

Keeping Up With Lupus: Exciting Progress in Research

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Introduction

Andrew Schorr:

Good morning on Health Radio Network. This is Andrew, and we're here week after week live with Patient Power talking about chronic illnesses and cancer as well. It's the only program on commercial radio anywhere where we do this week after week, not out to sell you anything but connect you with leading experts and inspiring patients so you can make important decisions for yourself or someone you care about, someone in your family, a neighbor, a relative, so that they get the best medicine that's available today. That's what this is about. Take a look at our website, patientpower.info. More than 10,000 people did last month, and that was a 50 percent growth from the week before. It's really growing. Because if you miss the program live you can download it and listen whenever you want, patientpower.info, and share it with people you know or your doctor.

You know, one of the conditions I've been wanting to deal with for a long time is lupus, where there can be fatigue and joint swelling, and it can be quite serious. And that happened to a woman named Kathy Hammond who unfortunately has a cold today. She couldn't be with us, but Kathy's from Bellville, Michigan. She's 47 now, and she is a nursing student at the University of Michigan. But that's after she had a life transformation. So I want to tell you about that story. So 20 years earlier she was diagnosed with lupus as a much younger woman and over the years kind of went downhill to the point where about seven years ago she was really at death's door, and her doctors at the University of Michigan were kind the throwing up their hands, very frustrated that here was a woman where they just couldn't turn things around. And she had had many, many medicines to try to make a difference, and they had for a while but then no longer were.

She went on the internet and, of course, said, desperate, is there anything else to do. And she found out that down the road in Chicago at Northwestern University and Northwestern Memorial Hospital there was research into another kind of approach using stem cells to try to reset the immune system and make a difference in an autoimmune

condition because certainly in autoimmune conditions and cancer your immune system has kind of let you down and acted inappropriately and let processes happen or malignant cells proliferate when normally the immune system would not let that happen.

So with us today while Kathy Hammond couldn't be with us and is home with a cold --and Kathy, we hope you get well. Kathy is doing well now, pretty well, everybody gets colds, even lupus patients, but we do have with us Terry Sanders, who is the president, CEO of the Lupus Foundation of America, Illinois Chapter, and there are about 30 chapters across the country. So, Terry Sanders, welcome to the program. Lupus has been an unnerving condition. We've have had sort of breakthrough treatments in a number of conditions, rheumatoid arthritis, psoriasis, some other autoimmune conditions, lupus has still been tough, hasn't it been?

Ms. Sanders:

Yes, it has been, Andrew. And there's a lot of reasons for that, but mainly it's difficult to recognize and diagnose because the symptoms can mimic many common diseases so oftentimes they're dismissed as nothing serious.

Symptoms of Lupus

Andrew Schorr:

And those symptoms are?

Ms. Sanders:

Things like fatigue, aches and pains, sometimes a fever, arthritis. But really it's more prolonged or extreme fatigue. Skin rashes and oftentimes folks with lupus will get a butterfly-shaped rash across their cheeks and nose. They have sometimes pain in their chest on deep breathing, which could be pleurisy, hair loss, some of normal blood clotting problems, seizures, mouth or nose ulcers. So there's a lot of symptoms but they could all be dismissed as something else.

Andrew Schorr:

So are there people out there, maybe some who are listening, who could have some of these symptoms and actually have lupus and don't know it, that it takes a while for people to get an accurate diagnosis?

Ms. Sanders:

Absolutely. We think actually it takes most people, the average is four years and three doctors to receive a proper diagnosis. So in those four years it can be very frustrating for the lupus patient. But there are a lot of resources. They can visit a rheumatologist who can help them with that diagnosis. Also on our website we have basically like a self test for people that they can take to at least get some idea if they have the symptoms of lupus.

Andrew Schorr:

What is that website, Terry?

Ms. Sanders:

It's www.lupus.org.

Andrew Schorr:

Okay. And so if people take the test and then if it looks like maybe something is going on then a rheumatologist would be the appropriate specialist to see. Is there a blood test, or what do they did to say, yes, in fact this is lupus?

Ms. Sanders:

Well, there are many, many different things, and they have to have several of the symptoms, not just one of them. There is also a blood test, and I know that we'll have a doctor on the show and he can probably talk more about some of the tests that would be performed to diagnose a person with lupus.

