

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'LLS Financial Assistance: How We Can Help'***

#### **Description:**

Join us as we speak to Gregory Proctor, a myeloma patient, and Erica Ali, the Senior Manager of Copay and Patient Financial Assistance Programs at The Leukemia & Lymphoma Society. In this episode, Gregory shares his story of his diagnosis with myeloma in July 2021 and how he has benefited from the LLS Copay Program, which provided financial support for his treatment. Erica discusses all of the financial programs that LLS has to support patients, what the funds cover, and how to apply for these programs. LLS Financial assistance improves patients' access to care and is accessible to patients of all blood cancer diagnoses when funding is available.

#### **Transcript:**

**Elissa:** Welcome to *The Bloodline with LLS*. I'm Elissa.

**Edith:** I'm Edith.

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

**Elissa:** Today we will be speaking with Gregory Proctor and LLS staff member Erica Ali. Gregory was diagnosed with multiple myeloma in July 2021. After going through treatment for several months, he reached remission in October of 2021. Since his diagnosis, he has been able to take advantage of the financial assistance that LLS offers to blood cancer patients. Now preparing for his stem cell transplant, he has been able to continue his life as an entrepreneur and podcaster for his show called *Kut2ThaChase Podcast*, which is focused on enriching and nourishing listener souls.

These activities along with establishing a new foundation called Kut2ThaChase Foundation, plus his lovely wife and two daughters, keep him very involved in the Greater San Antonio, Texas, area.



Erica Ali is a Senior Manager for the national copay and patient financial assistance programs with The Leukemia & Lymphoma Society. In her current role, she works on the team that manages all LLS financial assistance programs and is responsible for financial assistance outreach and engagement of patients and healthcare professionals. She is passionate about improving patient access to care, increasing awareness of LLS financial support, and being part of the solution for patients.

Welcome Gregory and Erica.

**Gregory Proctor:** Thank you for having me.

**Erica Ali:** Thank you.

**Elissa:** So, Gregory, let's start with you and hear more about your diagnosis with multiple myeloma. Could you tell our listeners what myeloma is and how you ended up being diagnosed?

**Gregory:** Sure, absolutely. So I always look at multiple myeloma as being, as most people say, a thorn in my side. And I can literally say that not in a facetious manner, but basically that's how, it started for me.

So back in May/June time frame while conducting multiple podcasts on my own, I started having a lot of back pain. And the back pain became such a horrific experience for me. I couldn't sit down, I could barely move, and I was just, like, something's really going on and I really needed to try to get to a doctor and figure out what was happening.

So one night I went to sleep and I couldn't get up the following morning. And the next day I called my local general physician and he said, "Well, if you can get here, please come on over. Let's, get you checked out." The thing that didn't happen when I went to go see him was he only gave me a steroid shot and something for the inflammation, but we didn't take any type of x-rays or MRIs, and so I was very disappointed at that time.



So later on that weekend after I called my wife, who was out of the country, I said, "Look, there's something going on. I can't move. I'm going to have to go see a specialist." I ended up seeing a spine management specialist, and at that point in time, they recognized that there was a tumor on my pelvic area across my sciatic nerve in my upper hip area. And realizing that the tumor was not benign or cancerous at that point in time, I was all freaked out, saying, "Hey, well what am I going to do next?"

And so we went from that experience to running multiple more tests. And that was the first time I began to hear the words multiple myeloma and very much just like the question you asked, "What is multiple myeloma?" At the time, I had no idea. I mean I've heard of all other types of cancers. I've heard of all different types of things that people can contract, but multiple myeloma was something that, in the back of my mind I'm like, well what is this? And as I started asking my network and asking people, friends and family, no one knew of this disease at all either.

And so the more my wife and I started to investigate, we realized that multiple myeloma is a blood cancer. We also realized that the cancer itself attacks the blood plasma. And a lot of people go, "Well, my God, it attacks the blood plasma." Well, what it does is it attacks the proteins and then it produces bad proteins which a body can't really utilize and it messes up your immunity system.

