Craig’s Story

Andrew Schorr:
Asthma affects people of all ages, and more than 22 million people in America have asthma. In this program, an allergist from Northwestern Memorial Hospital will discuss effective personalized treatments for people of all ages with asthma, and you'll meet a man who he's helped. It's all next on Patient Power.

Hello and welcome to Patient Power sponsored by Northwestern Memorial Hospital. I'm Andrew Schorr. There are 22 million people with asthma in America. Now, often you think of children with asthma and allergies. It's adults too. Sometimes people, as children as they age outgrow it, not always, or sometimes it comes back with a vengeance. It did for Craig Klugman. Craig is 65 years old. He's editor of one of the morning newspapers in Fort Wayne, Indiana, and that is the Fort Wayne Journal Gazette.

Craig, what happened when you were 31?

Craig:
I was walking to meet my wife at her place of business, and all of a sudden I had just a terrible time breathing. I had to stop, bend over, inhale what I could. It took me forever to get to her place of business, and later that night or the next day I had to go to the emergency room.

Andrew Schorr:
So it turned out that you had suffered from asthma and allergy as a child, gone all these years, and now it had come back?

Craig:
That is right. As a boy I had hay fever pretty bad with an occasional wheezing attack, and then it disappeared and I thought I was through it, but no, that wasn't the case. It came back with a vengeance after I turned 30.

Andrew Schorr:
Now, eventually you were hospitalized for eight days, and you began care with Dr. Paul Greenberger who is an allergist, immunologist at Northwestern Memorial, who we're going to meet in a second. What kind of treatment plan then evolved, and did it work?
Craig:
It did work. I gained my life back actually. He put me on different kinds of medication so that I could climb a flight of stairs, I could begin to exercise again. All of those things happened because of the care he gave me. He put me on new medications. He gave me an inhaler that, believe it or not actually worked, which was not my experience with the other inhalers that other doctors had tried, and he insisted on seeing me more than whenever I needed it. I would check in with him, see him on occasion for about every three months. I underwent a series of shots where he tested me. He gave me the scratch test for what I was allergic to, all those things combined.

Andrew Schorr:
So it was a comprehensive plan.

Craig:
Of course it was. It was not only comprehensive, it was detailed. He instructed me a lot on what I should be doing and what I shouldn't be doing, and I paid attention to almost all of it.

Andrew Schorr:
Well, you've been a patient of Dr. Greenberger for decades now, I think. How would you say your breathing has been?

Craig:
My breathing since I've seen Dr. Greenberger has improved quite a bit. I've been able to exercise. I've been able to function since I've seen Dr. Greenberger. The only time I've been hospitalized for anything related to asthma was when I developed pneumonia, and even though I was three hours away, Dr. Greenberger was on the phone with the emergency room doctors telling them how to treat me and what not to be doing, and basically he was the one who got me out of intensive care.

Andrew Schorr:
Wow. Now, you've learned along the way what has triggered asthma for you. So what are your triggers and what do you avoid now?

Craig:
My triggers, I'm acutely allergic, apparently, to fungus, mold spores, things like that. And so what I do immediately is of course avoid my basement, and I can feel it when I'm down there during a particular time of year. Also during as the seasons change from winter to spring and from summer to fall, that will also give me some problems. But mostly Dr. Greenberger has me under such good control that I don't really worry about those things much. I know enough not to go down and inhale the musty air in my basement, but other than that I'm doing pretty well.
Andrew Schorr:
Well, good for you. A man with severe asthma that's being controlled. Let's meet Dr. Greenberger who has helped you so much. Dr. Paul Greenberger is an allergist, immunologist on the staff of Northwestern Memorial Hospital. He's also a professor of medicine in the division of allergy-immunology at Northwestern University's Feinberg School of Medicine.

So, Dr. Greenberger, first of all, it must make you feel great that Craig is doing well and severe asthma has been managed over so many years. It shows that that is possible.

Dr. Greenberger:
Yes, it does. It does make me feel good, although I would like him not even to have to take medicines if I could help it, and we don't have him at that point, but it does make me feel good that we don't have him missing work or staying up at night wheezing and coughing or looking for his inhaler.

