



Highlights from the IG Living Teleconference, October 19, 2017

Topic: How to Advocate for Yourself and/or Your Loved Ones

[This is an edited version of a live teleconference presentation.]

Guest Speaker: Abbie Cornett, patient advocate for IG Living magazine

Tonight's call is about patient advocacy and being your own advocate or an advocate for a family member or friend.

I have worked in advocacy for about 15 years, and I was diagnosed with a primary immunodeficiency (PI) when I was 34 years old. Prior to that, I had had the typical story of a lot of patients. Physicians didn't know what was wrong with me. I was going from one doctor to another with no diagnosis. And, the one thing I learned is you can't expect the medical community to advocate for you. You need to learn to advocate for yourself.

While learning to advocate for myself, I became active with a number of organizations, was elected as a state senator for eight years and ran a nonprofit organization in Washington, D.C., that dealt with access issues for patients with rare diseases treated with biologics. Five years ago, I started working directly with patients when I was hired by FFF Enterprises, a specialty biologics distributor.

When it's come to advocating for yourself, the first thing you have to understand is to not doubt yourself. I hear from patients all the time that they begin to doubt themselves and their illness. Believe in yourself. The question that comes up frequently is: When should you start advocating for yourself? The time to start advocating is when you feel your medical team is not addressing your medical concerns. Many times, people go to the doctor over and over again, and they don't get a diagnosis or get an incorrect diagnosis. If medical concerns are not being met, you need to start advocating to your medical provider for additional testing, or you need to look for a new medical provider.

One of the other things you need to do is ask yourself: Are your medical treatments working? Frequently, patients are misdiagnosed. If your medications are not working or you are getting worse, then you need to start advocating for yourself.

Another question people constantly ask is: “What do I do if my doctor isn’t listening to me?” The answer: Don’t be afraid to find another doctor. One of the most important things you can do is build your team. Everyone with a chronic illness has a team of care providers: a primary care physician (PCP), specialists, personnel at the infusion center, etc. You need to build a team that is there for your best interests. If one of your providers is not providing you with answers to questions or is ignoring you, don’t be afraid to change providers.

When it comes to advocating for you, knowledge is power. You need to educate yourself. That doesn’t mean just Googling your symptoms. Choose sites very carefully. Verify your facts. A good way to do this and to keep up with current research about your disease is to sign up for Google alerts that send information your way when something new is published. I tell patients all the time: Read, read, read, and ask questions. Learn about treatment options that are available.

Many times, when you go into the emergency room or to a new doctor, they won’t know about or have not heard about your disease. That’s why I say knowledge is power. A lot of times, you are going to be educating your healthcare professional. Don’t get frustrated. They are there to help you, but you need to be there to educate them about what your disease is and what the symptoms and side effects are.

One of the best things you as a patient can do is find a family or friend who can advocate for you or help to advocate for you. Oftentimes, people with chronic illness become isolated and don’t reach out for help. If you have a spouse, parent, child or friend, they don’t need to be an expert on the disease, they just have to be willing to talk to the doctors for you, to fight for treatment and understand how you are feeling. You can help them by keeping records of everything such as copies of all lab work, a list of medications, a list of healthcare providers and their contact information and a list of insurance information. Have that in a place where it is easily accessed by you and/or your advocate. There’s nothing more frustrating than not being able to find information when you need treatment.

When seeing a doctor, write down questions you have so you don’t forget anything. Healthcare providers are very busy, and because you may feel pressured, you may not remember what you want to ask. Before you go to the doctor or before treatment, write down a list of things you want to ask about.

Patients often feel isolated. One of the best things you can do is find a support group for your disease. The Internet is one of the easiest ways to find a support group. There are a lot of online pages on Facebook or Instagram, where you can seek out other people who share your disease and feelings. You can teach them about your disease, and you can learn from them. The important thing to understand is you are not alone. Support groups can make you feel like part of a community.

I will now address some of the questions submitted to be prior to this conference.

Question: How can a caregiver navigate a crisis event?

A crisis can happen at any time, especially with a chronic illness. And, a crisis can mean different things depending on the disease state. Be prepared. If you are a parent or family member, make sure you have the names of all the patient's treating physicians, a list of all medications they are taking, a list of medications they can't take and copies of their insurance cards. People get very stressed during crisis situations, and they aren't thinking as clearly as they should be, so the best thing you can do to navigate a crisis situation is be prepared.

Question: How do I deal with an insurance denial?

Insurance denials are heart-rending, particularly for those with a chronic illness because they can result in a loss of needed medication. Remember that it's not personal. It's personal for you, but it's not personal for the insurance company or for the person you're speaking with. No matter how upset you are, don't start the conversation in a combative manner.

It's important to remember you only have a certain number of appeals and a certain timeframe. The first thing I recommend is don't start the appeals process on the phone. When calling an insurance company, the representative will often ask to talk about the information on the phone. If you do, that can be considered an appeal. Always submit everything in writing — not on the phone. When you receive a denial, make sure you speak with your physician and you address the questions in the denial in the appeal. Do not submit the same information that was submitted in the original request for coverage.

