

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Processing Our New Plan: Pete and Donna's Story'***

#### **Description:**

While studying for the nursing board exams, planning to retire from firefighting, and preparing to travel, Peter, an acute promyelocytic leukemia (APL) survivor, and his caregiver and wife, Donna, share with Alicia and Lizette from The Leukemia & Lymphoma Society (LLS) how a trip to the emergency room for extreme fatigue propelled them into their new roles of patient and caregiver.

#### **Transcript:**

**Alicia:** Welcome to *The Bloodline* with LLS. I am Alicia.

**Lizette:** And I am Lizette. Thank you so much for joining us on this episode.

**Alicia:** Today, we will be joined by Pete, a leukemia survivor, and his wife and caregiver, Donna. Thank you guys for being with us today!

Donna and Pete, take us back to the week that you were diagnosed with APL up until the day that you actually were diagnosed. How was life during that time—the things you guys were doing and maybe the things that you were planning around that time?

**Pete:** Okay; I will start with this. Acute leukemia is very quick and fast as it hits you. At the time, I was working for fire rescue and I just finished a nurse practitioner program. I was in the process of working and studying for the Board exams. Up until probably 2 weeks before I was diagnosed, everything felt normal. It was just like a regular kind of day. We work 24-hour shifts so it is a little bit grueling, but I did not notice any difference. I felt a little bit of fatigue maybe 2 weeks before, and I brushed that off to being just studying for Board exams. However, within about 2 weeks, I noticed a lot more fatigue; more than what I would rule out as being for studying. Part of the things we do at fire rescue is some drills, which are pretty vigorous and hard to do, and I noticed that I was getting really, really tired doing these training exercises. This concerned me, but I kept blowing it off thinking it was just stress from studying. I think probably the week before, Donna and I would go and do the yard; mow the grass. Normally, even though it is Florida and it is summer (it's miserable), it

was never a problem. We could do it pretty quick. It is not a very big yard. I noticed that I would mow maybe 2-3 rows and I was extremely fatigued—like on my knees, breathing heavily. Again, I brushed it off as being 100 degrees outside and I am tired from studying and everything else. But then, literally, 3-4 days before I got admitted, we did some drills and I got to the point where I was so tired that I was going to have to stop and I have never done that—ever—for fire training. I started getting concerned because if something happens for real—a real fire—I am not going to be very good. I am actually dangerous to my colleagues. But I kept working 2 more shifts and it was Tuesday, right? I worked a Tuesday, a regular 24-hour shift and I remember (we sleep upstairs at the firehouse) just walking up one flight of stairs, I was pretty gassed, which is not right. We were at a call and it was around midnight and I talked to my partner and I said, “I think I have some kind of anemia or something. This is weird. I feel tired. My legs are all tight and burning”.

I literally got off work Wednesday morning and I talked to Donna and said, “Listen, I don’t feel right. Let’s go see our primary care doctor.” She was able to set up an appointment. We went and saw him. I told him that I just feel like I have some kind of anemia. I just need some lab work to find out what’s going on. He gave me a script for lab work, but good for him is that he actually said, “Come back later in the afternoon and we will do a stress test on the treadmill.” I said that was fine. We went and shopped. Donna loves to shop. We were at Costco (and I joke about it now, thinking about it later); while she’s running around shopping, I am sitting down where they are selling furniture just reading magazines like an old man—just sitting there reading because I couldn’t keep up with her walking around. Now, I am still in my fire rescue uniform while this is going on.

We go back for the treadmill test at 4:00 in the afternoon and I, literally, only lasted maybe 2 minutes before I started seeing problems with the EKG and everything else. At that point, he thought I was having a heart attack or something worse. He called the emergency doctor and actually got me in. We went to the ER that night or later in the afternoon and he thought I was having chest pains and I thought I was going in there for a heart attack or pulmonary embolism, which got me up to the front of the line. They did all their blood work and everything. Of course, the ER doctor is thinking I am having a heart attack so he is going down that road and, of course, everything looks normal on the outside while I am sitting there. About an hour or two later, he comes back in with the news from the blood work, which was pretty horrible. At that point, I had enough information from all the experience I have had with healthcare as far as knowing that when he told me all the values for the hemoglobin, the white blood

cells and the platelets. They were all horribly low. When he said that, I knew that it was going to be either some type of leukemia or something else. I knew it wasn't going to be good.