Childhood Asthma Symptoms Returning in Adulthood

Andrew Schorr:
Now, here's a thing that I was curious about. Here's someone as a child, and we all know kids with asthma and allergies, and the hope is that maybe they can outgrow it or it won't come back with a vengeance like it happened with Craig. But do you see that, where asthma comes back?

Dr. Greenberger:
Yes, we do. To go back to the one- or two-year-old toddler who is wheezing with viruses, like cold virus, most of those toddlers do not go on to have lifelong asthma. But often by age of six the die may be cast, because some of the children who wheeze when they're two are still wheezing when they're six years of age and then could have lifelong asthma, but they may have five or ten years in there where they have no symptoms and then it comes back. And an example of this is a child, a young adolescent who has asthma up until maybe 10, 11, 12 years of age, and everything goes away for ten years, and then when the adult is now in the 20 years and there's an upper respiratory infection, cough, shortness of breath, and all of a sudden wheezing occurs and the asthma comes back.

So an infection, perhaps by a virus can bring back the asthma symptoms, and in some cases the asthma is pretty severe where quite a few medications are required, and this upsets everything because the person had had no symptoms for ten years.

New and Better Treatment Options

Andrew Schorr:
Right. And so severe in Craig's case that he went to the emergency room, and unfortunately where asthma has not been controlled we know I think there's about
4,000 deaths from asthma a year, and that's a tremendous tragedy. You mentioned the medicines you have to control it. Now, Craig started with all this again as an adult back in the late 70s, and he took prednisone and different medicines that were available back then. How is your armamentarium, if you will, for asthma now where you can pick the right medicines or group of medicines and personalize treatment for an individual?

**Dr. Greenberger:**
The armamentarium is bigger, although I'm sorry to say that from what I understand the pipeline in the pharmaceutical world it's not as plentiful as people would like to think, and there are different reasons for that, but we have more medicines. We certainly understand a great deal more about asthma than we did 30 years ago. Asthma is recognized as a very complex condition. In the 50s and 60s people thought asthma was psychologic, and it's not, but if it's not controlled or if a person is under a lot of stress then in fact there can be asthma from stress. In fact, recently there was a study showing that young people living in environments where there's high stress and violence, there can be more asthma.

But asthma is not a psychologic disease. It's a complicated inflammatory disease. We have a much better understanding of the inflammatory aspects of it, and we have still the inhaled corticosteroids. They're steroids, but they're not muscle-building anabolic steroids like an athlete might use or misuse. They are anti-inflammatory medicines that can be very helpful for patients, and we have a much better understanding on really who responds well to them and who doesn't.

And that leads me to what is called personalized medicine. My colleagues and I practice this as best as we can to come up with a specific diagnosis and a pathway forward to individualize or tailor make the care for the patient.

**Andrew Schorr:**
It's not a one-size-fits-all.

**Dr. Greenberger:**
No, not at all. And in fact certain patients respond much better to the inhaled corticosteroids, which are the mainstay for persistent or what used to be called chronic asthma. For example, patients who respond to albuterol or what are called the rapidly acting rescue medicines actually are the ones who also respond to the inhaled corticosteroids. It's interesting because some patients have 10 or 15 or 20 or 30 percent response to the albuterol, in other words a very healthy opening up of the airways. Those patients with the better responses to the rescue medicine actually respond better to the inhaled corticosteroid, whereas the patients who have a lesser response don't respond as well. So all within asthma, but the knowledge of who responds better to the rescue medicine, albuterol, actually helps us know or predict ahead of time who might respond well to the more important inhaled corticosteroid medicine.
And, conversely, if we look at the rescue medicine albuterol, it's well known now that African-Americans, who often bear a disproportionate burden from diseases, respond less well than Caucasians to albuterol and that Puerto Ricans, who also have a high burden with asthma, respond less well to albuterol than patients of Mexican-American background. So there are characteristics of patients that help us identify ahead of time who might respond better or less well to our standard medications.

Andrew Schorr:
And of course just to remind people, when we're talking about asthma we're talking about the narrowing of the airway to the extent where you have difficulty breathing or even could be in a situation where you just can't breathe, which would be when somebody is rushed to the emergency room, and we're trying to change that. So it's an inflammatory condition. Is there another thing going on at the same time, Doctor, or is it all just inflammation?

