Insurance and Access to Care in the US

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[00:00:00] **Intro:** ABCs of NMOSD is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder, or NMOSD, a rare relapsing autoimmune disorder that preferentially causes inflammation in the optic nerves and spinal cord.

[00:00:22] ABCs of NMOSD podcast series is hosted by SRNA, the Siegel Rare Neuroimmune Association and in collaboration with the Sumaira Foundation for NMO, The Connor B. Judge Foundation, and Guthy-Jackson Charitable Foundation. This education series is made possible through a patient education grant from Horizon Therapeutics.

[00:00:58] **GG deFiebre, PhD:** Hello everyone, and welcome to the ABCs of MMOSD podcast series. Today's podcast is entitled, "Insurance and Access to Care in the US." ABCs of NMOSD is an education podcast series to share knowledge about neuromyelitis optica spectrum disorder. My name is GG deFiebre from the Siegel Rare Neuroimmune Association.

[00:01:18] This podcast series is hosted by the Siegel Rare Neuroimmune Association, in collaboration with the Sumaira Foundation for NMO, the Connor B. Judge Foundation, and the Guthy-Jackson Charitable Foundation. This podcast is being recorded and will be made available on the SRA website and for download. ABCs of NMOSD is made possible through a patient education grant from Horizon Therapeutics.

[00:01:42] Horizon is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Horizon believes science and compassion must work together to transform lives.

[00:02:02] For today's podcast, we are very pleased to be joined by Marissa Shackleton. Marissa is the Executive Director at the Elliot Lewis Center in Wellesley, Massachusetts. Welcome, and thank you for joining us today, Marissa. Do you mind just introducing yourself?

[00:02:16] **Marissa Shackleton, MS:** Hi, good afternoon and thank you for having me. As you mentioned, I'm the Executive Director at the Elliot Lewis Center. The Elliot Lewis Center is a comprehensive care center for patients with NMO and multiple sclerosis located outside of Boston in Wellesley, Massachusetts. I work closely with our physicians, Dr. Joshua Katz, Dr. Andrew Bouley, and Dr. Ellen Lathi, as well as our nurses, social worker, research team, and onsite infusion center.

[00:02:44] I've been working with ELC for the last 10 years. I work with patients directly with NMO and multiple sclerosis, and I'm active with the National MS Society, the National Infusion Center Association, and I'm a national speaker on access, reimbursement, infusion centers, and practice management. I also serve on the Board of Directors for The Sumaira Foundation for NMO and the Infusion Access Foundation.

[00:03:08] I am extremely passionate about patient care, access to treatment, and affordable treatment. It's my goal to educate patients and practitioners, to make sure that patients can access the best medication for their disease and at a cost that is affordable, which brings us to our topic today. Today we'll be discussing health insurance and how to navigate access to treatment.

[00:03:29] **GG deFiebre, PhD:** Thank you so much. We're very excited to have you here for this really important discussion and one that I think is really complicated. You know, the insurance system is incredibly complicated and, you know, it's... especially during this time of open enrollment, when people are potentially picking insurance plans, you know, having this discussion I think is really great. So, to start, can you just tell us about what the different types of insurance are? So, for example, private insurance plans or Medicare or Medicaid.

[00:03:59] **Marissa Shackleton, MS:** Sure. So, those are really the three buckets for insurance, whether it's a commercial plan or a government plan, like Medicare or Medicaid. So, we can walk through those in a little bit of detail. Insurance can be provided through the government, like Medicare. So, Medicare is a federal program for people that are 65 or older, or those with disabilities, those who've received SSDI for at least two years. Medicare A pays for certain healthcare expenses. Medicare typically covers 80% of services. If patients only have Medicare, they'll be responsible for 20% of healthcare costs.

[00:04:37] Often, patients have Medicare with a supplemental insurance or a second plan that covers that 20% that's not covered by Medicare. Medicare has different parts. Part A and part B are standard and cover hospital, doctor visits, outpatient care, home health care, and durable medical equipment. Part D is drug coverage, covering the cost of prescription drugs, and this is an add-on to traditional coverage.