Andrew Schorr:

Okay. Well, let's go and meet that doctor. So what happened to Kathy Hammonds? We said she was at the University of Michigan Medical Center, which is an elite medical center for sure, one of the best we have, but they didn't really have a researcher looking at an approach that ended up working for her. And that researcher was Dr. Richard Burt. Dr. Burt is chief of the division of immunotherapy for autoimmune diseases at Northwestern Memorial Hospital. He is also an associate professor of medicine at the Northwestern University's Feinberg School of Medicine. So another elite medical center.

And Dr. Burt eats, drinks and sleeps looking to immunotherapy for autoimmune conditions, lupus being one of them. Dr. Burt, welcome to the program. So Kathy came to you, and she had a stem cell transplant. So help us understand what is this, what was the research idea you've been pursuing for somebody where drugs were no longer working?

Kathy's Story

Dr. Burt:

Well, good morning and thank you. As Terry had mentioned, patients can have mild symptoms or they can have very severe disease, and it's patients who have very severe disease, life-threatening disease, that we evaluate for stem cell transplant. And in those types of patients the symptoms are very remarkably different and of course much more severe than had been described by Terry. For instance we had a patient who was working, taking care of himself, living on his own and then started having some mental problems, was diagnosed with schizophrenia, then eventually ended up being unable to walk and was confined to a bed, virtually paralyzed until the diagnosis of lupus was made,

because that patient had lupus involving the brain and the spinal cord. With treatment the patient's mental status was completely cleared. The patients never had schizophrenia at all and is up walking again.

On the other hand we've had another patient come to us who was a young, healthy person, just got a common cold during the summer, thought to be a common cold for a few weeks and then suddenly had a respiratory arrest, was found basically dead on the kitchen floor, was revived by paramedics and spent six weeks in an ICU where they found out she really had lupus involving the lungs and kidneys, which caused her to stop breathing, eventually came to us, got a stem cell treatment, transplant which, you know, up, running around normal person now.

In the case of Kathy, she had a type of lupus that manifested in many different parts of her body but the predominant symptoms were in her lungs, and so she had been on oxygen for several years. And the problem was her lung function kept deteriorating.

Andrew Schorr:

Dr. Burt, I'm going to interrupt you so we just continue with that story in a minute and give it its due as we continue discussing lupus and new ways, experimental ways of resetting the immune system for treatment. We'll be back with more Patient Power, Dr. Richard Burt from Northwestern in just a minute.

Andrew Schorr:

We're here live on Health Radio Network, Andrew Schorr with Patient Power week after week. And this week we're talking about autoimmune conditions, and we're beginning our discussion of lupus, which is a widespread and chronic, life-long autoimmune disease that for unknown reasons causes the immune system to attack the body's own tissue and organs, joints, kidneys, heart, lungs, we were just talking about, brain, blood or skin. Some or all of the above. And Dr. Richard Burt is with us who is a researcher in lupus and other what are becoming increasingly we realize related conditions that have other names we'll get into. He's the chief of the division of immunotherapy for autoimmune diseases at Northwestern Memorial Hospital in Chicago and he's also with Northwestern's Feinberg School of Medicine.

So, Dr. Burt, before the break we were just relating the story of Kathy Hammonds, one of your patients who unfortunately couldn't be with us but gave permission where we could discuss her case. And Kathy was a pretty sick lady which she came down from Michigan to see you, and I think you were saying she did have this lung involvement of this autoimmune condition.

Dr. Burt:

Yes, she did, and it was life threatening. She'd required chronic oxygen, couldn't live without it. Always had to have oxygen on, and unfortunately her lung condition was continuing to deteriorate. And at that point is when she came to us after having failed all

available therapies. And the end result of that after the procedure is her pulmonary function normalized, and she's been off oxygen now for many years. But she gave a description that I think she want read that she provided to Terry.

Andrew Schorr:

Right. I just want to interject one thing. So Kathy is at home with a cold today, but she is a nursing student at age 47 after raising her kids at the University of Michigan where she had started treatment as a patient. And when I spoke to Kathy on the phone the other day she said that this whole story of diagnosis, treatment, going downhill and then really having her life saved by Dr. Burt was life transforming, and so now imagine she's a nursing school student trying to give back to people with serious illness. So really a great story.

