

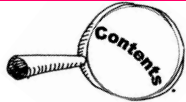


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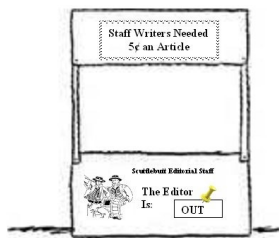


February 6, 2017

Volume-2, Issue-3



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Editorial Comment

Since my last newsletter was published, January 23, 2017, my thoughts of dialysis and my chemo treatments has pretty much taken up all of my time; this is not necessary an odd thing, when you consider that I have dialysis three times each week and chemo every other week. Actually I will be changing my dialysis treatments to two days a week, of course since the 23rd of January I have missed two treatment days, the first on a Saturday a health thing,



and the second on a Thursday a weather situation.

Of course, looking back at the past two weeks I have been pretty occupied in working out my chemo schedule, the schedule was trying to give me two weeks vacation, or better described, three weeks of no chemo treatment, which I did not agree with so I more or less haunted the scheduling center at the Rocky Mountain Cancer Center. Well to shorten this little tale, I fixed my schedule, so as it

stands, I have eight more weeks of treatment or let say 4 treatment days, plus 4 periods of 46 hours of pump time. Therefore, at the end of March, I will be meeting with the Oncologist to see what our next phase of treatment will consist of, and one thing I do know it will all start with another PETT Scan...then whatever.

I will have to admit, I have been suffering from the side effects of the chemo treatment has been a little more troublesome than it has been since I began receiving treatments. Some of the side effects began from the beginning but has not been like it is today. The effect of neuropathy for me is the cold on my hands was pretty painful, it was breaking the skin around my nails, something that does interfere with my typing of this newsletter, my fingers are numb and painful, this also effects my throat, mouth, and tongue throughout the day, I also have a rough dry cough and a tightening of my chest, including jaw spasm, and then of course there is the occasional bout of diarrhea. My eyes also are suffering more now with an irritation and watering that seems to stick with me. Well there are more side effect but these two bother me the most.

Now back to dialysis, as you might remember I mentioned that I would be changing my dialysis treatment, from the current three a week too two sessions a week. This means I will only be having my treatments on Tuesday and Saturday, which gives me two days off between Saturday and Tuesday, and three days off between Tuesday and Saturday.

Well the two weeks were not wasted, I did visit the Lafayette Kidney Center and provided copies of the newsletter (January 23, 2017), plus I had a chance to say hello to everyone, sometimes it is painful not seeing people you enjoy being around. Another good thing that happened, Doug and I had a chance to enjoy breakfast together at the Off Campus Café on the 1st of February. Hopefully, if my health holds up, Doug and I will enjoy more times to share a good banquet.



Rocky Mountain Cancer Center of Boulder,
 Lafayette and Loughmont,
 Kidney Center of Lafayette and Loughmont,



A Tale of Woe (Caregiver –Dialysis Clinic)

I was thinking of my beginning in the dialysis community and thought that it would, if I write it right, be a good story to share. So being the person I am, always searching for a story to tell, admittedly a good story or stories are few and far between; and that being the case, I have to grab one when it comes along. So having built that up for a failure, I will continue with my memories of my first venture into the dialysis treatment community; yes this story is a continuation of a story that I started back in **Volume 2, Issue 1, January 9, 2017, Caregiver:**

Lets pick up this story where I left off in Volume 2, Issue 1, after I had left the hospital and went home in Lafayette, with my future pretty much mapped out for me, not that I had much say about what it would be. I had been instructed to report to the Dialysis Clinic in Boulder the next day for dialysis treatments. Now to clarify this a little, I have to say I had had two or three dialysis sessions in the hospitable, and I can tell you it is mostly a blank slate, filled with noise and some visitors...anyway let me begin, the actual date is not a firm thing in my mind but lets say it all began during the first part of December of 2003 –

Picture if you will, a dialysis clinic, a place of hustle and bustle, chairs occupied with patients and the sound of the machines filling the air, as it goes about its business, the staff (PCT) quickly go about their individual duties answering to the machines and their alarms, and yes let us not forget the needs of the patients who are getting their blood cleaned though the use of the dialysis treatment.

Now if you were a patient that has been receiving this dialysis treatment for sometime; the activity taking place in the clinic would make some sort of sense, but enough of that, if you had been treated at the clinic on a regular basis you may have a more comfortable understanding of what is going on all around you in the clinic. Of course this can't be said if this was your first day in this environment, having just come out of the hospital, where I am sure they didn't explain anything about the treatment or the machine; speaking with first hand information or the lack of it, because in my beginning as a dialysis patient, nothing was explained to me what the dialysis treatment process was all about.