[00:05:03] So, if you have Medicare parts A and B, you may not have part D, but you can opt to add that to your coverage. There are also Medicare advantage plans which bundle all the parts of Medicare for greater coverage. Moving on past Medicare is Medicaid, which is an another federally funded program that is run at the state level to assist lower-income families or individuals paying for long-term medical care costs.

[00:05:31] The application process and eligibility varies by state. So, that is a quick overview of Medicare and Medicaid, the government programs. The private insurance that you mentioned, like commercial insurance, may be provided by the employer or purchased on the marketplace. For marketplace plans, you can enroll if you have a change-in-life event or during the open enrollment period. As you mentioned, open enrollment is now. It's from November 1st through December 15th. You can go to healthcare.gov for more information on open enrollment.

[00:06:10] **GG deFiebre, PhD:** Great. Thank you so much. And so, I know you mentioned, too, about Medicaid and how that kind of differs from state to state. And a question we sometimes get is about people who might have more assets than is... makes them eligible for Medicaid. And so, there are things called pooled trust or special needs trust or supplemental needs trust that can sometimes be used, you know, in a case-by-case basis to allow people to get long-term care through these trusts, even if they have more assets or above the income limits for Medicaid.

[00:06:42] So, I also certainly encourage people to look more, for more information about those trusts if they aren't eligible for Medicaid but, you know, are still interested in getting Medicaid as well. So, you know, you mentioned that people can have Medicare or Medicaid or commercial insurance. What happens if someone has all three of these which, which can happen, or two of these? But you know, how does that work?

[00:07:06] **Marissa Shackleton, MS:** Yeah, so having two of those is quite common. Having three is a little less common, but definitely still happens. In most cases, the commercial insurance pays first, followed by

Medicare, and then followed by Medicaid. When you have more than one insurance plan, it's important that they know about each other. This is called coordinating benefits. If the benefits are not coordinated, the insurance may deny claims stating that your other policy is responsible.

[00:07:34] So, for example, if you have two commercial plans, they need to know about each other so that it's coordinated who pays first, and the same goes for the government plans as well. It's important that they're all looped in. I'm finding now that it's more common that insurance companies are requiring patients to contact the insurance company annually to coordinate benefits.

[00:07:58] **GG deFiebre, PhD:** Great. Thank you. Yeah. So, my follow-up question was just going to be, is this, you know, is the person who is insured the one who is responsible for contacting the insurance and making sure that they're kind of all aware of each other?

[00:08:11] **Marissa Shackleton, MS:** Yes, the insured is responsible for that. As a private practice, we see it come up through our billing occasionally, and we reach out to the patients and try to explain the process of coordinating benefits. And really in the past couple months, I've seen it so much more frequently than I have in past years, that insurers are requiring confirmed coordination of benefits before they will pay your claim. So, it's possible that patients might receive a notice in the mail or a notification from the insurance company or one of your doctors that you need to coordinate benefits.

[00:08:45] **GG deFiebre, PhD:** Okay. Great. Thank you. And then, what terms should we know to understand insurance? So, I know that there is a lot of terms that get thrown around, and it can be kind of difficult to know what each of them mean, especially if you're trying to pick a plan. So, do you mind just talking about those different terms that someone might encounter when trying to understand insurance?

[00:09:04] **Marissa Shackleton, MS:** Sure, the terms that insurance companies use can really seem like another language. It can be confusing for people like myself who works with insurance companies every day. So, I can only imagine how much more confusing it is for patients that are not involved with their insurance company on a daily basis.

[00:09:21] So, we'll walk through a few of the most common terms. Benefits is one that I've already referred to a few times. So, your benefit is the healthcare items or services that are covered under your health insurance plan. If you are seeking a new medication or a new treatment, you would want to know, is that medication or treatment covered under your, your benefits in your current insurance plan?

