HealthTalk Webcast Transcript

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Announcer:
Welcome to this HealthTalk show. Before we begin, we remind you that the opinions expressed on this show are solely the views of our guests. They are not necessarily the views of HealthTalk or any outside organization. And, as always, please consult your own physician for the medical advice most appropriate for you.

Now here's your host, Rick Turner.

Rick:
Hello and thank you for joining us for Crohn's: It's My Money." I'm Rick Turner. Doctor visits, specialists, prescriptions, surgery, the list goes on and on, doesn't it? When it comes to living with Crohn's disease, it all boils down to a positive attitude, an excellent team of doctors and great health insurance. But what if your health insurance isn't so great, or, worse, it's nonexistent? Well, in this program, our expert will teach you how to advocate for the best possible care whether you have insurance or not by helping you navigate the insurance system, informing you of your patient rights and educating you about the alternative avenues available for medical treatment.

Joining us on the program is Jennifer C. Jaff. Jennifer is an attorney and founder of Advocacy for Patients with Chronic Illness, Inc., a tax-exempt organization that provides free information, advice and advocacy services to patients with chronic illnesses. She has taught and practiced administrative law, civil and political rights, and women and law, publishing articles in all of those areas. Jennifer spent over five years in the State of Connecticut's Attorney General's Office working primarily in the area of healthcare and social services. While at the Attorney General's Office, Jennifer also created a health insurance consumer advocacy program in which she negotiated with insurance companies and HMOs.

In private practice, Jennifer assists patients to advocate for themselves with insurers as well as is in applications for Social Security disability benefits and in the employment context. Jennifer has written extensively on Crohn's disease and patient advocacy issues. Her publications include "Know Your Rights: A Handbook for Patients with Chronic Illness," "Lawyering for Persons with Chronic Illnesses," and most recently, "Friday Tired," a book about her experiences as a patient and patient advocate. Welcome, Jennifer.

Ms. Jaff:
Thanks for having me, Rick.

Rick:
Jennifer, you yourself were diagnosed with Crohn's over 30 years ago, and just two

years ago you began the Advocacy for Patients with Chronic Illness organization. Tell us what led you from being a Crohn's patient yourself to becoming an advocate for people with chronic illness.

Ms. Jaff:
I talk about this whole chapter of my life in the new book "Friday Tired." I got very, very sick. My doctors were not aggressively treating my Crohn’s disease well enough, and my condition spun out of control to the point at which my kidneys were shutting down. I was literally in my house for three and a half years and only left the house to go to the doctor or hospital.

I started to look for support from other patients on the Internet, and what I found was a desperate need for information and assistance. So little by little, I started answering legal questions and insurance questions, and then I would write a letter for a patient here and there for free, and slowly but surely it became my entire life. And so I started Advocacy for Patients.

Rick:
Did it start there in Connecticut, or was it something where you knew people all around the country and were involved with them from the start?

Ms. Jaff:
I was very fortunate to have found the Web site, www.ibdsucks.com. The Web site has about 4,500 patients registered on it, and I went there to look for support. And like I said, what I found were people who were in desperate need of information. And they were from all over the country.

So we do this work nationwide, not just in Connecticut. It's a wonderful thing that I'm able to help people and even save lives once in a while from a computer, a telephone and a fax machine.

Rick:
So in the past two years since you began this Advocacy for Patients with Chronic Illness, how many patients have you personally dealt with, Jennifer?

Ms. Jaff:
We've responded to about 1,500 patients, which may not sound like that many, but the questions are fairly complicated, and about 400 or 425 of those cases became very involved cases like an insurance appeal or a negotiation over reasonable accommodations

in work or school.

Rick:
So with 1,500 patients in two years, that seems like a pretty big workload. Has this taken over your life?

Ms. Jaff:
It has absolutely taken over my life, and I'm thrilled. It's the best work I've ever done. It's the most important work I've ever done. Every time I get to make a phone call and tell a patient that we won their insurance appeal, it's all worthwhile.

Rick:
In terms of the types of cases you see, is there a pattern there, maybe a certain type of case that crops up more than others when it comes to dealing with insurance issues?

Ms. Jaff:
The most common question I get about health insurance is, “Where do I find health insurance that will cover my preexisting condition?” The second most common question I get is, “I have insurance, but my insurance company doesn't want to cover something that I need. What do I do?”

Rick:
When we spoke recently, you told me about the medical loss ratio, and I'd never heard of that before. What is the medical loss ratio, and what does it have to do with health insurance coverage and buying health insurance?

