then I think why cannot I also be someone like that?

Yesterday morning was about cancer trying to kill me again. Three weeks ago during an off week, people came back from my past only for them all trying to kill me. So, I gave cancer an FU and went on with my life. Yesterday, I had this dream that I was driving a bus full of people and I must have been up like 1,000-1,500 feet (this is only a wild guess at best) and the next thing I know, I thought I had killed everyone on the bus because I was feeling very exhausted and tired. But, a strange thing happened. Sure, everyone fell all the way down to the ground. But, no one died or had any injuries – including me. Yet, I wanted to cry because of what happened. Then, I woke up, and realized instantly that was another instance of cancer trying to kill me. Then, I went into full expletive mode with FUs, etc. and told cancer where it could go and that I have already defeated you, cancer. Then, I went on with my day.

That is what I will do each and every time a dream like this happens. Tell cancer where it can go when I wake up from the dream and continue on with my day. Cancer does not have me. I have cancer where I want it. Cancer cannot steal my mind or the things I use to be a positive agent of change in the lives of others. Cancer does not have a choice in this matter. Cancer cannot get in the way of my support network, both online and in-person. Cancer cannot get in the way of the adult autism conference that I am coordinating. I have spaced things out for the conference to account for the rounds of chemo and recovery from each round. I suppose you were not thinking of that, cancer. I am stronger, much stronger than cancer, and cancer does not stand a chance against me. Not a whiff. Cancer had its opportunity when I was diagnosed Stage 3b. Cancer wants to remind me through these vivid dreams about how much of an effect it wants to have on my life. But you know what cancer? I might feel the side effects from dealing with you, but this is for a season only. Nothing more.

Yes, I was wise to choose to take much off my plate when going into my treatments. Otherwise, I would feel a lot more exhausted and fatigued than I do. Being the kind of person who wants to accomplish much, I began to understand and realize that there is a time and place for everything and a time for each season. This season is about rest and getting a lot of rest for what will take place the second half of this year, months after I have started the remission process and begun the process of feeling like myself prior to colon cancer surgery last year. I realize and understand that it may not be until the end of this year when I start to feel like I have arrived like I once was. And that is fine. It is like coming back from a serious injury. You know you still go on living life daily, but you do not rush it too early and do more than you can. You take it in stages and go on to the next stage after being satisfied in the current stage.

I think a lot of this has to do with mindfulness, thankfulness, and gratitude. Being mindful that things are not going to be the way they are in going through treatment for colon cancer. That from time to time that chemo fog will set in my mind and that I am not always going to remember something. Which is ok, because I was not always remembering things before starting treatments for colon cancer. Being thankful that finally I listened to my wife, April, when she told me how much I needed to get a colonoscopy scan during the course of last year. Thankful that I got the scan, resection, port installed, and am going through chemo. Why be thankful that I am going through chemo? Because it could give me another 30 years to live after I go into remission. I am the kind of person to avoid putting drugs into my system. I do not like how drugs alter things in my body and such. I could have gone the natural route and all. But, I chose to go with chemo, and it was my choice. Being grateful because I am hopeful that this will be the only time that I go through chemo in my life. Grateful in that chemo is a medical cure for cancer (unlike autism, which chemo cannot have any effect).

The 5FU had an effect on sores in the rectal area when dropping stools into the toilet for about a week after round 3. It has been a good 24 hours since I last saw blood, so I think it is fair to say now that it take a week after starting 5FU in the Infusion Center for any blood to stop from sores that form down there. I realize and understand that this is something I will need to deal with, even as April got me a few items to deal with that.

I will stop here for now. Please try to have a good day, even if you feel the side effects from what you are experiencing.

Sunday, February 11, 2018

I am just relaxing today, after having a plateful of grilled onions, mushrooms, lo mein noodles, and lean chicken. Think I am starting to see why the Chinese were often characterized as being – skinny people. What I have been doing is pretty good, actually. Yeah, I have been eating to keep up my weight from the times I do not eat much from going through chemo and recovery. Excited at the prospects of going through Round 4 (of 8) on Wednesday. Side effects or none, I will keep moving forward one day at a time, one round at a time. Hard to believe that I will be at the mountaintop after completing this round and then through recovery. That will mean four rounds less of chemo to go with only four rounds to go. That excites very much, because I know the end will be near in about two months or so.