And so in the aspect of what my diagnosis was is, I was diagnosed with multiple myeloma IgA kappa. I had 100% bone lesions, which basically is where the cancer goes in and it begins to eat away at your bone marrow, and it begins to attack a lot of different aspects of the calcium in your bones. And I was in a very bad situation. Like I said, I couldn't walk. It was very hard for me to even do things on my own.

And so we were really in dire need and dire straight at that point in time to try and figure out how to move the treatment or my prognosis in a manner that would allow for me to get back to some sense of normalcy.

**Elissa**: Right. What were you looking at ahead then with treatment for that?

**Gregory**: Well, we started out when we were diagnosed with multiple myeloma to my spine management doctor, and he kind of looked at us and said, with his big glaring eyes, "You have to start some treatment, like, right now!" I mean I was, like, you know, "How severe is this?" He's like, "We can't wait!" "This is pretty bad."

And so he recommended an oncologist who was a good friend of his, one of his college buddies, which was down the street from his office. And then, of course, my wife had already taken liberty to look at other oncologists here in the San Antonio area.

And no one would take my case. No one would take my case in the very beginning, so we spent a countless amount of time and energy trying to find an oncologist that would take my case because it was so severe and I needed to be put on treatment literally right away.

And what we ended up finding after we got through our call list is that the last oncologist that was on the list of people to call who was part of the Oncology San Antonio, the name of the doctor is Jayasree Rao. She met with us on a Tuesday. By Thursday, I was hooked up for chemo and basically off to the races. And she said, "You're going to have to trust my better judgment on this. This is pretty severe, and my goal is to get this cancer in remission within three to four months." And that was the target and we achieved that. And so fortunately enough, things did work out, not only through blessings but also through a little bit of perseverance and being able to have a little bit of patience because, like I said, we were running out of energy trying to find someone to take my case.

**Lizette**: Wow! And I know that today we're talking about finances. And when someone starts treatment so quickly, you're not even thinking about finances. You're on automatic pilot thinking what do we do next. It's something to think about but not at that time. And I know that you're a small business owner. Even though you had



health insurance, cancer can have a really big financial impact. What were your thoughts about that at the time of diagnosis?

**Gregory:** Well, the one thing that became very apparent because the Internet's such a powerful thing, you can pretty much put in anything you want and it'll pop up and give you at least a plus or minus of this is what can happen. So we started looking at, what is the cost for treatment? We started calling the insurance company, my private healthcare, and started asking them, "What are the next steps that we could take, to ensure that we have proper coverages?"

And the sad thing about all of this is the fact that, literally you have to become an advocate for yourself because no one's going to do it for you. And it's very hard when you're being pushed with all these drugs and chemicals through your body and trying to deal with the chemo fog and deal with all of the other things of just trying to heal yourself and then have this 800-pound gorilla of financial obligation stacked on top of you.

And so what we found out very early on in talking with our doctors and trying to be very transparent, is that, there are opportunities out there, such as grants and other various things which LLS offers, that can kind of supplement some of those things, but you have to apply for those and you have to kind of fit yourself into a tranche to qualify for those type of things.

And so several things that we did upfront since we were unaware of LLS and some of the other foundations that are out there that offer this type of copay assistance and drug assistance is that we started up a GoFundMe page, which, we got a lot of support there. We raised somewhere in the neighborhood of about \$22,000 to kind of help us out.

And then on top of that, I started looking into all of the other extremities of, can I sell my life insurance policy? I had a huge coin collection. I had all these other various



things because I didn't want to have this copious amount of debt, which, in most cases, people typically have when they're dealing with cancer.

And it's one of those things that, when you're stamped with cancer on the back of your name, most people, unwarrantly just don't want to deal with you, I mean because they know how expensive it's going to be. And in my case, my overall treatment costs cost me about \$22,500 per week, is what they bill to the insurance company. So if you multiply that over the past seven months that I've had treatment, do the math. I mean I haven't even had my stem cell transplant, which is probably going to be in the neighborhood of 750,000 to a million bucks. But do the math. I mean and that's just within not even a year's worth of time just to try to ensure that I have some normalcy, you know, and quality of life.