Ms. Jaff:
This is one of those little hidden pieces of information out there that everybody should have if they're going to be a consumer of health insurance. Medical loss ratio is a fancy term for the percentage of every dollar that an insurance company actually spends on medical care. In the 1990s, the average loss ratio was close to 90 percent. So that meant that insurers were paying 90 cents out of every dollar that we were paying in premiums on health insurance, and only 10 percent was going to administrative costs. Today, the average medical loss ratio is between 70 and 80 percent. That means more of our money is going to pay the salaries of executives, and less of that money is going to pay for healthcare.

Rick:
So how does that help us as consumers make choices?

Ms. Jaff:
Your state insurance department collects information about the medical loss ratios of the various insurance companies. And if you're trying to decide what insurance to buy, you can check on the medical loss ratio. What you want is a company that's going to spend

more money on healthcare and less money on executive bonuses.

Rick:
Like a lot of the things we're going to be going over in this program, this bears repeating. So for people who want to find out what the medical loss ratio of a given insurance company is, how do they go about doing that?

Ms. Jaff:
The insurance companies are required to file a lot of things with every state insurance department, and one piece of information that has to be available at the state insurance department is the medical loss ratio. So you call your state insurance department, and you ask for medical loss ratio information regarding the plans that you're looking at.

Rick:
Can you describe the most common insurance plans and tell us what kind of coverage a patient will get with each type of plan?

Ms. Jaff:
Before we even get to the difference between say an HMO (Health Maintenance Organization) and a PPO (Preferred Provider Organization) plan, we need to back up just one step because there are two major categories of insurance plans. One is called self-funded and the other is called fully funded. A fully funded plan is what we all think of as insurance. We or our employer pays a premium, and the insurance company pays for our healthcare. A self-funded plan is usually a large employer who decides that it's less expensive to pay for the healthcare itself. So they don't pay a premium to the insurance company. They pay the insurance company to administer their plans, and the employer pays directly for the healthcare itself.

Rick:
How common is each type?

Ms. Jaff:
My guess is they're close to 50/50. It's very surprising, and it's almost impossible to tell the difference between the two. But if you have a large employer, it's a pretty good guess that you may have a self-funded plan. And the reason it makes a big difference is state laws apply to fully funded plans, they do not apply to self-funded plans. So, for example, here in Connecticut, insurance companies are required to pay for the first thousand dollars of ostomy supplies every year, which for many patients is all they need for the year. That law only applied to the fully funded plans. It doesn't apply to a self-funded plan.

So if you're an employee of a large employer and you've got these ostomy supplies and they're not being covered, it may very well be because your employer is self-funding that plan, and therefore the state laws don't apply at all. So the consumer protections that are out there to help us don't apply at all to self-funded plans. And what's perhaps most disturbing is there's almost no way, even for me as a lawyer with a lot of experience, to tell whether a plan is self-funded or fully funded.

Rick:
If you ask your human resources department at a company, would they know?

Ms. Jaff:
If you ask the right person, they should know. I can tell you how you know. If you get what's called a summary plan description or a summary of material modifications, you're in a self-funded plan, and that means that the state consumer protection laws do not apply to you. Then once we get past the self-funded and fully funded, there are a whole bunch of insurance plans – PPO, POS, which is Point of Service, HMO and catastrophic coverage.

Rick:
Do those all fall under both categories?

Ms. Jaff:
Yes, they do. That's one of the reasons why it's so hard to tell whether a plan is self-funded or fully funded because to a consumer they look exactly the same.

Catastrophic means exactly what it sounds like. It covers a major problem like a hospitalization but usually not prescription drugs or doctor visits. HMOs are plans with gatekeepers, which means you can't go to a specialist without a referral. And if you go out of the network of providers who have contracted with the HMO, you have no coverage at all. PPOs and Point of Service plans are somewhere in the middle. PPOs are actually technically considered HMOs because there's a network, but there's no gatekeeper, so you can go to a specialist without anybody's permission. And there's usually some coverage for out-of-network services.

Point of Service plans generally cover both – they don't really have a network. They cover both in network and out of network pretty much the same.

Rick:
If you're going to be purchasing insurance for yourself or deciding on a plan provided by your employer, can you boil it down for us as to the key things you would need to ask?

Ms. Jaff:
It depends on where you are health-wise. You'll be given a summary of benefits, and that's very important because it's going to tell you what's covered and what's not. I've seen plans that have prescription drug coverage, but there's a maximum of a thousand dollars a year, which for a Crohn's patient is worthless. So, on that summary of benefits, you want to look at the annual maximums and those kinds of things.