When I reflect on this journey that started last year and my first round was right after Christmas Day, I thought to myself how four months was a temporal amount of time and that I would be ok. Now that time has been cut in half to two months. We got this! I do not like the cancer dreams I have had last week and a good two or three weeks before that. But it is interesting to note that once I have had them that I do not have them again until a week after the next round. I have done the best I could to think deeply pleasurable thoughts that have nothing to do with chemo but what was in the life I share with my life before chemo. I am hopeful those thoughts (not the chemo ones) become reality again one day.

As I have mentioned, life is all about having hope and moving forward. Which reminds me about the tile of my future minibook and such. I asked people not associated with anything colon cancer-related what they thought of the title – Marching Forward. Too many negative ideas they told me. So, one person came up with the title of Moving Forward, which I like better than Marching Forward. Moving Forward is pretty clear in its meaning. Two words. Simple to understand. People understand what moving forward means. So, Moving Forward it is.

I consider myself fortunate every day that I am on the face of this planet. An opportunity to make a difference in the life of someone else. An opportunity to give back to others. An opportunity to live and make the most of every day – sunny, rainy, foggy, and in other ways. An opportunity to be grateful and thankful for knowing I do not feel the side effects of chemo/5FU every day. An opportunity of being grateful and thankful I almost feel like myself pre-chemo towards the end of the end of a two-week cycle before going into the Infusion Center and starting the process of getting sick and recovering all over again. The opportunity of knowing I am that much closer to being done with the eight rounds of chemo – one day closer, one round closer.

Maybe I am too much a social idealist and not enough of a realist to think what I am going through with the rounds of chemo. Yes, I do not know a lot of emotion when going through rounds of chemo and then through recovery. As much as I know others would like to take my pain from me, I know and acknowledge that I go on this journey while everyone else is supporting me in the process. I come across as being fearless because I have nothing to lose in going through chemo. Nothing. If I go through chemo and am successful, I lose nothing. If I go through chemo and die, I lose nothing. I just die knowing that I went through my last round of chemo and do not go through it anymore. I come across as being very positive, even though the battle against cancer is constantly being waged. I feel the side effects, and then some days are better than others. Same days I am not so sure at all. But though it all, I remind myself to be positive and to remain positive because I know what the consequences of the alternative - by not being positive. So if anyone wants to know why I have a positive vibe in going through this battle, now you know why. Negativity is not a word in my vocabulary on this journey, because I will not allow it to engulf me, swallow me, or anything else that is a vacuum to take me away from the person I am.

It is very nice to know I keep racking up commitments for projects after a few months I go into remission and into the second half of this year. Usually, when people are asking for me to help them left and right, I am like I have too much on my plate. Now, that I just have the conference I am coordinating on my plate (and that will be in July), I can focus on putting more on my plate in August going forward. This is actually a good feeling and an indication that my life will be returning back to what it was pre-chemo. That is why I agreed with myself (otherwise known as giving myself permission and negotiating with myself)

Round 3

Ok. Cancer gets a point for causing Scott to leave early a week from the Infusion Center due to the stomach virus about three weeks ago. While Scott complained about not being allowed to continue, cancer got away with one week while Scott had to wait until going through Round 3. With the additional point awarded to cancer, the judges gave Round 3 to Scott anyway by a score of 10-9. Scott headed off diarrhea by a day by taking anti-diarrhea tablets the morning after chemo started. This caused diarrhea to start on Friday instead. Side effects reared its ugly head, when mouth sores started happening the beginning of the week after chemo and lasted much of the week. Scott was far from happy about it, and wondered at times what to do. Scott found macaroni and cheese to be very helpful during this time. Easy to eat and swallow, with no additional flare-up of sores. During the middle of last week, Scott cursed cancer and let out a tirade of expletives that was a sight to behold (or not). The judges did not penalize Scott any points for the tirade in going after his opponent, a cross between Clubber Lang, Ivan Drago, and Mason - The Line – Dixon. Scott has gained additional supporters outside the colon cancer arena in his fight against cancer, and there is no quit in Scott. Every time that cancer seems to throw punches at Scott and where the side effects from the punches affect Scott at first and with hallucinogenic dreams that try to kill him, Scott bounces back and feels almost like himself pre-cancer. Can Scott continue the trend in Round 4? The 8 Ball says Absolutely.