Dr. Burt:

Yes, she's a wonderful person.

Andrew Schorr:

She is. She is. So Terry Sanders is president and CEO, as we mentioned, of the Illinois Chapter of the Lupus Foundation of America, and you know Kathy, and I know she recently gave a speech for your organization. Is there an excerpt from that you wanted to read so we understand how sick she was?

Ms. Sanders:

Yes. I did want to share a little bit because I don't know that people really understand the seriousness and what lupus can lead to. But Kathy was diagnosed when she was 19 years old, and she suffered some mini strokes that affected her speech on the right side of her body. She mentioned that 20 years of steroids left her at 254 pounds. She's not a very tall woman and severely cushingoid with cataracts and osteoporosis. She had a functioning IQ of 80. That's equal to being mildly mentally retarded, and she had severe memory problems. Sometimes she'd leave the house and couldn't find her way home or remember where she lived. And as Dr. Burt mentioned, she had a very severe form of lupus that affected her lungs. And according to her she said that when people are diagnosed with this they are oftentimes given only like 90 days to live.

When she came to see Dr. Burt she said she had about 18 percent of her lungs functioning, and she was on oxygen, and, as he said, 24 hours a day. And about seven years ago she went to see Dr. Burt. She was dragging her oxygen tent. She couldn't walk two blocks from her hotel room to Northwestern University, had to take a cab. But since that time and she had that stem cell transplant it has just transformed her life. And as you said she received her associate's degree in nursing. She's working to become an RN. She's 47 years old. She is slim and fit, so she is in such fantastic shape and condition because of this stem cell transplant.

Stem Cell Transplant

Andrew Schorr:

What a neat story. Now, Dr. Burt, so she comes to you for an experimental procedure, and I know Kathy told me she was Patient No. 5 I think in a clinical trial. It apparently has worked for her. What's the science behind what you're doing?

Dr. Burt:

Right. That's a very good question and gets to kind of the core the issue here. Something I began working on 16 years ago in animal models, and the concept was really simple, that your immune system arises from your bone marrow or blood stem cell. It's the same stem cell whether you get it from blood or bone marrow and that we can easily collect those stem cells and by giving them back to a person after we've destroyed that immune system we can regenerate a new immune system.

So in kind of laymen's terms, you take someone who has a computer, that is, their immune system, that is kind of going on the fritz and it's just not working and it's really severe disease, and you just kind of reboot the computer and oftentimes your computer will then work when you reboot it. So it's a somewhat simplistic way of viewing it, but it does seem to work that way, and it seems to have caused remission for a vast majority of patients we've treated with severe and refractory autoimmune diseases above and beyond just lupus.

But the question still remains can the disease come back. Could the computer go on the fritz again? And that's a question only time will tell us. So we take people who fail all therapies. They're suffering. They have organ threatening, that is they're about to lose their kidneys, go on dialysis, for instance, or life-threatening disease, and we do this stem cell transplant, giving them back their own stem cells to regenerate their own immune system again, and the vast majority of time it reestablishes homeostasis or normal balance and puts you in remission. But whether and how long that remission will last is what we're trying to follow now.

And what we reported in *JAMA, Journal of the American Medical Association*, back in February of this year is that at five years 50 percent remain in remission. And so one way of looking at that is, well, at five years the glass is half full or it's half empty, but I think the important thing to remember is we start, we start with an empty glass. That is, we start with people with very refractory disease for which no therapy a working, and we end up still at five years with 50 percent maintaining remission. So what will happen beyond that time will tell as we continue to treat patients and follow them.

There is another approach we've added more recently where we use another person's stem cells. And that concept is not only do reset or reboot the immune system but you change the software of the computer. In fact, you even change the hardware. So you're much more likely to prevent another crash of the computer or crash of your immune system, that is you immune system attacking yourself because not only do you reboot or

reset the immune system but you change genetic predisposition to the disease by using someone else's stem cells. So traditionally an allogeneic, that's called allogeneic, someone else's stem cells, transplant was more risky and dangerous than autologous, that is your own stem cells. The term "autologous" means your own.