But that's by far not the whole story. Your summary may say that prescription drugs are covered, but that doesn't mean that all drugs are covered. Most plans have what's called a formulary or a preferred drug list. You need to ask to see the formulary so that you can see if the drugs you need are covered or not. When I go to re-enroll every year and I have my choices to select from, I go to the formulary of each plan to make sure all of my medications are covered under that plan. And you can do that ahead of time. Most plans now have their formularies online, and they'll tell you where on the Internet you can look at that.

Rick:
These days, employers frequently offer something called HSAs, health savings accounts. What are these in a nutshell? And how are they best used to pay for treatment?

Ms. Jaff:
It's very technical. Just to paint the picture with a very broad brush, in a health savings account you're allowed to put a certain amount of your income into an account that you can use to pay out-of-pocket costs like deductibles. In 2007, an individual can contribute up to $2,850 into a health savings account. The big advantage of a health savings account is you're allowed to put in pretax dollars, or you can take a tax deduction for the amount that you put in for the year. So, basically, you're getting some value on your taxes by putting money in a health savings account.

But there's a big catch. You have to have a high deductible health insurance plan in order to qualify for a health savings account. In 2007, that means that for an individual your deductible has to be at least $1100, and for a family it has to be at least $2,200 to qualify for a health savings account.

Rick:
In terms of deciphering the plans, do you need professional help when you get something like that, or can I just go to my employer and figure out exactly what the plan is?

Ms. Jaff:
I think any patient with a chronic illness has to take responsibility for learning as much as possible about all of these issues. And the more we Crohn's patients teach ourselves, the more we learn and understand, the more power we have. So I think it's really important. And I think part of it is developing enough self-confidence so that you can ask the questions and not worry about feeling stupid. Stupid is buying something you don't understand. Stupid is not asking questions.

You ask all the questions you need to ask. But sometimes if you're having trouble understanding it, especially if you're buying an individual policy, going to a good insurance broker can be a very good thing to do. They will help you figure out what's available, what's affordable, whether your needs are going to be met by the plan. Sometimes it can be a little tricky to find a broker that's really good. You'll know if somebody is good because either they'll get annoyed by your questions, in which case you shouldn't use them, or they'll welcome your questions, in which case they're a good broker.

Rick:

Is it safe to say, Jennifer, that as a rule of thumb the more you spend on a healthcare premium the better coverage you're getting?

Ms. Jaff:
Absolutely not. In fact, of the three options that Advocacy for Patients has, we have chosen the least expensive option because it's the company that has the highest medical loss ratio. They spend most of their money on healthcare. We've also chosen them because there are very few complaints and appeals filed against them.

How many complaints have been filed against an insurance plan is another piece of information that you can get from your state insurance department. If an HMO has had many complaints filed against it in the last year, if you chose that HMO, you're going to be unhappy. And it doesn't matter that they're inexpensive or that they are expensive. That's not what you need to know. You need to know how they're spending their money.

Rick:
Suppose a Crohn's patient lets his or her insurance lapse, maybe they changed jobs or couldn't afford it anymore, would it be possible to get insurance again? What are the restrictions?

Ms. Jaff:
To some extent, the answer to this question varies from state to state. But, in general, if you have a break in coverage of more than 63 days, your preexisting condition can be excluded entirely if you buy individual insurance, and there can be a waiting period for up to a year if you're joining a group plan. If you lose your preexisting coverage and you're buying insurance as an individual, it's almost impossible to get it back.

Rick:
Then that preexisting condition can be used by companies to deny you coverage.

Ms. Jaff:
Absolutely, or they can offer you a policy that excludes your preexisting condition.

Ms. Jaff:
If you're in a group plan, they can't turn you down entirely, but they can make you wait a year before you've got coverage of your preexisting condition. And, of course, that year that you're waiting for coverage of your preexisting condition is going to be the time that you flare, and you need to be in the hospital and have surgery. And that's exactly how half of the bankruptcies in the United States have become attributable to medical debt.

Rick:
Is the moral of the story for Crohn's patients never to let your insurance lapse?

Ms. Jaff:
I can't stress that enough. It's the difference between bankruptcy and not, being able to afford treatment or not. I get just heartbreaking calls every day from people who lost their jobs, didn't have COBRA (continuation of medical insurance) and lost their insurance.