The response from Scott? Bring it on, bring it on – because I am waiting for you, cancer. I respect you, but you have no chance against me. None. Every time you throw punches at me, knock me down through hallucinogenic nightmarish dreams to try and kill me, use side effects to try and destroy me, and make my life miserable, I come out wanting to put YOU away that much more. Try as you might, rear your ugly head at me, or whatever, I continue to fight and fight strong.

Cue to Rocky theme, Gonna Fly Now, and Sirius from the Alan Parsons Project.

After three rounds, the score of this boxing match is Scott 30, Cancer 26.

Round 4 of 8 starts on Wednesday this week. Stay tuned! 12,000 words so far. Hard to believe. Thank you for ring those words.

Wednesday, February 14, 2018

Happy Valentine’s Day to everyone. I have been resting on my bed a few hours, after coming back from the Infusion Center earlier this afternoon. I am ecstatic that I have four less trips to the Infusion Center to go (save for having the tank taken out of the port on Friday this week). Why be ecstatic over something like this? I will be half way done, at the mountaintop with no higher to go to reach the halfway point. I started feeling my throat constrict a little bit this afternoon from drinking room temperature water. I will be gauging this very carefully over the course of the next couple of weeks.

Also, used the generic equivalent of Preparation H that includes the soothing gel (which would other be Anusol, which the pharmacist told me I would need to get a prescription from the oncologist). If you are going to buy the generic equivalent, you will want something like below (see picture). My wife did the supposed dirty deed this morning. Remember to take a shower first if at all possible to get the area as clean as possible. You do not want the person helping you to have a weird feeling on the plastic glove that he or she is using to get that area - down under (no offense to Australians).

In lieu of the cinnamon rolls this time, I decided to go to the local grocery store to pick up muffins for anti-nausea stuff in the mornings – starting with tomorrow. I still have the box of gingersnap cookies, which I will use in collaboration with the muffins. That way, I get ginger (a popular ingredient to combat nausea) in my system and a delicious taste of both cranberry orange and blueberry muffins. I looked at the muffins and they are not loaded with sugar on the muffin tops like the ones I bought at the local EarthFare a few weeks ago just before Round 3. I do subscribe to the idea of minimizing sugar when going through chemo and recovery if at all possible. I am not going to make sugar nonexistent entirely, but I feel I do a great job of minimizing it during these times.

I am holding up pretty well, although I think I dozed off in the Infusion Center on a few occasions. I do not want to begin thinking what other cancer patients must be thinking if they heard me snore. I suppose I would get a mulligan for that, because they are there to get their cancer treatments. One of the oncology nurses noticed I was watching highlights of the 1997 Masters golf tournament on the TV network at the Center and told me of her experiences of being at the Masters. I like the TVs they have there. Each chair has one, and I can swivel the TV in whatever direction and up and down and all around. Pretty cool. For the first three rounds, I listened to the Comedy Channel and that was pretty good. However, there are so many times that I can stand listening to That 70’s Show and Scrubs (reruns for both) before I tire of that. So, I thought to listen to sports when I was by myself. Had to get my sports fix this morning, even if it was a Masters golf tournament over 20 years old.

A few people from a local chapter of the American Cancer Society came by my chair and told me about ACS and what it had to do. Told them I was thinking of creating an in-person support group for those going into mediation, etc. They all thought it was a good idea and wanted to let me know when it would be starting so I could let them know at that time. I missed the in-person support group at the local hospital for February and will for March before going in April.

I will stop here for now and rest some more.

Wednesday, February 21, 2018

Feeling good for one that I have turned the corner on Round 4 (of 8) and look forward to getting through Rounds 5-8 before I ring the bell after having my pump removed in Round 8. So thankful the side effects I faced this round with being in pain the past few days have subsided and essentially are nonexistent now. Cancer thought it had me pretty good the past few days, but cancer does not have me. I may have to go to hell and back in dealing with side effects but I look at it this way. Short term pain for long term gain, so to me it is so worth going through the enormity of the side effects for the opportunity to live through another 25 to 30 years, perhaps longer. Another good thing is that I did not have the bad nightmarish dreams that I had after getting done in Rounds 2 and 3. Cancer does not have anything on me, period. And it will not either. Hasta la vista, cancer. I respect you for the numerous people who died from you. But you will not take my life, period.

