

Speakers:

Emily Knight

Audrey Hassan

Michael Grischenko (Diplomat Pharmacy)

?: ... Diplomat Specialty Pharmacy.

Michael Grischenko: How are you doing and I personally thank MDS for putting this on. It's not often that we all get together and discuss things that really need to be discussed, but I am Michael and I represent Diplomat Specialty Pharmacy and what that means is basically we are pharmacy like your neighborhood pharmacy like Rite Aid or CVS, but we go beyond just dispense your medications. As the physicians stated, a lot of these drugs that are expensive, Revlimid, (inaudible 0:34). Revlimid tends to be anywhere between \$7,000 and \$11,000 per cycle. So, your 28 days supply, it can be about \$11,000 and a lot of these patients don't tend to know the prices because they don't need to know. I mean, the last thing you need to worry about is the drug that could save your life or it could extend your life is \$11,000 and how are you supposed to obtain that money. So, what we do is upon receiving a prescription, we process it, we do the prior authorization and for a lot of Medicare patients, every Medicare patient actually, in the beginning of the year you will come out with a (inaudible 1:12) hole and that (inaudible 1:14) hole can vary between \$2,300 to \$2,800 and typically what happens is we reach out to the patients, say, "Hey, you know. This is your co-pay," and what the next step is. The patient says, "Oh, my God." That's the initial reaction and where do you go from there and we start asking questions. What's your income? How many household members do you have? Do you have any pass due medical bills? And a lot of times is, "Well, this (inaudible 1:40) currently. Yes, I have medical bills," or, "I'm supporting myself," or, "I have my wife is going through some stuff as well." Whatever it is. So we take that information and we apply it to a foundation and there is foundations throughout the nation, Chronic Disease Fund. They are a wonderful foundation. PAL, P (inaudible 1:59), Cancer Care. It's all these foundations that are put in place to help not only Medicare patients, but patients that cannot afford their co-pays and the manufacturers do help out a lot. I mean, they have co-pay cards, but those are geared towards patients who have private insurances because manufacturers cannot help a Medicare patient in that sense. They (inaudible 2:19) new drug if your off label or you have no insurance, but none. So, the next step is we apply to you to that foundation and depending on your income, you can vary on the co-pay. So, you could have a zero co-pay, you have a \$10 co-pay or \$5 co-pay whatever it is. So initially, we went from that 11,000 to whatever your insurance covered which is usually the rest other than the \$23 and then the foundation covers the rest. So, they grant you an amount. Let's say for... I know some of you took the pamphlet for Revlimid they can grant you up to \$10,000 a year. So, what does that mean? Let's say you have a drug that is prescribed to you (inaudible 3:00). There's a brand new drug and you're just diagnosed. The physician says, "Here's Revlimid." You came to whatever pharmacy and they ran your prescription. You have a co-pay of \$2,800. So, they apply you to a foundation as we did and the \$2,800 is covered. The next step is, next month February comes around. You run the refill and you then pay 5 percent which is called a catastrophic (inaudible 3:23). Five percent of that \$10,000 or whatever the drug is. I'm going to use 10,000 as an example. So, you have to pay \$500 in February for your co-pay. So for a Medicare patient, that's maybe every (inaudible 3:35) they get their \$8,000 a year for 2 people. That's quite a bit. So, the foundation because they grant you \$10,000, they'll last for the rest of

the year. So, your \$500 is covered in February. March, April... all the way until you either run out of funds or it resets which we then reapply. So, we are a pharmacy that does all that for you. So, some things that I'm going to say to you probably never heard of. You don't know what a (inaudible 4:02) hole is. You don't know that there's foundations out there for you and that's where we come into play is these drugs are amazing. Revlimid is amazing. (inaudible 4:12) is amazing, but if you can't get your hands on them, they're pointless. What are they going to do for you? So, whenever we help out that's what we do and people ask, "How (inaudible 4:26)? How much does this cost and there's a catch to everything. Nothing's free." Well actually, it is free. We don't charge for anything we do. This is compliance (inaudible 4:34). So, instead of you getting medication in a vial, we can patch you like this for free. You say, "I want a care pack." We do it for you like this because to be honest, I'm 25 and I don't know that's (inaudible 4:46) today. I don't remember. If I'm running 20 medications, the last thing (inaudible 4:51) is did I take this or not? How many am I supposed to take? What do these say? So, this is packaged however your physician prescribes it. Every other day, every other day, two pills a day, two pills a day, whatever it is. It (inaudible 5:03) daughter doesn't open it, so they can't get the drugs out. It (inaudible 5:07) to be a cost. So, all this and there are other pharmacies out there that do similar products and similar services ask. Always ask your physician and we always ask your nurse what could my co-pay be? What could this be? What could that be because unless you know, you're just going to come back to them and say, "I can't afford this. I can't take the drug. What's my next step?" or you will (inaudible 5:30), "I got to sell my car to pay for these services, to pay for these drugs." So bottom line is ask questions. My card is on the table. If you have a question, you can E-mail. You can call me and I'll be more than happy to help. Questions?