But to getting back to your question there, the thing that is so important with the programs that are out there is the awareness. And so for me, we were unaware of LLS. We were unaware of Co-Pay Assist and all these other, I mean I could go through the entire list. I don't think I really have to do that, but certainly we were just unaware of how you could tap back into reducing the costs of what the doctors would normally charge for drugs and run it through these foundations or run it through these programs to be able to kind of help reduce some of the things that were going on.

And I'm going to share this quick story with you so that everybody understands the severity of where we were. So, yes, as a small business owner, I'm paying like \$800, \$900 a month, but then my insurance company's saying, "Well we're only going to cover this drug. We're not going to cover that drug. We're going to do this, we're going to do that." And then by the time you realize all these bills start to roll in, you got \$4,000, \$5,000, \$6,000. These dollar amounts are hitting you left and right and you're going, "Wait a minute. Why am I not covered? I paid you \$15,000 for my copay. I paid you the expenses. I paid this, I paid that. You should literally cover me 100%."



And so when we started talking with my oncologist, they said, "Well, look, Greg, here's what we're going to do. We're going to go ahead and we're going to apply for LLS and that's going to help reduce your costs." I said, "Well how much do you think we're going to get?" And they said, "Well most of the times, it's \$12,000."

So you start scratching your head and you start saying, "Okay, so I'm getting administered this drug X number of times. How long is that \$12,000 going to last before I'm still going to be faced with this insurmountable amount of costs?" And then, of course, there were other programs that you could tap into and other various things.

But for me, it was a godsend to be able to kind of tap into those type of programs because of the simple aspect that when we started this whole extremity out in the beginning for my wife and I, my insurance company was the very last responsible party to actually pay. And so at one point within the first two months of my treatment, I was being, I won't say threatened, but I was kind of being forewarned, "If your insurance company doesn't release some of the cash that they owe us," because like I said, my burn rate was \$22,500 per week, my doctor was basically saying, "we're going to have to stop your treatment" And I'm going, "Well wait a minute. We can't possibly stop my treatment, not in the middle of where we are at this point in time." And so it became very heart wrenching and very concerning to me that we had to act very quickly to be able to move forward.

**Elissa:** And on top of that then, sometimes at or right after your first visit to the hospital, you're getting called by billing already, right, and they're like, "Can you put something down? Can we start a payment plan?" You're like, "Whoa!

**Gregory:** Yeah.

**Elissa:** "I just got diagnosed with cancer!"

**Gregory:** Yeah, yeah. Right.

**Elissa:** "Calm down." And so it's right in your face right-

**Gregory:** Right.

**Elissa:** -in the beginning.

**Gregory:** Right. It's very coincidental that you bring that up because, as a part of what I had to do to negotiate with my oncologist was the fact that knowing that our insurance was very, very slow to pay, because they're like, "Oh, we have to investigate. Oh, we have to get your records. Oh, we have to do this. "And I'm thinking to myself, you already have all this stuff. I mean come on, let's be realistic!"

So I ended up negotiating with the oncologist and said, "All right, look, we'll give you \$10,000," which most people typically won't have \$10,000 laying around, to be able to do that, just to kind of offset something in good faith. And one of the things that was so significantly important for us is that my wife and I, we ended up having assets and other various things that we could tap back into. Like I said, I had a coin collection that I ended up selling. We had a car that we weren't using, and we ended up getting rid of that. Just to try and make sure that we were in the right frame of mind because you're being hit from so many different aspects, not only it's the cancer, the financial aspect, the emotional aspect, the stresses, the anxiety, the mental capacity of this thing. And so there's just so many things that's being thrown into your washing machine that's causing all this turbulence that makes it very, very hard for you to critically think from one day to the next.

We were fortunate enough just based on the fact of as my wife says because, I always talk to her about project management, she says, "Now you are the project, and I'm the project manager, and so, therefore, we're going to manage you just like we manage any other project." And literally my wife has really stepped up to the plate and funnels all these programs, monitoring the drugs, monitoring the statistics, the analytics, I mean everything; she does all of that stuff. Probably knows it better than the doctors.



**Edith:** That's amazing.

**Gregory:** Yeah, yeah.

**Edith:** So, Gregory, our podcast today is about patient financial assistance through LLS. You said that your doctor connected you. What was the process for you to get financial assistance?