So we started with autologous and with experience and time and success in that area we've expanded into allogeneic, and now the FDA has given us approval for allogeneic stem cell transplants for a variety of immune, autoimmune disorders such as systemic sclerosis, rheumatoid arthritis, lupus, primary biliary cirrhosis and Crohn's disease. And so we're continuing on both avenues, using a person's own stem cells as well as in carefully selected patients using another person's stem cells to kind of change genetic predisposition as well as reboot the computer.

Andrew Schorr:

Okay. Wonderful analogies. We're going to get into this area of science and what it could mean to you or someone in your family as we continue on Patient Power right after this. Stay with us.

Andrew Schorr:

I'm hoping that Terry, who is president and CEO of the Lupus Foundation of America, Illinois Chapter, and Dr. Richard Burt at Northwestern, both in Chicago, will forgive me when I say go Seattle Seahawks tonight, because I'm from Seattle and they're playing the bears tonight. But anyway, we won't get into sports.

We're talking about really serious autoimmune conditions, and we've kind of led with lupus, which can affect people in a variety of ways. And Dr. Burt earlier talked about that man who was thought to be schizophrenic and it turned out to be lupus affecting his brain. And then Terry mentioned a minute ago, as we talked about Kathy Hammonds, the woman who is now training to be a nurse after her life being saved with a stem cell transplant for lupus, how she at one point had an IQ of 80 but it was really the lupus affecting her brain. And now she is at nursing school at one of the top universities in the country. So you see what treatment can do.

So, Dr. Burt, help me understand then. You talked about rebooting the computer or even giving new software or hardware with an allogeneic transplant. These treatments, though, are not easy, and they are for the sickest people. So Kathy I understand went through therapy for a long time and now it restored her life. So help us understand what it takes to do a stem cell transplant and the risks that go with it too.

Dr. Burt:

Yes. That's a very good question. We always design these treatments as salvage therapy for people who failed the available current approved medications for their disease and have organ or life-threatening disease. And the reason for that is that our treatment itself could take a person's life because in the process of destroying the old immune system and resetting it to establish a new one you go through a period where you do not have an

immune system. It's a short, short period, and we're very good at preventing the complications from it and it's nothing like a bubble boy or anything like that. We often encourage a family member to stay in the room, sleep during the night with them. And the hospitalization, the actual period where they're neutropenic, where they're at most risk for infection, is relatively short, about eight days. And we're very good at preventing infections.

Nevertheless, there is a risk that someone could die from the treatment. We emphasize that to the patients, and they need to understand that. But these go through you careful review process, through IRPs and through FDA, where this risk/benefit is extensively discussed and analyzed, making sure that the risk of our procedure hurting a patient or taking their life is less than the risk of the disease in terms of the possible potential benefit of the treatment. And so we've had very, very low mortality at our center, and we've treated more autoimmune, immune-mediated diseases with stem cells anywhere in the world, having been the center that pioneered it. Over 160 patients, 165 or so with different autoimmune diseases, and our mortality from the treatment is low, about 1.4 percent, much lower than anywhere in the world.

Part of it is the focus team doing it and part of it is our approach in that what we want to do with this is lymphoablate and reestablish the immune system to make new lymphocytes, which are your immune cells, and that is very different than in cancer. Some other centers have used cancer-specific conditions regimens used to treat for instance leukemia or lymphoma. Those regimens are more intense and they myeloablate, and they can have more dangerous side effects for a patient. So I kind of attribute it to the approach we use as well as the experience we have.

But nevertheless we emphasize to patients the risk of this. They have an informed consent that outlines all the risks. And patients know, though, when they came to us. They're fed up of suffering from their disease and not getting better and not having the possibility of getting better and just getting the same old failed therapy with the complications of that treatment, which can be life threatening as well from those therapies.

Multiple Sclerosis & Barry's Story

Andrew Schorr:

Dr. Burt, I want to introduce someone else who is fed up, another one of your patients, and that's Barry Goudy. Barry is 48. He works in the automobile industry. He lives south of Detroit in Woodhaven Michigan. And Barry, for you, it was another autoimmune condition, multiple sclerosis, and drug therapy was not working for you. So you were one of the sicker people with MS. You ended up at Northwestern as well. You had a stem cell transplant. It worked out for you so far, hasn't it?

Barry:

Oh, excellent. I'm very blessed. Very blessed.

Andrew Schorr:

And Barry, you were really determined to try to just watch yourself end up being in a wheelchair and just failing, so even though this was experimental you were willing to give it a try?