Q1: Question. I just got on the program. This is probably is my first time that (inaudible 5:54) and they okayed it for a whole year. What happens after that?

Michael Grischenko: It's probably (inaudible 6:05) program will be calling you telling the foundation or...

Q1: I don't know. I went through Cure Script and then I had to send (inaudible 6:12) financials.

Michael Grischenko: So basically, what happens is I assume they applied you to a foundation as that's what we're talking about.

Q1: I don't know what they did, but...

Michael Grischenko: So, if it's a foundation... If it's a foundation that they applied you to, it depends on the foundation. They either go by a 12 month cycle. So if you went from April, they would give you through April or some foundations (inaudible 6:32) you got approved in April it ends in December. Typically, a pharmacy, some do, some don't. I can't answer for everyone. Prior to you running out of funds or prior to those funds expiring, they will reapply you to that foundation.

Q1: So, I was under the impression that Revlimid... What is the...

Michael Grischenko: Celgene.

Q1: Celgene itself is actually the ones who...

Michael Grischenko: It depends on your situation. If you are an insured or you're off label.

Q1: I am insured.

Michael Grischenko: You are insured. Are you on Medicare? No, that's a private insurance. Then most likely Celgene got involved. I mean, I don't know your situation. I would need to know is it (inaudible 7:16) drug.

Q1: Yes.

Michael Grischenko: So, Celgene... So, your insurance is not being billed then or is it?

Q1: I don't know.

Michael Grischenko: You don't know. Okay. So, I would need to know because in a case where either your insurance didn't cover it or it's not a formulary, Celgene would step in. They would give you a year's worth of free drug. You need to then follow up with your physician and Celgene to see if they've reapplied you or if the pharmacy because once Celgene steps in, the pharmacy that you originally went through does not... doesn't have anything to do with because if we... if you process a prescription and it has to go through Celgene, we step away. I mean, we do all the paperwork. Once you get the drug we're good to go, but we don't fill the drug. They take care of that end. So, you need to know...

Q1: They could cut you off anytime they want.

Michael Grischenko: They will not cut you off anytime they want. No. They will... If you go over the years with the drug, Celgene would never cut you off. (inaudible 8:10) can go up, but we're not going to give you drug. They will try to help you obtain insurance or they will work with the insurance company to get it covered because, obviously, the drug is \$10,000. They're just giving it away. So, they'll do everything they can to help you out to get you on that insurance or to the right insurance whatever it is. Any other questions? No. Okay. I guess my contacts up on there. If at any point you come across a situation where you don't know what to do or have questions, just shoot me a line or give me a call.

Q1: Well actually, (inaudible 8:43), All of a sudden, there'd many... because for 3 months, I was paying and my insurance was paying \$10,000 for the drug and all of a sudden you don't pay anything. You go, "Am I getting the same thing? Am I getting like a recheck (inaudible 8:58)?"

Michael Grischenko: No. There is no generic of those drugs. The only manufacturer is Celgene and I assume it will stay that way because of the strict guidelines for this drug. You're not supposed to even look...

Q1: So, I'm getting exactly the same...

Michael Grischenko: You are getting exactly the same thing and it might even come with a bow on it. I don't know.

Q1: What?

Michael Grischenko: A bow. A bow. Kisses and bows. Hershey's kisses. So, well, thank you.

(Applause)

Emily Knight: Does anyone else have any questions about *Building Blocks of Hope* or anything we've gone over so far today? This is kind of just an open discussion time. So, anything just...

Q2: Maybe you covered this or it's in the book, but what's the background for this? I'm just curious how the story is how it came to be.

Emily Knight. Sure. So, the MDS Foundation. It's a...

?: Could you repeat that.