**Gregory:** Well, I mean unbeknownst to me, I was very oblivious to all these different programs, as I'm in this fog of trying to figure out just on my end what could I bring to the table to make sure that the burden was a little bit lesser than what I was seeing.

Their billing department really stepped up to the plate to kind of educate us to bring us forward with regards to these type of financial assistance programs being readily available. And, like I said, it was just a blessing because what we ended up finding out not only through being a part of the LLS program and, like I said, the money that was awarded to us which helped offset some of my drug costs, is that not every organization or doctor's office typically will take the energy and time to go through and be able to do this.

And so this happens to be one of these situations where whether or not it was unique to me, but the simple aspect of that's what they do in their office is to try and help patients through the financial assistance aspects where I've heard where other doctors' offices won't do that because of the red tape that it takes to go through it.

**Elissa:** Yeah. That's just really important for the providers and/or social workers or somebody to be able to help you and let you know that that's at least out there because if you don't know, you don't know.

**Gregory:** Right.

**Elissa:** And so, Erica, let's hear more about LLS's financial assistance program. What is the history of it at LLS and why do we offer it?



**Erica:** Well basically, I mean, Gregory said it best, right, where he described what his journey was like navigating the cost. We've been in the business of offering Co-Pay Assistance since 2007, and even before then, we had our Patient Aid Program, which we offered to patients to help offset some cost.

Gregory did receive financial assistance through our Co-Pay program, and that program offers patients help with their out-of-pocket after their insurance kind of divvies up their end. We're able to help pay for their out of pockets for their insurance premiums, help pay for their out of pockets for copays to doctors' visits, for labs and scans. Any prescription drugs we offer a Pharmacy Benefit Card where a patient who's awarded one of our grants could basically take that card and hand it over to the pharmacist just like they would their insurance. It gets swiped and any out-of-pocket costs get covered instantly.

We offer all of this through our Co-Pay Assistance Program and basically the goal for that program and all of our other programs is to make sure that, people have access to the treatment that they need, and that treatment becomes a bit more affordable. I mean we hear stories all the time of patients that struggle to have to choose between getting therapy, paying rent, or getting food for their family and people that forego getting the treatment they need because the costs are so high. And so we want to bridge the gap. We want to offer the assistance that these patients need and put them in the best position to get the treatment that they need.

**Gregory:** And I have to say to add on the back side of that, you guys do a phenomenal job compared to all of the other programs that my wife and I have dealt with over the past several months. So hats off to LLS for their amazing efforts and opportunity that they provide for financial assistance.

**Edith:** So, Erica, can you tell us about the different types of financial assistance that are available?



**Erica:** Absolutely. So as I mentioned, we definitely have our Co-Pay Assistance Program that helps with the medications, insurance premiums, for Medicare, Medicaid, TriCare, private insurance. So there are other programs that kind of can only help certain types of insured patients. We're wide open to everyone, all types. We help with labs and scans, and that program offers instant decision right now. We're excited about that because right now when patients apply, whether it be over the phone, on the portal, or healthcare providers when they apply, you get a decision right there and then in real time and real access to funding.

That program also has benefited from some recent enhancements. We now offer assistance to patients who are up to 600% above the federal poverty level. We have recently also increased some of our caps because we know that the cost burden is pretty heavy on the patient, so we've been able, with the generosity of our donors and reviewing the out-of-pocket costs for patients, increase some of the caps on some of our funds and offer, like I mentioned, that Pharmacy Benefit Card where patients don't have to submit receipts. We pay the cost instantly.

In addition to Co-Pay, we have our Patient Aid Program. This is a one-time grant. It's \$100. Can be used for travel expenses, food, any other out-of-pocket cost just to help the patient get along, and we also connect patients that apply for that program and all of our programs with the other LLS wraparound support services and education.

We have our Susan Lang Pay-It-Forward Patient Travel Assistance Program. This grant is \$500. It's meant to cover the cost of any travel, transportation, and lodging expenses getting to and from treatment. That's tolls, gas. Whether it be a hotel stay for the patient and/or their caregiver for treatment, patients can apply up to twice within a 12-month period, so that award coverage period is 6 months for travel.