And they’re left with very few choices, and none of them are any good. It’s a desperate, desperate situation. If you have insurance that covers your preexisting condition, do everything you possibly can to hold onto it for as long as you possibly can.

Rick:
Suppose a Crohn’s patient is low income, doesn’t have insurance, and treatment for their disease is moderately expensive or maybe even very expensive. Do people in that situation have any options?

Ms. Jaff:
Absolutely. First, there’s Social Security disability, and if somebody is disabled, there are two kinds of Social Security disability. Social Security Disability Insurance, or SSDI, gets you Medicare two years after your disability onset date. If you’re on the other kind of Social Security, which is called Supplemental Security Income, you get Medicaid automatically. So if you’re disabled and low income, that Medicaid coverage is going to be worth an awful lot to you.

There are other things that you can do if you’re low income. One critical safety net that few people know about and understand is a federal program called the State Children’s Health Insurance Program, or SCHIP.

Rick:
That’s been in the news just recently.

Ms. Jaff:
And that’s because Congress has to reauthorize it by the end of September, or it’s going to go away. Both the House and Senate versions will expand coverage to include more children, and in some states like Connecticut their parents are covered as well. These plans are partially subsidized on a sliding scale. So if you do nothing else political in the next month, call or write your senators and congressmen and urge them to stay strong on SCHIP reauthorization and expansion. President Bush has threatened to veto the bill, so this is very real. And this is a very important safety net for the so-called working poor who make too much for Medicaid but don’t have enough money for private insurance.

Rick:
What about Medicare for these people in these tough situations without insurance and very little income?

Ms. Jaff:
The only way you get Medicare insurance if you’re not age 65 or over is if you are disabled. So those people who are working, not disabled, but can’t afford insurance are the ones who actually have the biggest problems.

There’s also the issue of under-insurance. Sometimes you hear people talking about we should have Medicare for all. Well, Medicare has 20 percent co-pays. If you go for a Remicade (infliximab) treatment every six weeks and each treatment costs you $5,000, your 20 percent co-pay is $1,000. That’s eight to 10 of those a year, every single year.

But there are patient assistance programs that help with co-pays.

Rick:
What's the difference between Medicare, the traditional Medicare and something called the Medicare Advantage plan?

Ms. Jaff:
If you are on Social Security disability, do not leave traditional Medicare. Medicare Advantage plans are the privatization of Medicare the current administration has kind of slipped in there in the back door. Medicare Advantage plans are HMOs. They restrict your coverage to less than what you're entitled to under traditional Medicare. They're marketing extremely aggressively, and they often tell you that you don't have a choice, that if you want to participate in Medicare you have to sign up with them. Well, you do. The choice is yours. And you must stay with traditional Medicare.

I wish I could say just one thing to every disabled person in the United States. I have not had to file one traditional Medicare appeal. But the Medicare Advantage plans deny coverage more often, and so we have to appeal all the time.

Rick:
How are they marketing themselves? Why would anybody want to make the switch?

Ms. Jaff:
The marketing practices are extremely aggressive and extremely deceptive. I actually walked in on a client, who was disabled with severe dementia, and she was on the phone with a Medicare Advantage plan and she was giving them her Social Security number because they called her and said, "Don't you want to have access to the best doctors?" And she said, "Sure, absolutely." Well, who wouldn't say sure, except there are strings attached to doing so? So if you are being marketed at all for Medicare, then it's a Medicare Advantage plan. Traditional Medicare doesn't have to market to anybody.

Rick:
There are a lot of areas that we want to touch on in the limited amount of time that we have. COBRA and HIPAA, what do those terms mean? What are those programs?

Ms. Jaff:
HIPAA (Health Insurance Portability and Accountability Act) is the law that contains the provision that says you can't have more than a 63-day break in coverage to protect your preexisting condition. It's also the federal privacy law, which everybody knows because they've had to sign those papers every time they go to the doctor.

Most people know about COBRA (Consolidated Omnibus Budget Reconciliation Act) when they leave their job. COBRA allows you to continue your insurance. You have to pay your premium, but you can continue your insurance for up to 18 months. However, if you're disabled, the usual 18 months can be extended to 29 months. So that's one thing that a lot of people don't realize.

The other thing is that COBRA applies to not just when you change jobs. COBRA applies, for example, when an adult child can no longer be covered on his parents' health insurance policy. COBRA gives 36 months of coverage for that adult child. Also, when there's a divorce and you lose your health insurance, you can have COBRA coverage. So there are several circumstances in which you can avail yourself of COBRA.