Of course, continuing on, my first day or maybe, my first few moments in the dialysis clinic after having been discharged from the hospital was one of frustration and confusion, I can only remember that I was

bombarded with more paperwork than an average person would encounter in a lifetime, and in addition, I was faced with someone speaking a dialysis language that had no meaning to me whatsoever, and nobody took the time to explain. As I have mentioned before, I don't speak doctor, and I am more comfortable with the regular language of the street.

Working on my 14th year of dialysis treatment, I have watched new people arrive at the clinic and be confronted with what I had to go through, yes the same bombardment of paperwork, with forms to sign and a multiple of different people sitting in front of the new patient going through a song and dance, as they try to make the dialysis process clear to the new patient, but I can assure you nothing is made clear. Primarily it is a language problem, and of course we have a patient who has recently been released from the hospital and they aren't prepared to accept any information about what they have to face.

So many new patients come to the clinic alone, no caregiver accompanying them or there to assist in taking in all this new information that will be affecting them the rest of their lives. Okay we have a weak and confused person, who is placed in a position that needs their full attention but they are not equipped to handle what they will be facing at that moment of entering this new world. I will admit I was in the same position so many other new patients facing dialysis have been in but in my case I had a caregiver who traveled this mysterious road with me.

Can we recognize the problem; is there a fix to this problem? Is there a fix, or will we continue down the road paved by lawyer and corporate executive who spew out words for themselves when they should be preparing these information packets for the people who will be required to understand them and sign off on what they have been told by strangers.

How do you explain to a patient just out of the hospital that part of the treatment they will be receiving is that someone will come up to them, ask them to bare their chest or roll up their sleeve so the person assigned to them for treatment can have access to the catheter in their chest or the fistula in their arm, and that they will be strapped to a machine, which is as I see it, an anchor keeping them in one place for three to four hours. It might be a good place to begin by explaining what purpose the machine is, what it does and most important what part they the patient play in this role of blood cleaning.

**A Tale of Woe
(Caregiver –Dialysis Clinic) - continued from Pg-2**

Is there any preplanning to provide the new patients any guidance and instructions about the nature of what dialysis is all about; of course there are places online that will provide the new patient an animated presentation of dialysis, such as this site –
It is hard to believe during this day and age of our electronic society that someone doesn't have access to a computer, but it is true, so the access provided above for this very informative web site is not available. What does that mean, well in my point of view, these dialysis-providing companies, should employ someone to put together a simple but informative pamphlet that the new patient would find easy to read and understand. And said pamphlet should also contain a sec-

tion that takes the time to answer any all questions; they shouldn't wait for the patient to come up with the questions, answers should be throughout before hand. I think this should be approached on a one to one basis, so the patient has a mentor to fall back on to discover the mysterious world of dialysis. The companies providing said dialysis, should live up to their mission statements, invest in the patient so they enjoy a comfortable conversion from the blank slated patient, weak from their hospital that you first find them to a well informed dialysis patient.