Did want to mention that for Co-Pay, the award coverage period is 12 months, and as long as funding is available, patients can reapply every year.



We also have a Travel Assistance Program for pre-CAR T-cell. Those patients that are undergoing an approved pre-CAR T-cell therapy or going to sign up for a clinical trial can get similar travel assistance from LLS. That grant is \$2,500 and patients can use that grant to help with the out-of-pocket costs for lodging and travel for themselves and any caregivers that have to go along with them to support them through treatment.

And, finally, we have our Urgent Need Program. This is for patients in acute financial distress to help offset nonmedical expenses like rent, food, even cell phones, dental work that a lot of patients have to get before they can even start treatment. That program covers an array of services, and the patient will get a \$500 grant issued to them in a check to help cover those expenses.

And those are the programs that we have at this time. We continue to look into patient need, evaluate what's out there, work with donors, and continue to create programs to help patients.

**Lizette:** Wow, that's a lot of programs!

**Elissa:** One program that I love in particular is the Travel Assistance. We have a very large country and not everybody is next to an academic center or a major hospital. And particularly for blood cancers, it's so important to get treated with a specialist and those are usually at the major hospitals. So being two, three, four, five hours away from your nearest major hospital, or longer, can be such a burden when, what if you have to stay for a transplant or treatment for two or three months? I have a friend with Hodgkin Lymphoma who had to go and stay for two months in Baltimore near Johns Hopkins so that she could get her transplant, but she had to pay for that out of pocket to stay in a hotel for two months and this was during COVID, which made things even crazier. It's just such a, a burden, so I really love that program in particular.



**Erica:** Yeah. And we've got over, like, 60 local programs. Definitely for travel, we've got 3 national funds. We've got a national pediatric fund, a general travel fund that services patients across the US. We have a myeloma-specific travel fund. And then we've got some more local programs in the area where we've been lucky enough to get donors, local foundations and organizations to kind of seed money right back into their community to help patients in need in their area. And so if you visit our travel page, you can search by state and the programs are broken down by county and state and location. So it's been great and it continues to grow, which is a great thing.

**Gregory:** Yeah.

**Lizette:** Wow, I think this is the most financial assistance programs that LLS has ever had at one time, so that's very encouraging.

And I know that our financial assistance is largely dependent on funding and when it's available. Each diagnosis or program has a certain amount of funding at a time and can actually open or close, right? Can you just tell us more about how that works?

**Erica:** Sure. Like you mentioned, I mean we rely heavily on the generosity of our donors and our sponsors, so there are moments and times where we have the opening of a program, and some programs will fully subscribe depending on the level of funding we have quickly. Others stay open a little longer. Even those that appear to be closed on the website, or as we like to call them fully subscribed, we are still helping patients. It just means that I mean we like to reserve the money. So, say for our copay silos or our copay funds, disease-specific funds, once a person is granted that award, we kind of fully subscribe the program hold that money for that patient for those 12 months so they have that time to spend against that.

Same goes for travel. They have six months on their travel credit card to spend that money. And so even though we may not be accepting applications at that particular time, we are currently always helping patients who are working through and spending their grants.

**Lizette:** What happens when a patient doesn't utilize all of their grant? Is that something that happens?

**Erica:** It can happen, and that's one of the things that our team is working on continuing to do a lot of outreach with enrolled patients to remind them that they have an award. I mean Gregory mentioned it, as you're going through treatment and you're dealing with appointments, and you've got that fog over you. Your social worker might apply to programs for you on your behalf, right, and you may not even be aware that you've got money out there as you're just going through the motion.

And so we're constantly engaging patients or trying to re-educate them, remind them they have an award, remind them what we cover because any monies outside of that award period that kind of stay on the table get recycled right back into the program to assist more patients, but we would much rather see patients hit that max, especially in our Co-Pay Program.