Just a very short post today, but wanted to let everyone know I made it through the side effects in Round 4 and ready to continue kicking cancer’s butt forevermore.

Sunday, February 25, 2018

I am chillaxin’ this afternoon and enjoying time with family. I am grateful and thankful that I am not starting afresh with chemo again. Four rounds less of chemo to go with four more rounds of chemo to go – with Round 5 coming up on Tuesday. I have come so far, and there is no turning back whatsoever. If I was able to get through the first four rounds of chemo, then I think the second four rounds of chemo will go appropriately. April and I are going to do our best to ward off pain down under in advance.

When I started my first round of chemo around 2 months ago, how was I to think at the time that I would make it through the first half of this? Hard to believe. But, I did it, and I am ready to go for the last four rounds of chemo. No one stopped me in the first four rounds. No one is going to stop me in the last four rounds either. Very thankful to be where I am through all of this. I am looking so forward to getting through all of this, but yes I know. One round at a time, one day at a time. That is how I approached the first four rounds, and will be how I approach the last four rounds. I am ready to go Tuesday….bring it.

Round 4 – from the judges

Now that Scott’s battle with cancer has reached its halfway point in terms of treatment, let’s see how how Round 4 went. The mouth sores that seemed to exist in Round 3 were not prevalent in Round 4. However, the pain from Down Under (sorry, Australia, do not take it the wrong way) was quite painful but diminished about a week after starting Round 4. Nevertheless, Scott and his wife, April, are taking precautions about pain by doing the following: Taking anti-diarrheal tablets, taking stool softener, and a pain relaxer during the days when pain would be shooting out the rear. So about a four or five-day stretch. Will see how things go. Scott’s butt lips were very swollen, which enabled for restriction for what is usually done. We’re hoping that with this battle that things will go better. Also, keeping in mind Witch Hazel as well. Scott will be relaxing on the bed a lot the next four to five days after starting chemo. Other than that, some cold sensitivities, tinges of nausea, the usual suspects. Other than the pain, nothing much really stood out for Round 4.

First three rounds: Scott 30, Cancer 26. Judges score Round 4 slightly in favor of Scott, 10-9. After four rounds, Scott 40, Cancer 35. With this eight round heavyweight boxing match, it is half over already and Scott is holding steady. Will see what happens in the second half of this match.

Thursday, March 1, 2018

It is March today. Yay! Next month will be my last round of Folfox and chemo. It is nice to finally see how things are going. Am very blessed that I do not feel any – shards of glass – symbolically from beneath me. These are not real shards of glass, but the feeling of something like that. I am experimenting with something this round. All I know it has to do something with a clear, squirt bottle (think ketchup or mustard bottle in a restaurant), towels (plenty of them), liquid baby soap (Johnson & Johnson or equivalent), and warm water. In theory, this is how things should work (and we will see if in fact it does – so far this morning yes but not taking anything for granted especially with what I went through in round 4 (last round).

This may be a little TMI for some people but do not take it personally. This could very well help not just one person but at least a few people who are in the same situation as me that are part of this group. First things first. Make sure you have a stack of towels nearby you. Fill up the spray bottle with warm water. Put liquid baby soap in it. When done stooling on the toilet, use bottle and spray down in the front of you down there. Then spray the area that came out of you. Then take a towel and gently pat all areas where you sprayed. You don’t want to treat the towel like toilet paper. If towel is well brown or getting there, spray yourself down there both sides again, then pat down again with another towel. This solves two problems. The first is blood. In previous rounds (1-3), I would use toilet paper after the side effects kicked in down there. The problem is I was pressing on hemorrhoids and blood would appear on toilet paper. Do not want to do that. The second is you feel much better about yourself. There is no worse feeling than feeling something similar to shards of glass coming out of you. I felt that in previous rounds that it would make me cry uncontrollably, curse, and things I will not even disclose. By patting myself down and doing the things I described above, I felt better about myself after the trip to the bathroom. I did not have to rest my butt on a cool bed for 10-15 minutes to cool it off before I would do anything with my bottom. I did not have to wait until the pain would go away.