Rick:
Oftentimes, issues arise because insurance companies don't cover prescription drugs fully or at all, such as biologics that are very expensive. Is there anything a patient can do?

Ms. Jaff:
This appears to me at this moment to being pretty close to a brick wall. When Humira (adalimumab) was approved for rheumatoid arthritis but not Crohn's disease, insurers denied coverage of it because it was not FDA-approved for use in Crohn's disease. That's called an off-label use. Insurers pay for off-label uses all the time. For example, did you know that Asacol (mesalamine) is approved for only ulcerative colitis but not Crohn's disease? And yet every insurance company that I know of will pay for Asacol for a Crohn's patient.

Rick:
Is that because it's cheap?

Ms. Jaff:
It's less expensive. When a new and expensive drug like the biologicals come onto the market and are FDA-approved for one use but not another, not only will commercial insurers not pay for it but Medicare as well, and they seem to be able to get away with it.

Rick:
We mentioned the appeal process does exist if your claim a denied. What are some of the dos and don'ts that a patient should know when a patient is appealing a claim?

Ms. Jaff:
Number one, if you blow the deadline on filing your appeal, you're done. I can't stress enough the importance of meeting that deadline. People just kind of ignore that, and then they're surprised when the insurance company says we're not even going to let you appeal.

Rick:
Is there an industry standard?

Ms. Jaff:
Typically, with private insurance, the first level of appeal is 180 days. But it's not in every case, and you need to read the denial letter very carefully. The denial letter is required to give you that information. Try to find out whether you're only going to have one appeal or two appeals. Try to get as much information from the insurance company in writing as you possibly can.

But here's the other thing that's really important. Get medical records. If you write a letter that says that you need the treatment and are really sick without it, it won't work. Getting your medical records shows how you were doing before you used the particular, let's say it's a drug, and after, and it shows that it worked in your case. And that's the kind of evidence that you need. It needs to be in the medical records. Even doctors have a tendency to want to write a big long letter when what they really need to do is send the medical records.

Rick:
Does that go to the issue of an appeal before treatment versus an appeal after treatment?

Ms. Jaff:
The appeal before treatment is really critical because you can't get the treatment unless you win the appeal, or you can't get the insurance company to pay for the treatment unless you win the appeal. An appeal after treatment is all about money. The appeal before treatment is not about money, it's about your health because it's about whether or not you're going to get the treatment. You actually want prior authorization as much as you possibly can get it because you don't want to be stuck getting a treatment and not knowing that it's not going to be covered until afterwards because that can be a big problem. And if prior authorization is required and you don't get it, the insurance company will not pay that claim. So be very careful to know when prior authorization is required. It's required for almost every surgery and every hospitalization.

Rick:
And you mentioned this earlier, but it bears repeating, that the appeal process should be done in writing and not on the phone.

Ms. Jaff:
Absolutely. Do not phone in your appeal. The denial letter will say, "If you want to appeal, give us a call." Then what's your appeal? They're just going to look at the same information that they've already looked at. What you need to do is gather your medical records and send them things that they haven't looked at before that illustrate how

important, how medically necessary, it is for you to get this treatment. Again, we go back to that concept of medical necessity. And that's the standard. What you need to do is to show that the particular treatment is medically necessary for you.

Rick:
When can you tell when it's time to seek the help of a lawyer or an advocate?

Ms. Jaff:
The easy answer to that question is before you file the appeal. But truly, most lawyers don't do what I do. Most lawyers like to litigate. And even though you have to go through all of the internal appeals before you go to court, I think too often lawyers kind of punt on the internal appeals because they're trying to get to court as quickly as they can. We win approximately 80 percent of the appeals we file, and we never, ever litigate. So it's really important to take those appeals seriously. And so sometimes learning to be your own advocate, learning to do this yourself, is the best thing you can do.

Rick:
Let's say you lose the appeal and the company won't cover the expense of the medication that you're prescribed. What are your options then? You mentioned earlier that pharmaceutical companies themselves have some programs to help.

Ms. Jaff:
Almost all pharmaceutical companies have patient assistance programs. If you go to our Web site, which is www.advocacyforpatients.org, and you click on the left, you'll see a link to pharmaceutical company patient assistance programs. You can then look up your drug by either brand name or generic and follow the application instructions.

There is also a co-pay assistance through the Patient Advocate Foundation and through the Patient Access Network Foundation. The reason that's so important is that 20 percent co-pay for your Remicade (infliximab) will cripple you if you don't earn enough money to be able to absorb that, and those foundations provide co-pay relief to people whose income meets their standard.