Sometimes we hear from patients, "I didn't realize that I could be submitting my insurance premiums on a monthly basis." Sometimes people say, "Well I'm not in treatment right now. They've got me in watch and wait, so I'm pretty much just getting checked out." Well, we can pay for those labs and scans even while you're in watch and wait. Even if it's been some time and you're not in complete active treatment, if you just submitted those insurance premiums, let us cover that even the ones being taken out of your paycheck or your Social Security, use the money. The funds are there to be used.

We don't see that in the same way in travel where sometimes people may want to hold onto their travel awards and we tell them, "No, you use that to help offset." And any way you can kind of hold onto cash in a different way to help for when you are going to need it, you know, I think that's best practice.

So just to answer your question, we're always trying to remind people use the funding that's available to you when you have it. Any funds that are not used they go right back to other cancer patients for their needs.

**Elissa:** Now, Gregory, you had mentioned that you took part in the Co-Pay Program. Did you get any other financial assistance? Did you do the Patient Aid or anything like that?

**Gregory:** We did apply also for the transportation because the backstory there for us is, in the beginning, my insurance company had decided that they were not going to allow for us to have the transplant be done here in San Antonio. And so we were faced with, okay, do we go to Dana-Farber, do we go to MD Anderson, which all are more than three hours away from where we currently live. And so as we're fighting with the insurance company and trying to figure out, my wife found out that there was supplemental financial assistance for transportation, and we actually went up to Dana-Farber. We had several consultations with Dana-Farber, which kind of helped offset some of our costs, for going up there talking with the doctors and meeting with them to look at our options because, at the moment in time, we had no other choice, very much like what you explained about your friend earlier is the fact that we thought we were going to have to temporarily relocate somewhere else.

**Elissa:** That's a really good point in getting that second opinion as well that sometimes you do need to travel for that second opinion with another academic center or research hospital. So what impact has the financial assistance made for you in getting through your cancer treatments?

**Gregory:** I think it goes back to what Erica said earlier. I mean the most important thing is being able to offset some of the cost. In the case that my wife and I were running around frenzy going, "Okay, do we tap into our savings? Do we do this? Do we do that?" I mean you're just so overwhelmed. It's like a ton of bricks hitting you.



You're just trying to scramble around to figure out what's best suited to be able to move your livelihood forward.

And for us, every time we were able to get an award, it was like a hallelujah because it was like \$12,000 or \$10,000 or \$5,000 or \$500 that we're able to keep in our pockets. I mean, Erica summed it up well, can you afford groceries? Can you pay for your rent? Can you put gas in your car? I mean these things become very significant in the ability to survive when you've got so much money going out and very little money coming in. Particularly, in my case, we're right in the middle of COVID and, my consultancy business wasn't allowing for me to travel to visit customers or clients. Even though we were working very little bit remote, it wasn't really enough hours on the table or dollars coming in to cover what I would consider to be our budgetary needs on a monthly basis. So, my hats go off to the financial assistance that we received because it was needed at the time and it really kind of helped us get over the hump for sure.

**Elissa:** Yeah, definitely. That's a whole other thing in itself that, oftentimes going through cancer treatment you can't work or you have to take so much time off of work.

**Gregory:** That's right.

**Elissa:** So you're already bringing in less income and then you have so much going out the door too. And so, every little bit that you can get helps. I wish we will get to this point in this country where we don't have to do GoFundMe's anymore-

**Gregory:** Right.

**Elissa:** -but here we are. But every little bit helps and it's so good to hear that it made such an impact for you.

**Gregory:** Absolutely. I mean the only thing that made it somewhat cumbersome is the fact that you've got to be your own advocate, you got to be your own financial advisor, you have to kind of stay on top of it. So where I paid money in to kind of



offset some of the costs until my insurance company paid my doctors, then I had to get a check cut from them and it was like, you see the guy on the side of the street and he's got three cups and he tells you, "Pick the one that has the ball underneath it." That's the kind of scenario that you're going through as you're trying to navigate through these turbulent times of being able to keep your head above water because everything doesn't happen as quickly or as fast as you would like for 'em. And coming from an engineering mindset for me, time is always of the essence and as well as logic and so my patience was always running thin and my wife would always have to tell me, "Relax, relax, calm down. It's going to happen." But in a lot of cases, when you're a month or 45 days or 60 days and things are still not happening, it becomes heart wrenching and that's when these programs kick in and they get you over the hump in a manner that gives you peace of mind, serenity, and somewhat a little bit of tranquility because, it takes a little bit of that edge off.