Barry:

The treatments I was receiving they were just putting me in remission for approximately one to three months, and then I would have another exacerbation. And I would fall out of remission, and periodically I would go to the hospital and get the IV treatments of Solu-Medrol and get better for three months or two months or whatever. And that was just putting a Band-Aid on a wound that needed stitches. And Dr. Burt and Northwestern Memorial Hospital, I mean I've been MS free now for three years, and life is very good and I'm a very lucky person.

Andrew Schorr:

Dr. Burt, before we have the next break maybe you could start to explain. We're talking about autoimmune conditions, where I see it as your immune system kind of lets you down, often for unexplained reasons. So we talked about lupus. Barry has another condition, MS, and you mentioned that you're moving forward to try to do transplant for rheumatoid arthritis and other conditions where drug therapy hasn't worked. So are they all connected? Is it just other variations of where your immune system needs to be reset?

Dr. Burt:

Yes, that's correct. They're all connected in that your immune system, which is your police force to protect you from all the pathogens in the outside world, has gotten confused and is attacking your own body. Now, how it attacks that body, what organ it attacks kind of ends up giving it its name. So in the case of multiple sclerosis it's attacking the brain and the spinal cord. It doesn't attack any other part of the body, just the brain and the spinal cord, not the peripheral nerves or other organs. And within the brain and spinal cord it's attacking cells that myelinate, that wrap around neurons and protect them and allow rapid conduction of nerve impulses, which are called oligodendrocytes. It's attacking those types of cells which end up damaging the...

Andrew Schorr:

The myelin sheath of the nerves. We'll talk more about how this affects these other conditions and the connection between them. And then we'll go to Terry as an example with the Lupus Foundation to help people understand that you are not alone and how you can be directed to advanced care like you offer at Northwestern and get your life back as Barry did and Kathy did. We'll be right back with more of Patient Power.

Less Toxic Approaches to Treatment

Andrew Schorr:

Thanks for spending part of your Sunday with us live object Patient Power and Health Radio Network. Really appreciate it. I'm Andrew Schorr. Week after week we talk about serious health concerns and really connect you with some of the brightest minds in medical science in the world, and we're blessed with just really some really smart scientists in the US. So I'm really honored to feature them and also really inspiring patients and the representatives of organizations that can help you. So today we have the CEO of the Lupus Foundation of America, Illinois Chapter, Terry Sanders is with us. We have Barry Goudy who has been living with MS and then had an advanced experimental treatment, stem cell transplant and is living well and back to his job in the automobile industry in Detroit.

And then we've got really the international expert in this immunotherapy approach, Dr. Richard Burt from the Feinberg School of Medicine at Northwestern in Chicago and Northwestern Memorial Hospital. You can read a lot more about Dr. Burt if you just go to www.nmh.org, nmh.org, Northwestern Memorial Hospital .org. He's been on lots of TV shows, *Good Morning America*, written up in many journals.

So, Dr. Burt, just help us understand then, you were noting with your 16-year investigation of this approach the similarities between autoimmune conditions. You were talking about MS like Barry has, we talked about lupus that Kathy has. So still experimental, but are you encouraged that we will be able to perfect a kind of low toxicity approach for the sickest people with a variety of conditions where they can have their immune system reset and go back to a good life?

Dr. Burt:

We have protocols open and have treated patients with a variety of these less toxic procedures, less toxic compared to cancers, that is. And these diseases have gone well beyond lupus and multiple sclerosis but into other immune or autoimmune disorders such as systemic sclerosis and Crohn's disease, rheumatoid arthritis, myasthenia gravis, chronic inflammatory demyelinating polyneuropathy, polymyositis, dermatomyositis, a whole variety including ARRONs, which is actually an autoimmune disorder that causes blindness, and we've treated a patient referred to us from California, San Francisco Bay area for that.

So we're expanding these indications, and in fact we recently opened a study using stem cells for new onset type I diabetes with very phenomenal results, actually ran that study in São Paulo, Brazil, with my colleagues at the University of São Paulo in Brazil. And more recently we've just received FDA approval to use stem cells for autism. There is a subset of autistic kids, really severe autism that does that an immune-mediated component to it. We are still waiting certain other regulatory agency approvals before we can initiate such a process, but the applications and potential for this are far reaching and go beyond many diseases that can affect many, many people in this country, throughout this world, in fact.