The take-home from this for me, and this probably goes on with the rest of the discussion, is just how fast this whole thing just turns your life upside down really quickly because we were on this course to finish nurse practitioner, take the Board exams, retire from firefighting, then start as a nurse practitioner and do some traveling. That was the goal. Literally, with the snap of a finger, all of a sudden, the MD Anderson doctor comes in later and pretty much tells me, that after I got 5 units of blood and platelets and everything else; he says that "you are going to be admitted for at least 30 days and you start chemo tonight". And that was it. It was like "Game On" at that point. It was quite a shock to the system. One of my fire guys was asking me what was it like? I said it kind of goes back to the computer with the old "Control/Alt/Delete" and you reboot your computer. You have that kind of time when it is rebooting. I think that the process for me was that you can't get your mind around it. You hear people talking, but you are not really processing it. You are here in a state of disbelief; especially someone like myself. I have been pretty active and physically fit. Then all of a sudden, this totally changes your universe. Long-term plans, short-term plans, everything just gets totally to a ground halt pretty much from that. I guess the best thing is that you are in shock and you just don't expect it. It comes right out of the blue. It's not like something that was lasting in the air for months and months—you are feeling bad for months and months. It wasn't like that. It was like I felt great. Actually, before that, Donna and I took some vacation time in May and went on a trip to North Carolina. We were fine. We were hiking up and down hills with no symptoms whatsoever.

**Lizette:** And you were studying medicine so, at the same time, you understood what you were seeing.

**Pete:** Right; that was one of the things when they came in to tell me the results. The big medical term is called pancytopenia which just means your white blood cells are low, your platelets are low and your red blood cells are low. There are only a couple of things that cause that so I knew enough, and sometimes if you know too much it's bad, but I knew enough to know that this was not good. It was going to be some type of aplastic anemia or leukemia. Like I was saying at the time, your brain is processing that this isn't good and things don't look right, but at the same time, your mind just can't wrap around it. Donna was able to call and make sure I had a consult with MD

Anderson, which I did not know about at the time. Honestly, I was just trying to get my mind around it. The guy that was on call for MD Anderson for the ER that night, his sub-specialty happened to be leukemia. It was just the irony and I just got lucky. He came in and told me, "I am 90% sure I know what you have, but you are going to start chemo right now. We are not going to wait." later on during the process of the chemo treatment, he told me that if I didn't come in, I had probably one week, maybe 2 weeks left. It was that low. I compensated for it pretty good, but again, if I had waited another week, I would have been one week too late. I applaud her for being able to get MD Anderson on board.

**Lizette:** Peter, you have a really rare form of acute leukemia. You have APL. We encourage everybody that has a blood cancer diagnosis, or thinks they have a blood cancer diagnosis, to get a second opinion just because blood cancers aren't as common as other cancers. Donna, how did you know to really encourage Peter to get a second opinion?

**Donna:** Well, July 20, when he was admitted, like he said, the ER was just such a blur. I remember just looking at my watch every hour and, of course, he was on a stretcher waiting a lot for results to come back. Meanwhile, our 3 daughters from Pensacola were coming in and they got there around 11 o'clock at night. One of them did and the others were about 3 in the morning. They were crying so I'm trying to console them. Then, I am thinking; okay, I need to go home. I went home and then I was told, okay, he needs to go with MD Anderson being my father is a physician in Jacksonville, FL for 40 years. I remember my Dad saying 6 months ago that they arrived here and we got to get them. Over the phone, I did this while I was home because a lot happens and we are 50—almost an hour—from the hospital from where MD Anderson is in Jacksonville to where we live. I remember just calling the ER nurse and saying, "who is in charge of my husband, Peter?" Luckily, I got this nurse and she asked if I wanted a second opinion and I said, "Yes, I do. I want MD Anderson." She said, "really, right now, this other group has already come in to see your husband, put the business card on the table in the ER." I didn't see any of this because I was back home. I said, "yes; right now; I want MD Anderson to follow my husband". Luckily, they did that. They didn't know me from Adam. I never introduced myself before I left the ER because I didn't know all this was going to happen and go down while I'm in my home for just a few hours. Luckily, when I got back to the hospital, they had seen him and I just knew, in the back of my mind, MD Anderson, that's what I want.