**Erica:** And, Gregory, you mentioned that you were lucky enough to be able to have resources to tap into to kind of make an initial payment, right. And a lot of patients are not in that position, and so just wanted to highlight that within our Co-Pay Assistance Program, even for those who are able to make that initial out-of-pocket payment, we're able to reimburse the payment back to the patient for something they've paid for or in the instance where the patient doesn't have the resources, we can pay those providers directly. We can pay the insurance premiums directly or the doctor's office directly to help assist in those scenarios.

**Gregory:** Yeah. Well like I said, it was a blessing for us, that those things were well thought about years and years in advance. As they always say, "Set aside for a rainy day." And I typically do that all the time and that's probably where my coin collection had gotten so large that it allowed for us to go, "All right, it's time to sell off some of this stuff" so that we could actually not have this 800-pound gorilla on top of us.

But you're absolutely right, most people won't be able to kind of deal with these type of things. Maybe they don't have the family support or maybe they haven't thought

that far in their lives and my heart goes out to those type of folks and that's why it's so important for me to be a part of what we're discussing today because these things are out there and it's just a matter of people having the awareness to know where to go and how to, how to participate in these programs because, half of what you have is success in understanding how you get through the treatment and navigate through the treatment is knowledge. And sometimes, you've got to be an advocate for yourself because no one's going to take care of you better than you.

**Lizette:** And I think your wife would probably say that she takes good care of you too.

**Gregory:** Oh, of course. Absolutely. She is the number one caregiver.

**Lizette:** And, also, one of the biggest things too that we want to remind people and that you mentioned, Gregory, is that a lot of times people forget that they're paying for something, especially like you said, Erica, where there's premiums coming out of somebody's paycheck. So usually you don't see that, right. You don't see that going out, but it is going out. And if we could pay for that, then you actually do have that money for food, for something else. But I think it's really easy to forget about that money that continues to come out on a regular basis that you don't physically see. And I think that's a big benefit to our patients that we can really pay that back or pay for it so you do have more money available to you.

**Gregory:** Yeah.

**Lizette:** Erica, I know that there's been lot of changes in the program. We've had our financial assistance programs for a while, and I know that even folks that have been able to be a part of our programs since inception and for a while now that there's been a lot of changes. And I think that those folks need to know about those changes because maybe they're in the program and they don't know the new things that we are able to pay for at this time.



What other new things are there?

**Erica**: Yeah, we're able to help patients who fall within 600% above the federal poverty level and so we do offer a guide on our website. We always encourage patients, like, "This is just a guide so don't hold back from applying." Always apply, right.

**Lizette**: Always apply.

**Erica**: Always apply.

**Lizette**: Right, Gregory, always apply.

**Gregory**: Absolutely!

**Erica**: In addition to where you kind of fall within the 600% of the federal poverty level, we also take into account the cost of living, so where you live and how much it costs to live where you live. I mean we factor that into our income eligibility criteria making sure that, people that are in need are getting the assistance.

**Lizette**: And that used to be 500%, right?

**Erica**: Yes.

**Lizette**: Now it's 600%, so a lot more people are able to qualify for the program now.

**Erica**: Correct. In addition to increasing some of our caps, we were able to do that and also expand the services that we cover. Like, we mentioned we cover insurance premiums and we mentioned that we cover treatment and so treatment coverage is beyond just the chemotherapy that you receive. It's in, say in the doctor's office, right, through IV, it could also be that pill that you pick up right at the pharmacy. We also cover pretty much all prescribed medications, even supportive medications like anti-nausea, just any types of pain medications, anything related to managing your treatment prescribed by your doctor, the LLS Co-Pay Assistance Program will cover the



out-of-pocket cost for the patient. So as long as it's been prescribed and related to your treatment, this program will cover that. And so we're really fortunate to be able to offer that type of assistance.