Rick:
I want to get to a couple questions before we get to the audience questions. But we hear about these horror stories where people either lose their insurance or it's inadequate, and they basically lose everything financially in their lives. How common is that these days? Is there some kind of social safety net in this country that's available to catch those people who fall?

Ms. Jaff:

If I've talked to 1,500 patients in the last two years, and there's not a day that goes by that I don't hear from at least one that is in this situation, then it's very common. What's very sad about it is I've had patients say to me, "I'm so embarrassed. I've never missed paying a bill before in my life. I've never been in debt before. I've never had a problem with my credit rating. And I got sick. And that was the end of everything." They lost their house, their job, everything.

There's not a social safety net. There needs to be one. Other countries have ways of ensuring that everyone has healthcare, and we can debate the merit of the various plans, but in my opinion these stories are way, way too common. And I feel so awful when a patient calls me and says, "I'm ashamed." And I say, "How can you be ashamed because you're sick? You didn't choose to be sick. You didn't do anything wrong." And yet there is that shame that comes with it, and it's just heartbreaking.

Rick:
A couple weeks ago, you said insurance advocacy and reform for the chronically ill is the most important civil rights issue of our generation. Tell us why you feel that way.

Ms. Jaff:
Patients have to decide every day whether to pay their rent or pay their insurance premium, whether to pay their utility bill or pay for their medication. None of us should have to make choices like that in the richest country in the world. We have made progress on many of the other important issues – race, gender, age and so on – we have not made progress for the chronically ill.

It's very hard to prove that chronically ill people are "totally and permanently" disabled because their disease can go into remission at any time. We are the square pegs that we're trying to fit into round holes. And until those holes get square like we are, we cannot stop fighting for our rights.

Rick:
We have e-mails coming in, so let's get to them. One is from Brian, and he writes, "I am an independent contractor, so I have to pay for my own health insurance, and it has a lifetime maximum benefit of a million dollars. What are my options after this has been used up? I can't seem to get insurance from anyone else because of my preexisting condition. Any recommendations?"

Ms. Jaff:
Depending on the state, there are options for people with preexisting conditions. For example, many states have what are called high risk pools, which are insurance plans designed for the chronically ill. Some of them are really lousy coverage and very

expensive. Some of them are excellent coverage and reasonably priced. So you have to look hard and ask a lot of questions. So that's one possibility.

Rick:
So that varies by state?

Ms. Jaff:
Is does vary by state. All of this varies by state, unfortunately, once we get to this point. Many states have what are called guaranteed issue policies, where the state says to the insurance companies, "If you want to do business in this state, you must offer everybody some policy." Again, you have to look at what the coverage is and how much they're going to charge you, but they have to offer you something.

So there are things out there, and hopefully by the time Brian uses up his million-dollar lifetime max, if he ever does, hopefully we will have a social safety net that will answer this question better than I can answer it today.

Rick:
Wanda in Miami, Florida, writes, "We just ran out of our COBRA insurance, and I can't afford my Remicade (infliximab) treatment every eight weeks. I have a type of insurance that's not major medical and of course won't pay for preexisting conditions for one year and still won't pay for Remicade after that. My husband has three years remaining on a trust that pays 50 grand a year, but that barely covers the mortgage and bills. What should I do? I can't imagine going without Remicade treatment. It's the only thing that has helped since I got Crohn's four years ago. Should I stop the Remicade? It seems to be the only solution."

Ms. Jaff:
No, definitely not. It's not the only solution. The solution is to go to the Remicade patient assistance program, which the manufacturer of Remicade sponsors. The manufacturer's name is Centocor. If you go to, for example, www.needymeds.com and look up Remicade, it will take you right to the application form for the patient assistance program through Centocor. You can get your Remicade for free.

Rick:
Next, we have an e-mail from Heather in Appleton, Wisconsin. She says, "Are there any lenders out there that will provide unsecured loans to help pay for Crohn's disease treatment?"

Ms. Jaff:
Not that I know of. And if they do, there would have to be strings attached because if you think about it from a lender's point of view, that wouldn't be very smart. There has to be a

catch in there somewhere. So if someone is offering you an unsecured loan, knowing that you're chronically ill, to pay for your chronic illness costs, ask a whole lot of questions.

Rick:
In general, is it a bad idea to try to get a loan to pay for your treatment?