If you need help with a denial, I can work with you or refer you to someone who can help. A denial is just the beginning. Most patients get denied at some point in their lives. But, 70 percent of appealed denials are won. Just be sure to read the denial letter carefully, read your policy very carefully, and look at the number of days you have to appeal. Under the Affordable Care Act, patients have 180 days to appeal, but there are different time frames depending on the circumstances.

Question: Is it always necessary to get pre-approval for medication prior to being treated?

When it comes to pre-approval, especially for expensive drugs such as immune globulin, be sure to be pre-approved before being treated. Make sure you have coverage ahead of time. It's different to get an insurance company to pay for a claim when they deny it.

Question: How do you manage when your employment switches insurance coverage at the start of a new year?

This can be a long process because, frequently, patients with chronic illness have a lot of paperwork. I wrote an article about this earlier this year for just that reason. When your insurance plan changes, you have to start the pre-approval process all over again. Therefore, as soon as you find out your insurance is changing, start getting your paperwork together, and let your doctor know you will have to start the process all over again.

Question: How can a person work with a PI?

As a PI patient, I am fortunate enough that I have not been out of work. Working at home is a great option for people who have a PI. As technology advances, more opportunities are opening up to work from home. The question is: Can you make enough money working from home? The workforce is expanding much more into flextime, shared time and working from home. I was working with a patient a couple of months ago who was too ill to go to work, but because she is a good employee, she worked with her human resources department, and she is now working from home full time, although she has to go in for meetings twice a month, as well as for work on her computer. Talk to your employer to see if they can accommodate you.

If you have to go on disability and apply for Social Security Disability Insurance (SSDI), you can still work. Basically, SSDI is like a prepaid insurance plan. You pay into it every year while you're working. When you've reached enough quarters, if you are declared disabled, you can receive SSDI and continue to work part time or with income restrictions. And, that's where working from home or a part-time job may be good.

Question: What type of assistance is available for the cost of medication?

All pharmaceutical companies have co-pay assistance programs. If you're working with a specialty pharmacy, they can help you with this. Also, Patient Services Inc. has a program that can help with medications, although there are a limited number of available slots. I can email you the different links for the organizations. But, I would recommend you go to the pharmaceutical website or to your specialty pharmacy provider to see if they have assistance programs.

Question: What do you do if your PCP won't send you to a specialist?

If the PCP is treating you for your illness, demand to see a specialist. If he or she won't, and you don't feel your needs are being met, find another PCP.

Question: How do I deal with illness when the people around me say I don't look physically ill?

This comes up all the time. IG Living publishes a number of articles on invisible illnesses. When people see someone in a wheelchair or on crutches, they understand that person is ill. But, people with invisible illness like PI, people don't physically look ill, so family members and friends often don't understand. The best thing you can do is educate them.

Before I was diagnosed, I was in and out of the hospital constantly, and my husband's family was not very supportive. It wasn't they weren't sympathetic; they just didn't understand. I got frustrated when one of my husband's cousins got cancer, and they had a fundraiser and brought meals, etc. And, then it dawned on me that cancer is something they understand. People don't understand what PI, myasthenia gravis or a neuropathy is unless you explain it to them. So, when you are educating yourself, take the time to educate the people in your life.

People don't mean to be cruel; they just don't understand. In my circumstances, I printed out articles for family members for them to read. That's one of the best things you can do. And, don't get upset when you have to cancel. You have to take care of yourself first. Try to educate your family and friends. But, at the end of the day, if they don't understand, you have to take care of you. So, educate and then accept.

Question: Why does it take so long to get a diagnosis?

We've all seen the zebra campaign. Physicians were taught years ago if "you hear hoofbeats, think horses." That means don't look for the obscure. If someone comes in with fever and vomiting, look for the most obvious. Unfortunately, that has led to a lot of patients' diseases being overlooked. Their physicians take a lot of time to diagnose them because they are not looking for the obscure.

This happens a lot for rare diseases. The average time for a PI diagnosis is at least seven years because patients go to the doctor for frequent colds, and the doctor doesn't see a pattern. It's only when the patients get really ill that the doctor starts testing for other things. So, if you feel you have a problem that isn't being addressed, talk to your physician and look for a specialist.

Question: How do I manage the interactions between the specialists I see? And, how do I ensure the different combined treatments do not create a negative impact on my health?

Last year, I wrote an article on palliative care. People know what hospice care is, and they think palliative care is the same. It isn't. Palliative care specialists are people who work with people with chronic illnesses. Chronic illness can mean a shortened lifespan, or it can mean a chronically ill long lifespan. People who specialize in palliative can go over different treatment options and drug interactions. They use a very holistic approach by addressing the whole person: comorbidities, medications and mental state. People don't realize depression goes hand in hand with chronic illness. Palliative care specialists are trained to ensure you don't have negative impacts from medications and you are receiving the care you need.