[00:09:47] Something else that we talk about a lot are the out-of-pocket costs. So, out-of-pocket is the dollars that you are expected to pay in conjunction with the insurance or before they will pay their part. So, one of those out-of-pocket terms is deductible, and that's the amount that you pay for your healthcare services before your health insurer pays. Deductibles are based on your benefit period.

[00:10:11] They usually reset once a year, not always coinciding with the calendar year, but most often they do. Another out-of-pocket cost, a payment that you're making, is a copay. You are probably... of all the insurance terms, copay may be the one that you're most familiar with. Co-pays are the amount you pay to your healthcare provider at the time you receive services.

[00:10:33] Other items that we talk about our network status, whether you're in network or out of network. Your insurance network is often dictated by selecting your primary care provider. Your insurance may require you to stay in network, meaning seeing specialists that are part of the same hospital system as your primary care physician.

[00:10:53] Some insurers allow for out of network visits, but it may be at a higher cost. Other insurers are also open network, so you can see any provider in any network. It's important to understand what networks your primary care provider is in and what network your specialists are in, and if that's acceptable to your health plan or if you're going to have a larger cost if they're in separate networks. These are some factors that are important to understand when you're choosing your insurance plan.

[00:11:22] If you are purchasing your insurance from your employer and have options on plans, it's important to take a close look at the deductible, that out-of-pocket cost you have before your insurance company starts paying. If you have regular MRIs or receive treatment for a chronic disease, you can often assume that you'll pay the entire deductible each year.

[00:11:44] With that in mind, is it worth paying more per month for an expensive plan if that means a lower deductible? It's seeing to do a, a mass calculation here on what your cost is going to be at the end of the year. Do you want to pay less each month, but then have a higher deductible when you have an MRI or a treatment cost? Or would you pay more each month in opting for a lower or no deductible plan?

[00:12:09] It really comes out to how much are you going to end up spending over the course of that year. If you're purchasing health insurance from the connector, from that healthcare.gov site, you can visit the website to see your options and if you're eligible for any subsidies. You can call or schedule an in-person appointment with an application counselor if you need assistance.

[00:12:31] I really find that patients don't take enough advantage of these counselors and call them, make an appointment with them. Ask them to walk through your options. If you have Medicare or Medicaid, there are counselor options for you as well. You may consider speaking with a SHINE counselor - that stands for Serving the Health Insurance Needs of Everyone.

[00:12:52] These are insurance counselors focused on government insurance. They could assist you in exploring Medicare or Medicaid plans. They can review your existing coverage, provide benefit comparisons, assist with applications, enrollments, and appeals, and review eligibility for financial assistance. I know that was a lot of insurance terms that you may not be familiar with. Luckily, this is recorded, and you can go back to listen for some more details, and we'll be taking some questions at the end.

[00:13:22] **GG deFiebre, PhD:** Great. Thank you so much for that overview on all of those terms. And so, what happens if someone can't afford a medication that they need or that their doctor has prescribed?

[00:13:34] **Marissa Shackleton, MS:** Yeah. So, this is something that we deal with regularly with our patients. Affordability is key to accessing treatment. So, in specific relation to NMO, there are three FDA-approved medications for NMO, and they are considered biologics. These medications are considered more complex and are typically more expensive.

[00:13:55] They often require a prior authorization from the insurance company in order to be approved and administered. This means that the insurance company decides if they will cover the medication or not. Your provider's office submits documentation about why you need the medication, perhaps what medications you've tried before, and confirmation of your diagnosis.

[00:14:16] The insurance company can approve immediately, or they could request additional medical history, or they can deny coverage. In the case of denying coverage, there are still options. It's really important that these decisions for treatment are made between the physician and the patient and not the insurance company.

[00:14:35] So, I want patients to understand that there are options if coverage is denied, and if the medication is unaffordable, there are financial assistance options. So, if both the patient and the provider are in agreement on treatment, both need to be advocates to get insurance approval. Your provider can submit additional medical records and documentation in support of the therapy choice through an appeal process. Many manufacturers will assist the providers by providing letters of medical necessity.