**Lizette:** How did you find out he had cancer?

**Donna:** When the ER doctor came in there.

**Pete:** When he came in and told me the results, I looked over at Donna and said, “This is not good”. Before that I was thinking maybe I was just bleeding somewhere, but when he told me the other data, I thought, okay, this is most likely some form of leukemia. That is what I mentioned to Donna. Then, of course, the next thing out of the ER doctor was, “You need to have a hematology/oncology consult.” I knew enough when you hear the word oncology, you know what that means. It’s like, “Okay, that’s cancer”. I am glad she was able to have the foresight to do that because, for me, in the ER, it’s almost like you get that information and you kind of go into a shock mode where people are talking, but you are not processing it. I didn’t even process the fact that the first hematology/oncology guy who came in, was from somewhere else. I had no idea. It was good to have Donna and it may have been better that she wasn’t there at the time to make the phone call and you are not wowed up in the whole ER experience.

I was in the ER for about 18 hours before they actually had a room for me. The next step, of course, he is saying you are going to start chemo tonight. You are going to be in the hospital for at least 30 days and you can’t leave. Then, you have 13 months of extra chemo after that. All the plans that you had as far as retiring and all of that just totally changed. I am still in my uniform. This can’t be real. I am sitting here. I just got off work. All of a sudden, I am going to be in the hospital for 30 days. That’s the kind of wildness that you deal with.

**Alicia:** As a patient being told you have cancer is one thing, but as a loved one watching someone being told that they have cancer is a whole different experience. At that moment, Donna, how were you emotionally?

Donna: A basket case, if that. Like I said, I came home just to shower and get some clothes for Pete even though he wasn’t going to be wearing those. He would be wearing a gown, but that is the other thing, he wouldn’t put a gown on. For the whole 30 days, he wore his shorts. He said, “I am not going to be a patient. I am not sick.” But I came home and I cried. I had 50 minutes in the car to drive home and cry. This can’t be happening! I barely even heard of leukemia. A friend on your street had died of leukemia, but he was a kid, I didn’t know adults—like I said, I didn’t know. I didn’t want to look on the computer. I just came home and cried. I had nobody here with me. All the kids were at the hospital. I hadn’t even told my parents yet. I just wanted time. I am not working. Pete is the sole provider. What am I going to do?

You don't know what to do. I was barely able to get clothes together, to take a shower, go back to the hospital again and then with the nurses here and the tests and running this and, oh (sighs) you just finally just have to wrap you head around it. The kids are crying and the girls. I was mainly just saying to the girls, "It's okay, it's alright. We'll get through this." It wasn't until maybe you are admitted up onto the floor, then more people from MD Anderson would be coming in and things would look a little more clearer, but the first couple of days, I didn't know what to do. I could get in the truck and drive there and get there safely and come home. I was a wreck.

**Pete:** Yes; it emotionally messes with you pretty bad. As far as for me, I am sitting there thinking--okay, all of a sudden, you're thinking I am definitely not going to retire. I have to figure out what to do for income because the retirement insurance changes. Now the insurance becomes the big driver for us because this is not going to be cheap (this treatment) and regardless of what kind of chemo you are getting, it is going to be extremely expensive. I'm sitting there calling up the people at the fire administration telling him what's going on so he could do all this FLMA leave and all the little administrative things that have to happen. Your mind isn't right so you are lucky to have people. From the fire department, I have to admit the guys from the top to bottom have been really great as far as helping me out because I don't know what I have to do. They have to bring paperwork for me to sign for FLMA and there is a Union time full leave to extend your hours so you are getting paid without burning up all of your leave time. All of those little administrative things on top of the fact that you are getting a pick line and getting hooked up to. . . That was the other thing, the treatment is like a sidebar as far as APL which is sort of good news in that they figured out a really great treatment process for this stuff, but the treatment is very unique. When you tell people what you are getting, they kind of freak out. You tell them that, well, as long as it is basically Vitamin A at toxic levels and then the other is arsenic. It has a great cure rate which is great news. After they did the bone marrow biopsy, that is what the physician told me. He said, "I have great news for you. This is the second-best news you will have. First would have been never seeing him and the second was being diagnosed with APL." Okay, I'll take the second-best thing so, yes, it looks good. Right now, we are at this juncture where you want to get through the first year clean so you are still a little bit nervous about that. As far as the stress goes, that whole first 30 days in the hospital was crazy. I don't even think you got to the point where you fully understood what's going on because the hospital, the nurses and the doctors are still in "do" mode. They're sticking you with needles. They're pumping chemicals into you and doing all these things. You are sitting there letting them do all



these things and you can't really figure out what exactly is going on. It's that whole rebooting of your brain. You are kind of numbed out for it.