Ms. Jaff:
I've seen people lose their houses because they did that. The whole notion of debt consolidation gets very attractive when people are trying to fend off bankruptcy, but generally you do have to give security, and that usually means your house. And miss a payment and you lose your house.

Rick:
Yes, indeed. Next, we have an e-mail from Bedford, Texas, about an issue that you stressed, but we can talk about it again, "What happens if I lose my health insurance coverage? Is there any way to get insurance again, or will my Crohn's be excluded as a preexisting condition?"

Ms. Jaff:
It depends whether you go into an individual plan or a group plan. If you go into an individual plan, your Crohn's most likely will be excluded forever, or they just won't offer you insurance. If you're going into a group plan, chances are there will be a waiting period for your Crohn's to be covered, and the waiting period can be up to a year.

Rick:
So, again, if you can possibly avoid it, don't let that insurance coverage lapse.

Ms. Jaff:
Avoid more than 63 days.

Rick:
We have an e-mail from Orlando, Florida, "My son will need to pick up health insurance to bridge the time that he loses eligibility to be covered under my Blue Cross plan and the time he has coverage from his full-time employer. Are there any good systems that will cover his Remicade treatments that are reasonably priced?"

Ms. Jaff:
Well, first of all, he should continue health insurance coverage with COBRA. That's the most important thing. People don't realize that COBRA doesn't just kick in when you lose your job. COBRA also kicks in when you're an adult child who loses coverage under your parents' policy. And not only that, but COBRA can be extended to 36 months in that kind

of situation.

If you can’t afford COBRA insurance, then your other option is to go through a patient assistance program, fill out the application and hopefully qualify based on your son’s income to get his Remicade for free.

Rick:
An e-mail from Oceanside, California, says “Is it always better to choose a PPO (preferred provider organization) over an HMO (health maintenance organization)? We chose an HMO because all of our doctors are within the network, but now my gastroenterologist wants me to see a gastro-surgeon who is not contracted with Aetna because there is not one within the network. We have only begun the process to try to get my insurance to cover it. Do you have any suggestions?”

Ms. Jaff:
An HMO is always going to be more restrictive than anything else, a PPO, a Point of Service, whatever other plan there is. HMOs are gatekeepers. You can’t go to a specialist without a referral from your primary care physician. You can only go to in-network physicians. And once you’re in the HMO, it’s almost impossible to get coverage for out of network. And the answer is that your HMO is not going to cover it.

Rick:
The next question comes to us from Trevor, Wisconsin, “I find if I change jobs, the new insurance company will not cover my supplies or medical that I need for my Crohn’s. How can I get these covered and remain covered all the time?”

Ms. Jaff:
Actually, this comes under the heading of under-insurance. So it’s not as though you don’t have any insurance, but the insurance you have isn’t adequate to meet your needs. It’s actually in some ways a worse problem than being uninsured. For the uninsured, there are things like patient assistance programs. Those patient assistance programs are not available to people who have inadequate insurance.

So being underinsured can actually put you in a worse circumstance. Whatever the insurance won’t cover, you should appeal the denial of coverage and try to get it covered. And if you feel like you need some help or pointers, you’re welcome to call or e-mail me and I can see if I can try to help you.

But beyond that, if you lose all the appeals and you can show that your income is such that you can’t afford to pay for the service yourself, you may still be able to get into one of the patient assistance programs. That’s the only other thing that I know of that’s available out there.

Rick:
We have an e-mail from Vancouver, Washington. This listener writes, "I'm currently on unemployment and have to pay COBRA payments, $440 a month. I am concerned about this cost to keep my insurance and also whether I'll be table to locate another job that will have any decent coverage plus allow me to keep my same doctors. What do you suggest?"

Ms. Jaff:
I suggest that you start researching now before your COBRA runs out so that you can find out what's going to be available to you. This may sound strange, but I have chosen jobs based on the health insurance. If I have two job offers, I'm asking to see the health insurance plan. That would make a big difference to me in terms of which job I'm going to choose. The key is planning and research and not waiting until you have that lapse in coverage.

Rick:
Next, we have an e-mail from Memphis, Tennessee, "What do you do if you have no insurance?"

Ms. Jaff:
Other than trying to find insurance, you try to find whatever you can to meet your needs so that, for example, if you need prescription drugs, you apply for a patient assistance program and you try to get your meds for free.

If you need to go see a doctor and you don't have insurance and you can't afford to see a doctor in private practice, you go to what's called a federally qualified health center. And you should be able to find a list of federally qualified health centers in your state on the Internet. And those generally operate at a sliding scale and can go all the way down to free.