Dr. Greenberger:
It's inflammation plus the bronchoconstriction or the shrinking of the bronchial tubes. The diameter of the bronchial tube shrinks and it can go from whatever size it is to a fourth of that size and make a person critically ill like you've described. It can also open up again, and this distinguishes it from emphysema or what's called COPD, where the shrinkage is for most practical purposes not something that can be reversed or opened up again.

Andrew Schorr:
Now, I've heard of this concept called airway remodeling, where if someone continues to have this change going on that it becomes permanent, that it doesn't go back to the way it's supposed to be. Is that still thought to be true?

Dr. Greenberger:
Yes, it is. It applies to some patients.

Andrew Schorr:
So putting off care would not be a good idea.

The Importance of Proper Treatment

Dr. Greenberger:
Putting off care in the first two years of symptoms seems to be associated with a less beneficial response to the inhaled corticosteroids and reduced lung function, breathing power. So yes, indeed, there is a price to be paid for patients who have cough, wheeze, shortness of breath, trouble breathing who don't have asthma diagnosed and don't have it treated properly.

Andrew Schorr:
Now, in listening to Craig and his long-term relationship with you, I have this image of a partnership between a provider and a patient so that somebody is tracking
what seems to aggravate their symptoms. Craig knows if he goes into his moldy basement that's trouble. He knows certain times of the year are trouble, certain situations. It might be different for someone else, smoke or some environmental factor or pets. So there has to be that dialogue. Craig, you'd agree with that, right? That's important.

Craig:
Absolutely, I would, yes.

Andrew Schorr:
And, Doctor, what about from your point of view, that partnership?

Dr. Greenberger:
Allergy-Immunology takes care of patients with asthma and other conditions, but we do have a partnership. When we don't have a partnership, then the health of the patient will suffer, and nowadays it's even a bigger issue because it costs the healthcare system dollars through insurance payments, for example, or what have you. So, yes, not only is there life or death issues but there's economic cost to people not being in a partnership with a physician.

Andrew Schorr:
Right. And you're trying to determine which medicines work for people. Some of that is sort of self-reported whether it be--I know you use tools like peak flow meters to get a quantitative number of how they're breathing, but some of it is keeping a diary, self-reported, what was their situation, how they were doing with different medicines, right?

Dr. Greenberger:
Yes.

Developing a Treatment Plan

Andrew Schorr:
All right. So how does someone start? If someone comes to you, maybe in Craig's situation, maybe they've had a hospitalization or they've had an incident like that, how do you start? Take us through how you develop a plan.

Dr. Greenberger:
Well, one is I'm aware of some of the studies that my colleagues and I have carried out here in Allergy-Immunology to identify the high-risk patient, meaning the patient at risk for an emergency room visit or hospitalization or even a worse attack like someone landing up in an intensive care unit or a death. So when we discuss the patient's severity we want to find out if they are at high risk. But what do I mean by that? Are they up at night wheezing and coughing, looking for the rescue inhaler? Have they been in the emergency room in the last year or two? Have
they been in the intensive care unit? If they go to somebody's house where there's a cat or dog do they get very, very ill and turn blue or can't breathe? In other words, what's the level of severity with different exposures. This is our approach.

And we take other information as well. We examine the patient. We measure the breathing capacity and what the characteristics are of how the person breathes air in and breathes it out. And after that we obtain information for what's called IgE, or the allergic antibody to the common allergens, like dander. And right now there's tree pollen in the air. There's grass pollen in the air, just started. And there are molds, which Craig already mentioned. So there's a triple whammy going on right now in the air, and we determine what the person is allergic to.

And combining that with other information such as the presence of gastroesophageal reflux disease that may cause asthma by the mechanism of heartburn-related symptoms, or chronic sinusitis, now called chronic rhinosinusitis, because that can cause postnasal drainage and also driving asthma. So we look for other factors we call co-existing conditions or comorbidities. We're going to explore that, and I can also tell you that in somebody who has the severity that Craig has had we would ask ourselves does this patient have unrecognized sleep apnea because we do find patients with sleep apnea as well and they need to see a specialist in that area to have proper diagnosis and treatment.

Andrew Schorr:
Craig, you're a journalist as well as a patient. When you listen to Dr. Greenberger speak and you've known him for so many years and you think about asthma, wouldn't you agree that there's sort of an art to this area of medicine?