**Alicia:** Donna, while this is all happening and he is going through his tests and he is doing what he has to do, as a caregiver, , how did you find yourself saying, "Okay, instead of wallowing in my emotions, I have to actively be this caregiver?"

**Donna:** After a while, this is going to be the new normal for a while and I just had a routine. I am a very routine person and that is what gets me through the day. At this time, I am going to do this; this time I'm going to do this. At first, I would walk into the room and see him with his back to me in the bed and I would say, "Okay, I don't know if I can do this". I would walk out of the room. I would walk actually down to the library (they had a library at the end of the hall) trying to find some information on APL or whatever. Nothing! There was nothing down there. It gets back to the fact that it would be nice to have more information on APL because I could have understood it. I could have come home at night and read it instead of crying and saying it's going to be okay. You just went on what the doctors and the nurses would tell you about it. It's a good one. There's a 95% cure rate. I kept thinking that. Oh, this is good. This is cool. He is going to survive this. This is alright. But still, the stuff he had to go through. Every time they would hang an arsenic bag and the severe side effects he got, that was tough watching him; that was worse actually than dealing with the chemo—dealing with the side effects of all that. I tried, at that point, to Google about it, get more proactive about it just trying to understand it.

**Pete:** It's weird. What Donna does for her side hustle, if you will, is that she actually does caregiving for elderly folks so she is used to doing it, but it makes it different when it actually somebody in your family or your husband, obviously. It's a totally different thing when you have an emotional attachment. It is a lot harder to deal with. I can only look at it from the patient's side and I know, from the caregiver's side, it is totally different. You get to a point where you are probably not being your best self when you are going through this treatment. Usually, I'm pretty joking around and fun, but after a while, the side effects and the fatigue, you get beat down and you are not the most agreeable person. I think that is hard on the caregivers. This isn't normal. He is not usually this crabby.

**Lizette:** Was he crabby? Donna, was he crabby?

**Donna:** Oh, yeah; very crabby.

**Pete:** Not all the time.

**Donna:** I wanted to walk down the hall with him and the nurses wanted him to put a mask on. He would not do that and that made me mad because I didn't want him to catch something just walking down the hall.

**Lizette:** I know, Donna, that one of our biggest goals at The Leukemia and Lymphoma Society is to make sure that we are there for patients once they are diagnosed. I know that you didn't meet The Leukemia and Lymphoma Society at the beginning of Pete's journey. What other supports did you have and what supports really did you think would really help you when he was first diagnosed?

**Donna:** I didn't see anybody, like I said, from The Leukemia Society the entire time we were there. Not even a social worker. The nurses—that was it. Then, just me googling it. I would have loved to know there was an online chat. I would have gone there that night.

**Pete:** It would have been helpful to just have the links that if you have this, log onto there. It is almost like somebody has to put it in front of you or there is something in front of you like, "here it is" because it is not like you are thinking to ask about it because you are in the daily grind of getting chemo and this and that; and thinking about what you are going to do. No one is presenting it to you. You are almost on your own to try to find it. This is all retrospective, after the fact, you start thinking about it. It would have been nice to have at the time. No one is presenting that to you. The nurses—they are busy. They have other things going on so they give you your specific. Here is a printout on APL. You can read all this. It is like the medical journal. I'm looking at it and saying, "yeah, I get it." This isn't anything as far as that other support. There were the chaplains.

**Donna:** The chaplain was the only person who would call every day.

**Pete:** That was nice, but again, it wasn't like you wanted to drill in a little bit more and it just wasn't there.

**Donna:** MD Anderson would have a group, a posse, that would come in every morning; the oncologist, 2 nurse practitioners, and I just expected one of them at MD Anderson since they go back over to the building to have some information on this or



APL. They just kept saying, "It's a good cure rate". It's all we kept hearing. Okay, in my mind, I kept processing that "I guess I don't really need to know any more other than it is a good one." But no! It is so much more than that. For the caregivers, it's the support. How are you, Donna? No one asked how I was doing the entire time. My husband was always taken care of—always. He had a nurse at his beck and call when I wasn't there. If he needed something, but me, it's 50% of the equation is the caregiver and no one understands that. It is such a vital role to have a good caregiver. The stress level was just so intense. Life had to go on. I had to put bills in here; I had to take care of the house. We did have people come and cut the grass, but still, there is a lot to do in the house here. The fire guys said, "hey, we can help you cut the grass" or "we can bring Pete meals" and I was appreciative of that. That was very nice and it helped us get through it. They took his mind off his problems because they came in every day or if not every day, every other day. They brought their little kid; a little girl, she was 3-years old and looked at the water and he liked that. That was nice.