Andrew Schorr:

Okay. So, Barry Goudy, you have MS, and it would sound to me, tell me if you have this reaction too, that there may be some people listening where they get diagnosed with one of these conditions, some of them even more rare, but an autoimmune condition, and at their local medical center they're kind of told all hope is lost. You're either going to continue to get sick or in some conditions like lupus, die, or you're just going to be in a wheelchair like you worried about. It's just going to go downhill. But it sounds like if you can be the proactive patients and really go the extra mile in your research you may connect with a research center like Northwestern and a world-renowned researcher like Dr. Burt, and there may be a new line of hope for you. Would you agree?

Barry:

Oh, most definitely. Most definitely. When I was diagnosed I was put on Solu-Medrol IV drip and I did Avonex, a shot once a week, and, you know, the only thing that would do is prolong the exacerbations, and eventually they would still come through, and there was no way to solve the problem. And Dr. Burt and the staff at Northwestern gave me the opportunity. And it's very blessed to know there's something out there to help people who have MS and other autoimmune diseases.

Andrew Schorr:

Yeah, you need to know. Now, Terry Sanders, you're with the Lupus Foundation, and it sounds like you feel from your position that for some of the sickest people where the drug therapies that you have now may not be working, and they were not working for Kathy Hammonds who we've talked about earlier in the show, that you can help them find out where research is going. So if they go to lupus.org or call their local chapter that's a question someone can ask, right? To know, first of all, they're not alone, there are other people with these conditions, and, hey, they can say who is specializing in research, are there clinical trials, etc. You can give that sort of help. Am I right?

Ms. Sanders:

That's right. They can go to the website, www.lupus.org, and then they can find out a lot of information about what's happening in lupus on that website. They can also click the Chapter Locator tab and find a chapter in their area.

Andrew Schorr:

Okay. We're going to take a break, get some final comments as we look into the latest science related to these autoimmune conditions. We'll be right back on Patient Power.

Hope for the Future

Andrew Schorr:

You know, we've done more than 120 hours of programs like this. Really it's unmatched around the world, so I urge you to take a look at patientpower.info and pick on the health topic that's important to you or someone you care about and then hear these very high credibility programs with top experts.

So today we've been looking into the new world of understanding autoimmune conditions and then restoring or resetting the immune system for the sickest people. And Barry Goudy and your MS, I bet you're really glad you went that extra mile. What would you say to people who feel all hope is lost?

Barry:

Keep a positive attitude, okay. And look and look and look. You will improve your quality of life. Dr. Burt has given me the opportunity to do that, and my quality of life now is how it was back in 1994 before I was diagnosed with MS. And, you know, the stem cell transplant has given me the opportunity to do that. And just don't give up hope because there is a lot of help out there for you. Just be positive and improve the quality of your life.

Andrew Schorr:

Well, Barry, we wish you all the best.

Barry:

Thank you very much.

Andrew Schorr:

I'm going to drive some new car some day and your fingerprints will have been on it. Thank you for what you do up there in Detroit.

And Dr. Richard Burt at Northwestern Memorial and the Feinberg School of Medicine, certainly we wish you well with your research. And it sounds like you're encouraged. As you said, this could have far-reaching effects. I know you have a lot of skeptical people in the medical community who think this is sort of a drastic approach, but you must be gratified when the people like Barry or Kathy who are going on with their lives when there was a question of whether they would or how well they would.

Dr. Burt:

Yes, very much so. You know, when I first started working on this 16 years ago I was a lone voice and very much felt that way, but since that time now many people around the world are doing this in countries throughout Europe, in Asia, in South America, centers around America. So it's been very gratifying to see this expand.

Andrew Schorr:

Keep at it. I want to give your phone number real quick. 312-908-0059. 312-908-0059 will get you the department for Dr. Burt at Northwestern. Take a look at nmh.org, put in Richard Burt, and you can find out more. And remember, folks, knowledge can be the best medicine of all. Next week we're going to talk about transplants for cancer patients with docs from the Seattle Cancer Care Alliance near me. Different application, some different treatment but the new world of immunotherapy, very exciting. And also go to www.patientpower.info.

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