Craig:
Well, yes, there is an art. The doctor really has to know the patient and has to listen carefully to what the patient says. And the comment that Dr. Greenberger just made about sleep apnea is that, a really good example of that, that the doctor has to be attuned to whether that is going on. But I also think that once the patient begins to understand what's happening to him the patient has a responsibility here too. He has a responsibility to know what the medicines he is taking are doing to him, how he is responding to them, and he has to be very precise in telling the doctor what's going on. This is not a one-way street, doctor to patient. The patient has to be a part of it.

Andrew Schorr:
Yeah, I can really see that clearly here. Dr. Greenberger, so if you get to that point, can we most of the time be in a situation like Craig has, where he's doing the activities he wants to do, he knows his limits in certain areas, he doesn't go to the basement, he knows to be more mindful, knows how his medicines work and how they can help, that, where we are today that asthma can be controlled?
**Dr. Greenberger:**
Asthma can be controlled, but it's actually been reported in several studies that when phone calls are made, not the doctor calling but if phone calls are made to patients who have self identified themselves with asthma, in fact people who are on the appropriate medicines are not always as well controlled as one might think they are. And I mean they don't have the exercise ability that they should have, and they're using their rescue medicines too often. So really we have a lot of work to do. And that's when I said about asthma being complex, it can be quite aggressive, and physicians have to be aware that the patient may not be as well controlled in terms of limiting lifestyle or whatever, and we have to look out and inquire about it.

And the other part that I want to just focus on is that in terms of our medicines there is this what's called heterogeneity, variations in responses in different people. And physicians have to know how the patient is doing, as Craig said, and the patient can be helpful in that regard. And the physician has to be aware that some people are going to be better responders to certain medicines and worse responders to some of those medicines as well. We have to be watching out, and then we have to tailor make or personalize our care. And there will be more and more ways to do this going forward because that's where a lot of the research is, and this should result in better patient outcomes and also avoiding harmful effects of our medicines.

**Craig:**
Dr. Greenberger said something that really struck me, and that is something about the doctor paying attention to the different ways patients respond. Patients, on the other hand, I know that in my case that it took me a while before I understood that I shouldn't let my problems with asthma go on too long, that I have to be letting my physicians know that I'm falling apart, that I'm struggling going up stairs, my exercise isn't as good, I'm just generally having trouble breathing. Whatever the issue may be, the doctors need to know that sooner rather than later.

**Andrew Schorr:**
Well, I have this image that maybe some people maybe in previous years, maybe in some part of the country now think that, well, you come up with a treatment plan for an individual, figure out what they respond to, and then you're good to go and it's a lifelong condition, and just stay with that. Conversely though, Dr. Greenberger, do we need to reevaluate somebody's treatment plan and really question what we think was good enough or has something changed? In other words, do you have to take a second look periodically?

**Dr. Greenberger:**
We have always taught our med students and internal medicine residents to take a look at how the patient is doing, and if the patient is not doing as well as anticipated take a step back and determine what might be going on. Is there a co-morbidity like sinusitis or allergies or reflux or bronchitis or unrecognized smoking or something else, or do you have the patient on medicines that really aren't customized for that patient? So, yes, this is really not a new thing, but it's
getting more emphasis. And as genetic tests become more precise that will help us to personalize the care based on genetics. We're certainly not there yet, but I hope within ten years we have more useful information to actually use the genetic information that patients have and we can customize the care.

Andrew Schorr:
So, Craig, do you have checkups from time to time and you keep in touch with Dr. Greenberger?

Craig:
I see Dr. Greenberger every three, four or five months, and then I'm in e-mail contact with him or with somebody on the Northwestern staff. And it has worked out very, very well for me. Even a matter of routine importance like getting a refill on my prescription, I almost always get a call if not from Dr. Greenberger from one of the residents there calling to ask me if I'm doing all right. Now, why are we getting this Xopenex? Well, it's just a matter of it's run out, I'm doing fine. Or, this doesn't happen often but, well, actually I've been struggling a little bit more, and then we stop and talk about it. They're right on top of it, and I'm seeing Dr. Greenberger I think relatively frequently.

Andrew Schorr:
Dr. Greenberger, let me just ask you for our listening audience who could be anywhere in the world or certainly they could be anywhere around Chicago, when would you advise somebody getting a second opinion? Because again asthma maybe had been seen by some as just a simple treatment plan, and what I hear from you is it needs to be individualized and it may be more complex. When does it make sense to see a specialist such as yourself?