And then we also did expand labs, and scans, and tests, right. Where it wasn't previously covered, say about a year ago, we were able to get the approval to be able to offer that assistance to patients. And it's a really detailed list and it's posted on our website, but bloodwork, labs, scans, and tests are covered through our program. We can pay the out-of-pocket portion for the patient.

**Gregory:** If I could quickly add because I've gone through three bone marrow biopsies and the bloodwork and the labs that come out of those bone marrow biopsies, they average anywhere between \$10,000 to \$15,000 just for the lab work. So it's a quite expensive undertaking and if insurance company only picks up 70%, 80%, 90%, you're still faced with several thousands of dollars that you're still having to come up with out of pocket to cover the remaining balance of that cost.

**Elissa:** And even just regular blood tests, a complete blood count, or CBC, can be \$250 to \$400 from the lab, including your office visit plus the lab fees. It's expensive and when you're having to get monthly tests or quarterly tests or something like that, it, depending on how big your deductible is, that could all come out of out of pocket, which is crazy.

So, Erica, this is such great information. Could you share then how patients can apply for financial assistance?

**Erica:** Sure. We offer patients, caregivers, healthcare provider, as well as pharmacies, two easy ways to apply. They can call our general call center number to apply over the phone. We've got specialists who are on the phone able to walk people through the application process for all of our programs, as well as an online portal where patients can securely put their information in and submit an application online. And whether they're on the phone or on the portal, they'll instantly get, for our Co-Pay

Program, a decision and access to that Pharmacy Benefit Card to access their funds immediately and go over and pick up that prescription if they need to.

**Elissa:** That's great. And so, we'll make sure to get that in the Show Notes for all of our listeners so they can check that out right away.

**Edith:** Gregory, on our patient podcast home page, we have a quote that says, "After diagnosis comes hope." After seeing how cancer can cause a great financial burden, what would you say to fellow patients and caregivers to give them hope to make surviving and thriving at the front of mind and not the financial burden of cancer?

**Gregory:** This made me become more humble in the aspect of understanding that I have to take care of self. And a lot of times, we lose sight of that mental aspect of self-care and awareness. And even though you've got the financial gorilla, you've got the chemo treatment and all these other different various things, if you're not happy with self, as you look in the mirror every single day and understand that you can deal with this battle and you can overcome this battle, and you got to have a standard of measurement that you're holding yourself up against, and I use the power of prayer as my standard measurement and my faith. Those type of things carry you a very, very long way because, at the end of the day, even though you have caregivers and loving family members and all these other different support groups that are out there, you have to really understand that it's internal, that's the fight. And when you turn on the switch that says, "You're going to accomplish this," at the end of the day, there's nothing that you can't do. You're unstoppable. Doesn't matter if you got cancer or not.

And that's the same thing I had to do for myself is turn on the switch and say, "I'm going to beat this" and be in a position to where regardless of what it takes, I have not lived my fullest life, and I want to see more.

**Elissa:** I love it. Well thank you so much, Gregory and Erica, for joining us today. I know at LLS we just really want to make sure that surviving and then thriving is a



priority for patients and that we have to worry about the financial burden a little bit less and have that on the back burner. That that is not ever going to prevent you from getting treatment and surviving and living that life because there is so much more of life to live. And so thank you. We appreciate you, Gregory for sharing your story and, Erica, for telling us all about the financial assistance program. We hope that you will get a flood of calls of people applying after this.

**Erica:** Yes, that would be great.

**Elissa:** And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families. To help us continue to provide the engaging content for all people affected by cancer, we would like to ask you to complete a brief survey that can be found in the Show Notes or at [TheBloodline.org](http://TheBloodline.org). This is your opportunity to provide feedback and suggested topics that will help so many people. We would also like to know about you and how we can serve you better. The survey is completely anonymous and no identifying information will be taken.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to [LLS.org/PatientSupport](http://LLS.org/PatientSupport). You can also find information about our Patient Financial Assistance at [LLS.org/Finances](http://LLS.org/Finances). All of these links will be found in the Show Notes or at [TheBloodline.org](http://TheBloodline.org).

Thank you again for listening. Be sure to subscribe to *The Bloodline* so you don't miss an episode. We look forward to having you join us next time.