<http://www.kidneypatientguide.org.uk/site/intro.php>

Chemo Progress

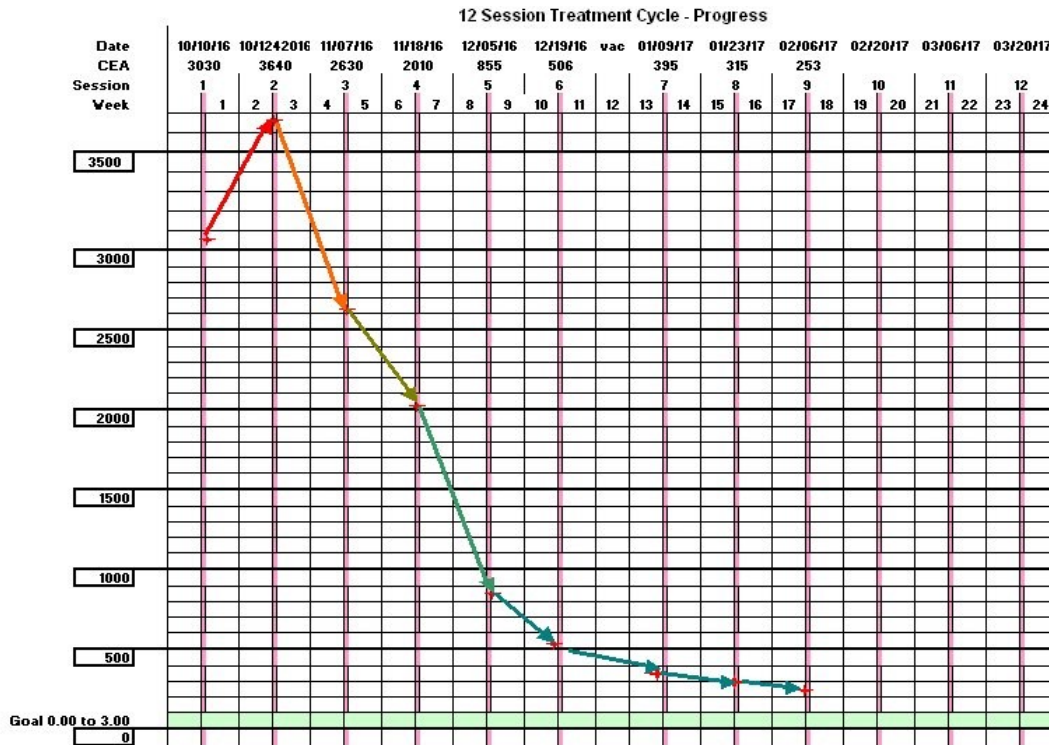
Well here we go again, we are now at the ninth phase or cycle of my chemo treatment. Actually, I have been looking forward to this treatment, and I know you are wondering just why I might be looking forward to this treatment; well let me explain, as you may have noticed, my progress has been so good, I was wondering if my progress would still be progressing to a successful victory over my cancer, and each lab is one more step to realizing a remission. So my first appointment on the 6th of February is that my blood is drawn and sent to the lab for processing and of course while my blood is being tested, I seat quietly, well as quietly as I can, in my treatment chair situated in the infusion room, hooked to a couple of chemo IVs containers, that are slowly dripping into my PICC Line under my upper right arm. To just sit for me would be boring, to just stare at the person sitting opposite me, I can assure you it is not something I can do, so what I do to pass the time is to listen too the 50's music on a Delphi satellite portable radio XM, that my family got me for Christmas; you wouldn't believe how surprised I was in getting it, gee how many times do you have say 'I don't want anything?'; well anyway, while my mind is busy writing down ideas that flash through my mind. I sit there with high hopes on the results of my treatment and that my labs will demonstrate that my hopes aren't all thrown to the wind and it will demonstrate, not only to me but for others that all is well and progressing in the right direction as my body battles the cancer that it is currently plagued with. Time will tell.

Well I guess it is time to put in here the updated chart; so lets see what the results are regarding my Tumor Markers:

Chemo Progress, continued on Pg4



Chemo Progress, continued from Pg-3



Memory Lane

My transfer to the Longmont Kidney Center is an accomplished occurrence; I have now had two labs draws, and the first one wasn't what I would call a good thing. There seemed to be many things wrong with it, for instance, my weight was wrong, and I never got a report on my kt/v, it was going to be retaken but never was for some reason. Anyway, my second lab day was February 7th, haven't got the results back as yet; I am kind of holding my breath hoping it comes back the way it should...we'll see. Actually, I do need this lab because it will be the foundation, lab was, that I could refer back to in comparing my future labs with as we go through my stay at the clinic. In case your curious, it has to do with me only undergoing dialysis twice a week as I did before.

Well, enough about labs, this article has to do with my reason for transferring to Longmont, I know I have probably mentioned a number of reason for me doing what I did, but I didn't really share the truth about my reasons for doing what I did.

So to pull the veil aside, let me explain –

If you are a loyal reader of the newsletter, you will remember that my life was turned topsy-turvy back in March of last year when my wife died of cancer; now of course if you are a first time reader you can catch up on my life by visiting my website (<http://ron-wicker.weebly.com/scuttlebutt/html>) where you will find all of the previous newsletter. So having lost my wife of 48 years, I worked to adjust and cope with my loss, which if you know me you know that I was failing miserably to grow beyond my loss. To confound my life it was in September of last year that I learned that I also had cancer and began chemo treatments.

In my trying to adjust to my new condition and life style, I was taking my dialysis treatments in the Lafayette Kidney Center, which I had some memories but sadly not the warm memories that I had when I was previously in the Longmont Kidney Center. Even though the Lafayette Center provided people to speak with, they didn't quite fill my needs to enjoy my memories of my wife that have kept me going. So looking for any excuse that would put me



Memory Lane, continued from Pg-4

in a place where my memories could be fresh and warm in my mind, I put in for a transfer to Longmont, which you know I was able to get at the end of last year.

The good part of all of this is that I was able to get my old chair back in the Longmont Clinic; it was nice to be able to sit in a position and chair where I have always felt comfortable. While I sit looking out into the open floor area of the clinic, I can imagine my wife and granddaughter visiting with me almost every time I was there for my treatment.



While I sit there I feel my wife is still with me, and even though I do suffer from many side effects from my chemo treatments, having her there in spirit or if only in my mind the idea of it is very heart warming for me.



Notices & Tips



No Notices or Tips in this issue, of course I am always open to add some, all I need is someone's

and



All you have to do is drop me a note, using whatever avenue of communications you care to use.

For those of you who might be interested in getting your future copies of Scuttlebutt online, please go to the link provided below -

<http://ron-wicker.weebly.com/scuttlebutt/html>

Scuttlebutt



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