Dr. Greenberger:
First of all, anybody who has been in the hospital with asthma. Anybody who has been in the emergency room where they're not on a plan that really has brought them under control. The third would be if people are concerned about molds or pets or pollen. And the fourth I would say is when people are not satisfied or don't have confidence in using their medicine. And finally if there's just a need for additional information we're happy to provide that to the best of our ability. We want our patients to be doing well, and we take pride in that. And we've published a number of studies on different aspects of asthma or these other conditions that complicate it, so we certainly want the patients to be doing as well as they can.

And, as Craig pointed out earlier, our job is to make sure that if the patient has asthma we have them on the best program, and we reevaluate how they're doing and then try to get it so the severity of the asthma is reduced, which can happen, so that the asthma does not control the patient and that the patient can be at work or in school, not up at night, as I said, and lead as close to a normal life as possible without having the asthma be the dominant factor or condition in their life.
Patient to Patient Advice

Andrew Schorr:
Craig, what would you say to people listening? There may be people out there who are suffering or just sort of living life as best they can but sort of limping along and maybe haven't sought such care.

Craig:
I would say a couple of things. I would say that if they are really--if they are struggling, if life is not treating them well, if they can't move very well, then they absolutely need to see a specialist, and they need to see one sooner rather than later. The second thing I would say is the moment you have a doctor who tells you not to get a second opinion that's when you need to get a second opinion. A second opinion is always useful. In my experience, I haven't done it with asthma but with another condition, a second opinion made me just feel a whole lot better about what I was going through, and the second opinion is I think a hallmark of good medicine.

Andrew Schorr:
I really agree with that. That's why we call this program Patient Power. And the downside of not getting it right, like with severe asthma, trip to the emergency room or, as we said, so tragically, some people who don't make it, you don't want to ever get to that point, and you certainly, as you said, Dr. Greenberger, you want to limit or prevent hospitalizations, certainly fatalities, and really give people the best chance at a full life. It sounds like, Dr. Greenberger, you've made a lot of progress with good medicine. It sounds like, though, you still feel there's a ways to go.

Dr. Greenberger:
There still is a lot to go, and when we did studies with the medical examiner's office in Cook County, which is in the Chicago area, we had permission at the time to contact surviving members of family or friends, and it turned out that many of the patients were not on the appropriate medications.

Andrew Schorr:
Wow.

Dr. Greenberger:
So this was not in a way a shock, but it's very troubling because the knowledge is out there.

Andrew Schorr:
The knowledge is out there, and this is preventable. Well, first of all, I want to wish Craig Klugman a long and happy life with asthma in control, and thank you for taking time out from your job as editor of a newspaper to be with us to really support Dr. Greenberger. Would you like to thank him on the air?
Craig:
Of course I would. Dr. Greenberger, thank you very much for all that you've done with me. I've been seeing you since 1977, and that's a long time, and, as I said earlier in the program, you gave me my life back.

Dr. Greenberger:
Well, those are very kind words, and I can say that Craig also participated in some research we did on asthma, and he's been a pleasure for me to take care of. I wish my cure for you, but we're working on that.

Craig:
Yes, we are indeed.

Andrew Schorr:
Wouldn't it be great if we could cure asthma, but as our listeners can hear, it's really connecting with the right provider for you, having the right tools used in your case that are evaluated and reevaluated, and then really a long-term partnership to make sure that asthma does not control your life. I want to thank both of you for being with us. Craig Klugman from Fort Wayne, Indiana, thank you.

Craig:
Thank you very much for having me.

Andrew Schorr:
I really appreciate it. And Dr. Greenberger, Craig's doctor and a doctor who has helped so many others and trained so many other doctors who treat asthma, thank you for being with us, Dr. Greenberger.

Dr. Greenberger:
Thank you, yourself.

Andrew Schorr:
Well, this is what we do on Patient Power, time after time, is connect you with really inspiring patients and leading experts, and Northwestern Memorial certainly has so many, and Dr. Paul Greenberger for decades has illustrated he's really lived that and been a mentor to so many. I'm Andrew Schorr. Remember, knowledge can be the best medicine of all. Thanks for joining us.

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