**Pete:** The other thing with this as far as the treatment goes. Every chemo regimen is different. This one—at first, he told me it was going to be 13 months after the induction phase. I was, "that's a whole year of this misery", but then what he did, he compressed it to 8 months. What that meant was that I would have 20 days on Monday through Friday, 4-hour chemo every day. Then, the pills are every 14 days sitting on top of that. For 20 days in a row, driving an hour each way because we were talking about maybe we need to live somewhere; maybe with her folks or whatever. After a while, I said, "I need to have some kind of normalcy." That put an enormous amount of strain. The fire guys would come and one of the guys set up a driving schedule that made it easier because there is a lot of stuff that has to happen at the house that Donna was trying to do, plus worrying about me going to chemo every day, which was tremendous. I think with Donna and caregivers, and I am talking ahead as far as we do the chats and stuff now, and the caregiver chats are always full with lots of people. She really likes it. I think just having that information right then and there where she could log on and say, "Oh my God", it would have been great for her. At the time when you are going through it, you are not thinking of these things at all because it doesn't even cross your mind. That would be my take home as far as the Leukemia Society or Breast Cancer and all those folks; especially the oncology-type hospitals, to have something where there is an area where the patient's family congregates, either a break room or a library or something like that, which would have all of that stuff really visible and not hidden in a drawer, but pretty visible for everybody to see, would be beneficial. The doctor and his entourage come in and

it is all just clinical stuff. It is all just medicine. Okay; your blood counts are here and this is this.

**Donna:** Going over your labs and tests.

**Pete:** All sorts of wild stuff. I remember that. They are all about the medicine and how are you progressing and everything else. They don't really talk about any real emotion. I mean this is typical of medicine in general, not just for cancer, I think it is typical that is all kind of business, not really talking about emotional support issues or anything like that. They maybe send you to a social worker or a chaplain to talk about that, but as far as the daily grind, it was all about where your levels were. Something would spike and they would be worried about that for a while. There is always something going on in the hospital that was causing them some degree of concern. It could end up being nothing, but it wasn't fun going through it.

**Alicia:** Donna, in a New York Times article that was written this month, it focused on the caregivers and the emotional and physical issues that they experienced, stating that "along with the abandoned career, the hands-on tasks, the medical scheduling, the insurance tussles and the disruptive sleep, another trial that develops is social isolation". Now I know that you mentioned that the materials weren't readily available, but did you experience family being uninvolved or friends disappearing.

**Donna:** Family. My parents are in their eighties and it's about a 7-mile drive to their house from MD Anderson. There was not a lot of that. They did call to say how's Pete doing. I felt a little bit more could have happened. I have 2 sisters that live in Jacksonville and maybe once out of the whole 30 days, she came to visit him, but they would text or call me and I would say, "Yeah, he is doing the best he can." The fire fighters by far were the most helpful and that was pretty much so in January that started getting a schedule up and taking him. Peter did have a lady from the American Cancer Society that drove him. to help us out once a week because I remember, "God, there has to be somebody who can help with the driving here". She had to stop doing it because she didn't feel well, but I did it from July to December—going each day, but I can't imagine not. Yes; that was my life.

**Pete:** It also helped a little bit later when some the neighbors would come by. Family-wise, for me, all my family is either deceased or my sister is in Cleveland. They were only able to come down once. Once everybody is kind of involved. The fire guys did help out. That was the main thing.

**Donna:** So much.

**Pete:** Otherwise, I would agree with that article that you are saying. Once it tamps down and you are in that consolidation phase of the treatment, nobody is around. You are on your own. Of course, you are dumping more on the caregiver because you are not feeling up to doing anything.

**Alicia:** Are there any resources that are lacking for you guys now that you would like to see one year from treatment?

**Pete:** I am sitting here now almost in the exact same mode as I was when I got diagnosed. I am sitting here. I am working. I am taking my Board exams again. I had to cancel them and postpone them. They are coming up in another 2 weeks. At some point, I am saying it is de ja vu all over again, thinking, "Oh my God, am I getting tired again?"