[00:15:06] They can also provide letters to patients to help with the appeal and approval process. When I speak to patients, I advise them to be their own best advocates, reaching out to the insurance company directly to advocate for treatment approval. The last thing the insurance companies want is to pay more money for one of their insured. It's helpful to have them understand that treatment with medication will reduce the long-term cost compared to if the condition was left untreated.

[00:15:34] **GG deFiebre, PhD:** Okay Thank you. And so, you mentioned an appeal process which someone can go through to try to get coverage. So, what happens if an insurance company still denies coverage after an appeal?

[00:15:48] **Marissa Shackleton, MS:** Sure. Unfortunately, this does happen. And there's usually an option for your physician to speak with a physician at the insurance company as a last attempt for coverage. This is something the insurance companies refer to as a peer-to-peer. If this is unsuccessful, you may be able to receive free medication through the manufacturer. There are free drug programs for patients who are considered uninsured, under-insured, and have no coverage.

[00:16:15] **GG deFiebre, PhD:** Thank you. And so, you also mentioned a letter of medical necessity, which is kind of part of the, you know, getting coverage or appeal process. So, what exactly is a letter of medical necessity?

[00:16:28] **Marissa Shackleton, MS:** Sure. I know we're hitting a lot of terms that are truly used by, and exclusively used by, insurance companies. A letter of medical necessity is a document written by your provider's office confirming the request is required. This often includes confirmation of diagnosis and rationale for the requested treatment or equipment. Letters of medical necessity may be required for a new medication or for durable medical equipment, such as a wheelchair.

[00:16:56] **GG deFiebre, PhD:** Great. And then, what are someone's rights regarding appeals or denials with an insurance company?

[00:17:03] **Marissa Shackleton, MS:** Patients have the right to appeal the insurance company's decision. In most denial letters, the patient's rights are included, along with steps to appeal to the citizens.

[00:17:13] **GG deFiebre, PhD:** Okay, great. And then, what happens if a medication, you know, ends up being approved but is too expensive?

[00:17:23] **Marissa Shackleton, MS:** Right. So, it may be covered by the insurance but not until your deductible or out-of-pocket is met, which could be several thousand dollars. There are many financial assistance programs available. Commercially insured patients like we talked about earlier that have purchased plans, not government plans, are eligible for co-pay programs. Copay programs are a little bit confusing in, in name, that they do not just cover your $25 copay to see your provider, but they can reduce the cost of your medication significantly. They can cover several thousands of dollars. And there are generally not income requirements to these programs.

[00:18:03] In respect to NMO, the three FDA approved medications - Soliris, Uplizna, and Enspryng - each of those have manufacturer copay programs for eligible patients. NMO advocacy organizations can provide resources on these programs, including information about the approved therapies, as well as links to copay programs and details on eligibility. If you are not eligible for copay programs because of your government insurance or other reasons, there are patient assistance foundations to help with the cost of medication. These may have income requirements for the assistance funds, so contact your provider or your medication manufacturer for financial assistance options.

[00:18:46] Many assistance foundations have not previously provided funds to patients with NMO. Just recently, foundations such as the assistance fund opened their funding to patients with NMO. Educational and advocacy platforms like this presentation help bring attention to the need for more financial assistance for patients with NMO and with all chronic disease.

[00:19:09] **GG deFiebre, PhD:** Thank you. And then, we've talked a lot about insurance and, you know, appealing insurance and the terms that are used to kind of understand how insurance works. But what happens if someone is uninsured or doesn't have insurance?

[00:19:23] **Marissa Shackleton, MS:** Sure. So, someone who does not have insurance or considered uninsured, they are often eligible for free drug programs. They need to meet the prescribing criteria for the medication and may need to have a financial assistance screening in order to qualify. Again, contact your provider or the medication manufacturer company to see if you can qualify for free drug as an uninsured patient. Just because someone is uninsured does not mean they should not have access to treatment.