Of course, I am not taking anything for granted. I am just grateful and thankful this morning that I did not have a sensation similar to shards of glass coming out of me. Psychologically, that is huge. Last round, I took a coat into the bathroom with me and clamped down on it with my teeth to absorb whatever pain was going through me. I did it again this morning, but did not feel the pain. Again, I do not take any of this for granted and am thankful and grateful I did not feel any pain this morning.

Other adjustments I made as well, and this is what is working for me. I noticed that the sensations would start two days after I started a round of chemo. So the day AFTER I started this round of chemo, I began to take two anti-diarrheal tablets first thing in the morning just for that day. Along with that, I took Hydrocodone-Acetamin at the same time (to relieve pain). An hour later, I took two tablets of stool softener (which I didn’t take any of the previous rounds). As long as I didn’t have diarrhea, I didn’t take any additional anti-diarrheal stuff. But, I did continue taking the Hydro every four to six hours. I took stool softerner when needed. Then today, the second day after chemo started, I took stool softener and the Hydro. But did not take any anti-diarrheal tablets until diarrhea started kicking in. So it is a balancing act between the anti-diarrheal tablets and the stool softener tablets because they tend to work in reverse of each other.

About to have pump removed out of my port in an hour or two, so that is always great. Just will keep monitoring every time I use restroom and make adjustments. Thanks.

Thursday, March 15, 2018

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Hello and good afternoon. I am long overdue for a blog post, so here goes. I just had the tank removed from my port for round 6, so just two more rounds. My wife reminded me that chemo for stage 2 involves only six rounds (for those who wanted to pursue chemo), which means I would have been done today and ringing the bell if maybe I would have been diagnosed earlier than I was last year. But that is ok. I am still very young, have nothing like diabetes or other health conditions to deal with and all. So, I can not complain in the least bit. I figure, let us get through the side effects for round 6 then play it again Sam for rounds 7 and 8. Can not ask for more than that.

It is hard for me to actually believe that I am 75% done (six of eight rounds), as I type this. I think back to late December right after Christmas day (December 25) when I started round 1 and having no clue what I was going to get myself into or anything else. A friend of mine who picked me up from the local Infusion Center on Tuesday this week after the tank was put into my port told me that I should be awarded a graduate degree on everything I have been through with my colon cancer journey. I said, “Don’t I wish?” LOL.

I have agreed to what my wife suggested that I drink this auspiciously looking mixture of kale, greens, beets, etc. and do so once per day for all the antioxidants I can get in one glass of whatever it is called each day. Come to think of it, I would not have remotely drink anything close to it with a 39 ½ foot pole (Dr. Seuss reference about The Grinch). But, given what I have been through and my immense desire to make the changes necessary to live on as long as I can years after chemo, I will drink an auspiciously looking mixture each day for the rest of my life if needed. If it will help having something like honey or something in it to make things sweeter, add the honey and make it sweeter. Like I said, I would not have come near to drinking anything like that in the past. But to give me super antioxidants with one glass per day, I will do it to prolong my life.

Going through this cancer journey has shown me a lot already and will show me that much more going forward into my life. Yes, I realize I could eat a lot of the same things I did. But, nothing is guaranteed. The remaining amount of time in our lives is not guaranteed. I will be slimming down via Weight Watchers sometime this summer and carry that forward into the fall, etc. Mindfulness will play a large part of the following chapters of my life regarding food. Before I started my colon cancer journey, I had three feet of colon. So, I was an admitted foodie and went to all kinds of buffets. Now, I have one foot and that is it. No more. So, as I started eating smaller portion more times of the day. When I am done with this chapter of my journey, I will continue eating smaller portions. I do not want an episode of “blowing up” a restroom or to leave anything seen.