**Donna:** Every time he gets tired, you think, "Oh Lord, it's coming back". You worry about that.

**Pete:** It changes you. You start worrying about things you would not normally worry about. But as far as resources go, I think that Donna has gotten the most utility out of the online forums.

**Donna:** I love the caregiver chats. I never miss it ever. Everything else is scheduled around that. The caregiver one, I log on, I give him the computer and say, "Here". One night, he really didn't feel well so I said, "talk and I'll type". In fact, we are going to meet one of the guys who is coming to West Palm Beach. He has just gotten into remission and his doctor gave him the okay. We are going to meet him at a Cracker Barrel here in St. Augustine. I am excited to see him.

**Alicia:** That is awesome!

**Donna:** That is cool. Real nice.

**Pete:** I think that has probably been the best thing for you. I think if you would have had that earlier in the process, it would have been a lot better for your emotional.

**Donna:** So much better. And Ky Marie and Kerry are wonderful. I compliment them every week--how wonderful they are as moderators. People will enter the room and this is their first. Their husband was just diagnosed, or their wife was just diagnosed, the day before. And so "we will help you" and so 30 minutes of the program is dedicated to them. Make sure you do this and they say, "thank you guys. I don't know what I would have done without this." Let me tell you, I'm thinking I did a whole year not knowing about this. Definitely, the chats are 100% helpful and wonderful.

**Lizette:** What else did you do to take care of yourself because if people always say, "You are a caregiver. You are taking care of your loved one." How can you take care of your loved one if you are not taking care of yourself?

**Donna:** Right. That's true. A routine. Just getting into a routine and making a point when I would come home; or when your friends would take you in the morning, I would walk around the neighborhood, or I would bike, or I would go shopping, or I would do something. There was always me. I would make sure there was me time for me. I would go to a movie on Tuesday and then I would go see Pete at the hospital. After a while, you're right, I would say, "Listen, I'm living like hell right now and I'm not feeling good. Something has got to change." I would just come home and say, "Okay, every hour I am going to do something. I am going to get up. I am going to do this. Pete's going to survive this. It's okay. You say, "this is a positive thing. He is going to get through this." You just go out with friends. I did it. I don't know how, but I did it. I am surviving.

**Pete:** Following along on that, basically, it is respite care for the caregiver. If we didn't have my fire friends taking me--there are other people with a different situation where other people are going through this alone, that would be to me a big thing that the Society could help with. We were lucky because we had all those folks to take me and it gives you that time during the day that you can relax, take a nap or do whatever you want to do. Other folks that don't have that, I could see that it would really—especially if they are going through the type of regime that I did which was 20 days everyday kind of grind, that it would be helpful if there is something like that available. Whether it is the Society working through other groups, a caregiver for the caregiver kind of thing to help out.

**Lizette:** Sure.

**Donna:** Not everyone is an hour away from their place of treatment. That was a decision we made. The driving just got—in fact, I broke down on I-95 one night and ended up in a very bad section of town. I had to call the cops and they came and sat with me while my truck was towed. They took me back to the hospital and I spent the night there. The next day he had that fourth bone marrow biopsy.

**Pete:** That was crazy. She calls me up from the side of the road and I'm hooked up to a drip. What am I going to do? We ended up calling the fire guys. I told her to call the cops so you don't get robbed. We ended up calling one of our guys. He drove an hour. He told the tow guy (he actually knew the guy, ironically) and so they towed it to his house and he actually fixed the truck for us. He then drove Donna back to the hospital and she slept on the couch there. If you didn't have that type of support, it would have strained it a lot worse than it was.

**Lizette/Alicia:** It is a totally different perspective at this point. What would you tell others that are going to be diagnosed tomorrow with APL? From both a patient standpoint and from a caregiver's standpoint?

**Pete:** From the patient's standpoint, I still can't beat Dr. Gorak's comment, "it's the best news you are going to have." You have APL. At least it is curable. They are going to give you rat poison, but you might survive this. I think the thing I would tell people is that it is almost like the horse is out of the barn when you have it. It's really understanding your body and knowing when to really get checked because this stuff really goes fast. After going through it and thinking about it, I could have easily struck this out another week or two and that would have been that. You have to really pay attention to your health. Yes; somebody else is going through it, it is tough because they may not realize it, but it is totally going to turn your life upside down, but it doesn't mean that it is all bad. You are going to recover from it, but you have to be flexible in the process. That is really hard to do when you are like us. We had plans. Plans are great until something like this happens. Then, there is no plan for this. You don't really have a plan for it. You have to just organically deal with it. Having the help and support as much as you can, whether you have family and friends support, that is great, and if you don't have it, then definitely log in or find the societies that will do it.