[00:19:51] And it's something that we've seen particularly in COVID, that when patients have perhaps lost their jobs or lost insurance, they are nervous that they're no longer going to have access to medication. So, it's really important that patients and providers know that these programs exist for patients who don't have insurance. Just because you're uninsured doesn't mean you shouldn't get your treatment.

[00:20:13] **GG deFiebre, PhD:** Great. Thank you. And so, we sometimes also hear the term under-insured. So, there's uninsured and then under-insured. So, what does under-insured mean?

[00:20:24] **Marissa Shackleton, MS:** So, under-insured means the insurance coverage is inadequate, having only partial coverage. You know, we talked earlier about Medicare patients, how they're only covered at 80%. These Medicare patients are considered under-insured if they don't have supplemental coverage. 20% of their costs are not covered by insurance. So, this shows the importance of having supplemental coverage with Medicare. But if patients are under-insured, they may qualify for free drug programs the same way that uninsured patients qualify.

[00:20:57] **GG deFiebre, PhD:** Thank you. And I know we, we've talked a lot about kind of all these different aspects of insurance and accessing care. But are there any kind of additional items to consider?

[00:21:07] **Marissa Shackleton, MS:** There are a few other items to consider for financial options. Some patients have been successful through personal fundraising. I don't find this to be as common for medication costs because of the options we already discussed, like the copay programs and third-party assistance programs and the free drug program. I have personally seen fundraising for items that are not covered by insurance or financial programs, such as durable medical equipment or service dogs.

[00:21:38] I think that here, the bottom line when it comes to financial challenges is to ask for resources. There are pharmaceutical programs, third party assistance programs, and advocacy organizations with

resources. If you do have out-of-pocket costs, there are often options for payment plans and be empowered to ask about assistance options.

[00:21:58] **GG deFiebre, PhD:** Great. Thank you. And just a question, I know you, you kind of mentioned briefly how there have been some issues with, you know, if someone loses their job, for example, and then loses their insurance. But have you seen any kind of other ways that COVID has impacted insurance or access to care?

[00:22:14] **Marissa Shackleton, MS:** Sure. Certainly, changed the way that we do a lot of things and especially around health insurance. So, I mentioned the challenges with patients losing insurance. Also, the, you know, added benefit of, of telehealth services that are covered for insurance and that are now covered by insurance companies. There's also, health insurance may cover some COVID treatments. It was covered fully. Now, it seems that it depends on what the insurance is and what the situation is.

[00:22:48] **GG deFiebre, PhD:** Okay, great. Thank you. And then, any kind of last thoughts or any, anything anyone else should consider as we kind of move into this open enrollment period of time or potential resources if people want additional information about insurance access?

[00:23:03] **Marissa Shackleton, MS:** Yeah, patients should really take the time to understand their insurance plan. Kind of going through those terms we talked about. What are your benefits? What are, what is your out-of-pocket costs, your deductible? Do you have the opportunity to change plans? Is that a wise decision right now? Are your medications covered? And are you paying an out-of-pocket cost for your medications, for your treatment, for your physician visits? And are there co-pay programs or financial assistance programs that you're eligible for? It's very common that I find that patients don't know that they are eligible for assistance or that patients think they have to have a financial... they have to prove they have a hardship in order to receive these services.

[00:23:47] And that's not the case in many, in many situations. Patients should really investigate their options and, and take advantage of them. They are there for you. Please use them, please ask your provider about them. Please reach out to your medication manufacturer or advocacy groups. They can steer you in the right direction.

[00:24:08] **GG deFiebre, PhD:** Great. Well, thank you so much. We really appreciate your time and expertise. You know, as you said, this can be incredibly complex and difficult, even if you know how the system works. So, we really appreciate you taking the time today and explaining these important terms, you know, especially at this very critical time in terms of insurance. So, thank you so much.

[00:24:28] **Marissa Shackleton, MS:** Thank you. I appreciate you having me. And I hope that the patients and attendees are learning something new.

[00:24:34] **GG deFiebre, PhD:** I'm sure they are. Thank you.