So it's kind of piecing together. The drugs you get covered through the patient assistance program. Doctor's visits you go to a federally qualified health center. Hospitalizations, obviously, you go to an emergency room.

Rick:
Do some states have state sponsored medical plans or are there government programs?

Ms. Jaff:
Medicaid, SCHIP (State Children's Health Insurance Program), and the high risk pools,

which are not state subsidized but they may be available, those are the resources that I'm aware of. There may be some little plan in some state that I'm not aware of. There's actually a wonderful plan that was put in place by the comptroller of the State of Connecticut, Nancy Wyman, who started up a little plan that covers municipal employees and employees of nonprofits, and that's how we have our insurance.

Rick:
We have an e-mail from Liz who writes, "I would like a natural way of taking care of my Crohn's, maybe with a holistic doctor – any suggestions as to getting this type of medicine covered on insurance?"

Ms. Jaff:
Actually, some policies are starting to cover naturopaths, for example. But it's still rare. And if your policy doesn't cover it, I have no suggestions for how to get it covered. People are really focused on the need for universal healthcare, and I think probably alternative treatments are going to be a way down the road.

Rick:
We have a listener who says, "Who can afford Remicade treatments with a co-pay of $167 a week? I make $8 an hour."

Ms. Jaff:
The Patient Advocate Foundation has a co-pay relief program, and the Patient Access Network Foundation has a co-pay relief program. Both of those foundations have Web sites that you should be able to find very easily. And if you don't have a computer, go to the public library and use one there. Get the application information, send it in, and you will get help with your co-pays.

Rick:
And we have a brief question from Arizona, "I tried to get assistance for my Remicade by going directly to the company but was denied because I make too much money. But you're right, 20 percent co-pay is more than I can afford." So this person is in the middle. What can they do?

Ms. Jaff:
You may be able to get co-pay relief even if you can't get the Remicade for free altogether. So, again, Patient Advocate Foundation, Patient Advocate Network Foundation.

Rick:
With that, we're just about out of time. But I want to thank you, Jennifer Jaff, for joining us. You've been great.

And thank you in the audience. If you didn't get your question answered, check out our reference feature for more treatment and coping information or our Ask the Doctor feature To ask a question on your own. Also, at that address look for archived shows on this topic.

And many of you have been asking for podcasts of our shows, and we now have them. Just click on the orange podcast link on the HealthTalk Crohn's home page, and you'll go right to the available HealthTalk Crohn's podcasts on iTunes. Or you can also go to itunes.com and search for HealthTalk to find all of our available podcasts.

From HealthTalk, I'm Rick Turner.

Your summary of benefits may tell you that prior authorization is required for certain things like a big surgery or a hospitalization, but they won't tell you what the criteria are for deciding whether you're going to get that authorization. So the definition of medical necessity is absolutely critical, and we almost never see that until we get a denial letter. You have a right to see the plan itself. You have a right to see your certificate of coverage, if it's a fully funded plan, or your summary plan description, if it's a self-funded plan. You may ask your human resources people to see the entire document, and you absolutely have a right to do that.

Rick:
And if you got all that information plunked down in front of you, would it be indecipherable to most people, or would you be able to understand some of it?

Ms. Jaff:
A lot of it is pretty superfluous, and you don't really need to know, but you want to look at what kinds of things are excluded. Your summary of benefits that you get every year never tells you what they're not going to cover. It only tells you what they do cover. But if you look at the certificate of coverage itself, there will be a whole section called exclusions. And you can see what's not covered.

Another big issue for Crohn's patients is the advent of new drugs and how quickly they get added to the formulary. In fact for biologicals like Remicade (infliximab) or Humira (adalimumab), they may not even be considered prescription drugs. They may be considered injectables or infusion therapies. So you need to ask if you don't find Remicade on your formulary if Remicade is covered, and ask to see the portion of the policy that says infusion drugs are covered.

Rick:

I understand that another thing that is critical to learn about your insurance coverage is the appeal process – why is that?

Ms. Jaff:
When you get denied coverage, you have a right to appeal. You have at least one level of appeal. And I have to say I've only once seen a plan that only had one level of appeal. Most plans have at least two. And now most states have a third appeal, the state insurance department. What's important to know is what is the standard the plan going to use for deciding whether to grant your appeal? It's going to always go back to the concept of medical necessity. So you want to look at the actual plan document and look at the definition of medical necessity and see if the treatment that you're getting is going to come within that definition.