**Donna:** From a caregiver's point of view, from Day 1 when you find out your loved one has APL, when you get up on the floor there, ask the nurse. Say, "listen, I need some information about APL. Can you get a social worker to come in here?" These

nurses see this day in and day out. They can say, "I can get someone up here to talk." Then you say, "listen, I have help, or I don't have help; and I don't;" so, "let me pair you up with somebody who has been through this." You get out and go get your nails done or go to a movie—just something to get you out of there for an hour or two. Then, you will feel refreshed enough to go back to the room and deal with what you have to deal with. APL is curable as long as you stick to the regimen and you do what the doctors say. You need "me" time for sure. You can have all that even if you don't have help. You can still have "me" time. You just need to get friends together and say, "Listen"; especially if they have to travel like we did. Get a schedule going. Say, "Can you help drive my husband here? How many times?" Circulate it. Don't be afraid to say, "I need help." A lot of people just take it upon themselves. It eats you up and you can get sick yourself from it and be a mess. Our kids are all in Pensacola. They are 6 hours from here. We can't ask them to come here. The kids ask, "how's Dad doing?" I'm thinking to myself, he is not doing well this week, but I cannot say that to them because they would get in the car and immediately come and they got jobs. Then, I worry about them being upset on the interstate driving 6 hours so I say, "your Dad's fine. I have it under control, girls." Deep down, it would have been nice to have the company, but I turned to neighbors and thank God for the fire department. They were awesome—awesome! They got us through this. If they weren't bringing lunch to him, they were cutting our grass or they were whatever. It was just and still, "is there anything we can do?" I do need this. I was not afraid to say what I needed.

**Pete:** It took a while to get there.

**Lizette:** I am glad that you are taking part in our online chat because they do provide a forum for a lot of patients and caregivers that may not be able to go out and meet each other face-to-face. Maybe their blood counts are low; maybe they are in the hospital so I think it is a great way to meet people and I encourage both of you to be part of our peer-to-peer program where you can speak to newly diagnosed patients as well as newly diagnosed patient caregivers. Caregivers of patients who have just been diagnosed that don't feel that they have that support. A lot of times, Peter, you are right, your treatment team will come in and they will talk to you about blood counts. They'll talk to you about how you are doing with your medication. The part, I think, you really brought out is the importance of talking about support; talking about your entire life--meaning talking to you about how is the transportation affecting you. Do you need help with all these forms you are filling out? You are not feeling well, but you have 50 forms to fill out for different insurance. A lot of people don't talk about



that and I am glad that you are bringing that to the surface today because people need to know that they are not the only ones dealing with it. They are not the only ones feeling overwhelmed because it is an overwhelming process, but at the same time, here you are a year later, you are about to take your tests to be a nurse practitioner and life has gone on for you. You struggled, but I think you are a lot stronger at the same time.

**Pete:** Oh yeah, it hardens you up that is for sure. It just goes to show what you can actually endure. You don't realize it until you are actually put under the test. You kind of endure. It is not over yet. There are all sorts of residual stuff, but you sort of get used to it and say, "okay, these are just residual side effects and it is just going to be the way it is." You're okay with it. For me, you get focused and get back on track. Again, not sweat the small stuff. If you want to go on vacation, go on vacation. We still have to go to Costa Rica. When I get back in a certain shape, we will go there. That's on the list. It will happen.

**Alicia:** We want pictures when it does.

We would like to thank you so much for joining us today. We love hearing how well you are doing, Peter; and Donna, we commend you on how great and diligent you were when you were caring for Peter. We hope others will hear your story and be motivated to be their best advocate and put their best foot forward. We wish you both well and the best of luck Pete on your Board exams. We want to hear how well you do when it is all done.

**Pete:** The pressure is on now. I have to study.

**Donna:** One-year remission. Next Tuesday, the 15<sup>th</sup>, is his one-year remission anniversary.

**Alicia:** That is great! That is absolutely great! Thank you guys so much!

**Pete & Donna:** Thank you.