Emily Knight: She wanted to know how the *Building Blocks of Hope* came about and it's the MDS Foundation is a group of nurses, doctors, who work together throughout the US and other countries and came together and decided that there needed to be better hands on education for patients and over time work together to come up with this, the book, and you'll see in there all the participants who helped bring it together.

Q3: Do doctors get some of your literature and some of these (inaudible 10:48) because I almost feel that we go to oncologists and they have so much more dramatic cases that I almost feel like we're like step children and... in an oncology office. So, do they get information of support, what we need and all that?

Emily Knight: We can send them the information if it's important if they reach out to us or the nurses there reach out to us and ask for it. We don't just send out the information.

Q3: I keep making (inaudible 11:20).

Emily Knight: You could mention it to them and maybe by chance they would... the nurse or the doctor would be interested in getting their hands on some so that other patients there have that available to them. Yes.

Q4: If they haven't found a match for a person, what do you recommend that he or she do or is there anything that can do if they can't find a match?

Emily Knight: For stem cell transplant?

Q4: I'm sorry. Yes.

Emily Knight: Yes. No. So if they can't find a match then just we'll be continuing then whatever treatment you're on to try to keep things stable, continue with transfusions, continue with whatever if it's chemotherapy, Vidaza and then they can continue to search through the National Marrow Donor Program, continue that bone marrow search.

Q5: I was just going to add if you're in a community and you're close to either a church or some kind of community organization. I know in our community, we have... it's really an easy test to do (inaudible 12:37).

Moderator: Yeah. It's just a swab. So some people, if they have a family member or friend that is need of a transplant and they can't find a donor, they put together drives where they get people to swab and donate and I think the website is just NMDP, National Marrow Donor Program.org. You'd probably be able to get information on there.

Q5: And help putting a drive together.

Emily Knight: Exactly. Yeah. Good question. Yes.

Q6: Is there any support group in Northern California?

Emily Knight: Let me check with Audrey because she helps put together support groups. If there's not a support group... Yeah. Is there a support group in Northern Arizona... or Northern California?

Audrey Hassan: Yes and if I'm not mistaken in your packets... No, it's not in your packet today. I'm sorry, but on our website there are two groups that meet in Northern California. One is at Stanford and it's actually up on our website on [www.mds-foundation.org](http://www.mds-foundation.org). You look on our calendar, we have all of the meeting dates on our calendar and it gives the location. Once you leave here, if you're interested in going just E-mail me or get onto the foundation website and there'll be a link to E-mail me and I can give you that information and then there's another group, too. They meet at a Presbyterian church, I think, quarterly and I can't think of the name. It's near Palo Alto though just on the outskirts, but there are two groups. The one for (inaudible 14:26) at Stanford and it's led by Lev Vector (sp? 14:30) who's on our Nurse Leadership Board just like Emily is. So, it's a great group and they meet regularly. So, it's up on the calendar, I do know, on our website.

Emily Knight: Does anyone else have any questions about... You know, we can take questions about anything really. Part of the segment today was quality of life and I know that when you have MDS and you find out you have MDS, you have to change how you live because of appointments, if you're on treatment, transfusions and that can be hard to deal with. So, support groups can be a big help. We want you to know that you can go to the MDS Foundation website, reach out to us if there's information or support we can give you. We'll be there for you.

Q7: Are there contact people like patients that you can contact through them and have a conversation?

Emily: There is an online support group through the Foundation website which you'd be able to... if you go the website, you'll be able to find.

Q8: Does MDS have any type of advocacy behalf of MDS... One of the things that just discussed after the break, during the break, is the fact that all hospital don't collect the cord blood from birth which simply is, I say, go to waste. It's not used and with MDS and other diseases similarly, it just seemed to me like how would you justify just throwing that away? Is there an advocacy of some sort and whatever that would encourage hospitals to collect that and maybe they do need some type of central storage or some form of doing that, but it just seems such an awful waste for that not to happen and I don't think any of the mothers would object to that being collected.

Emily Knight: Right. I don't know that there is an advocacy group that looks at that, collecting all cord blood. I know it's probably a financial issue. I don't know how much money is involved and then you have to figure out storage. So, there is a lot of logistical things to think about, but yeah. Definitely something that could be looked into. Well if no one has any other questions, we can... you're free to go, free to chat amongst each other. I hope you found the meeting today helpful and informative.

?: I'd like to say thank you very much.

(Applause)

(Inaudible conversations 17:35 – 19:33)