I do not know what will come of my body or anything else so I will continue to pay close attention to this group for guidance once I go into remission. I was talking with a nine-year survivor of a different type of cancer a few weeks ago. I asked her about she was able to move into remission without thinking about what she went through and such. She told me pretty much that “the time you’re going through right now will be like a blip many years later because you will not be thinking about it all the time”. That made me feel much better. I guess it is one of those things when something first happens, you think about it a lot because it is recent. But, as time goes by, you think about it less and less and less until one day it only comes back to your mind because someone brought it up in conversation. But, you never forget about it because it happened to you.

The closest example I can think of is my living as an autistic adult. Over ten years ago, I was diagnosed with classic autism (I did not speak until the age of four). I thought about it a lot at first after the diagnosis and subsequent adjustments I made. Then, as time went on in my life, I thought about being on the autism spectrum a lot less as I became the person I am today. In the same vein, sounds like that is what colon cancer will be like for me in the future chapters of my life. I am already looking forward to working with the Northwest Georgia Healthcare Partnership later this year to speak about colon cancer and pancreatic cancer (NGHP wanted me to focus on two types of cancers to talk on) before groups. I look forward to sharing as much of my experiences with them as I have about this group.

Just got to make it through the side effects now, especially from the oxaliplatin. But for now, I am at calm and rest and know I will make it through the next two rounds. I was at the top of the mountain two rounds ago after round 4. I am halfway down the mountain after round 6 and am starting to see the finish line. There is no stopping me, cancer. Hasta la vista, baby!

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Monday, March 19, 2018

Resting up today. Past recovery from Round 6 and should be past side effects in a couple of days. Then, Round 7 is next week and Round 8 (and last round) is two weeks after that. We got this! The potassium pills have been helping a LOT. Have been taking it once a day in the morning in the middle of when I am eating breakfast. Was told that it is best to take with food. I have been drinking 8 full ounces of water with the med, and my wife suggested that I only needed to take 4. Actually, until this morning, I had been drinking 8 full ounces with the med, and then another 8 ounces after I got done eating for a total of 16 ounces. I have been doing good with water intake, getting anywhere from 8-10 cups of water a day (64 ounces to 80 ounces). I push myself whenever needed with getting water in my system. The great thing about this round is that I do not have any spasms coming out of the rectal area. While I may feel the shards of glass but only at the beginning when I use the restroom,

Very excited about getting past this stage in my life. Will be working with hiking orgs and groups in my local area this summer to see what kind of hiking opportunities exist. As we all know (and the research is not like something that is strange to most people even if they do not know the total numbers), people in general do not get enough exercise. I am looking to change that after I go into remission and begin taking on a new hobby – hiking. The autistic population, especially, is notorious for not getting enough exercise. I was told that five days a week at a minimum of 30 minutes a day is what will be needed for me. And, I will abide by that, even if it means I exercise first thing in the morning after dropping the grandkids off at school during the month of May. My life is on the line, even after going through treatments for colon cancer. I may have done what was needed after going through treatments,

Yes, I have had a very positive attitude going through the treatments, which cannot be denied in the least bit. Yes, I have an amazing support system (probably in the neighborhood of hundreds of people) who have been praying for me and throwing support my way. I do not deny that either. I wish I knew how to repay everyone back after I go into remission, because I feel like I owe so much to everyone. How does one thank everyone for their support during this time in my life? I do not have an answer to that, except that the autism and disability communities need me after I go into remission and start to work on becoming like myself like I was pre-chemo but with less weight. After all, if one of my favorite Chicago Cubs players, Kyle Schwarber, can lose 30 pounds in the offseason, then I can do it as well and make my chances for recurrence become much less.

I feel like this cancer journey has become a life changer for me. Not only will I feel happier when I go through “the other side” into remission and begin working on making my life better than it has been to date, but I see and envision a fire that is burning in me that wants to reach out to a lot of people even more so than I have already with adult autism advocacy. I am not a “transcendent” type of figurehead or person but I know at some future point that I want to influence a lot more people than I have to date. I do not seek glory or fame. What that means, I do not know. I just know that the future will be very interesting for my wife, April, and me in the direction it goes. It has been often said that people find a second career in their 50s. I have a feeling this will be true for me, because I think there are doors of opportunity awaiting me that I do not even know about yet at this time and may not know for a couple of years, probably.

May everyone have a great day today!