



Former White House Cancer Moonshot Leader: Challenges and Hope for Cancer

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Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr in California, and we're joined by someone that you may know or have heard of, and that's Greg Simon who is the former Executive Director of the White House Cancer Moonshot Task Force. He continues to work with former Vice President Joe Biden, very personally both of them affected by cancer and with the Biden Foundation as the Executive Director of the Cancer Initiative. Greg, thank you so much for joining us.

Greg Simon:

It's my pleasure. It's terrific to be here, and I'm especially excited about being able to communicate with so many patients at one time.

Andrew Schorr:

Right, and family members, of course. Now, Greg, you have a personal story. I think it was in 2014, routine blood test, you were diagnosed with chronic lymphocytic leukemia and then later treated with what I had and what many people with CLL have had, FCR. How are you doing?

Greg Simon:

I'm doing great. Thank you very much. I get tested—my care is now at George Washington University. I was treated at Sloan Kettering, but I get tested now every three months, so that's good, and my numbers are right down the middle. And a month ago after a year of taking a lot of drugs to deal with the immune system rebuilding, I'm off of all those drugs. So now I'm down to baby aspirin, so that's a good thing.

Andrew Schorr:

Good for you. Now, Greg, so you've been touched by it personally, and many people know the story of Joe and Jill Biden and the death of their son, how personal it is. So here we're all hoping that we can move cancer forward towards cures. You've helped devote a lot of your life to that. Where are we now?

I mean, you're not in the White House anymore, now you're outside the White House, and also in the context the latest budget proposal from the White House looks like it's cutting back on research dollars. Are you concerned?

Greg Simon:

Short answer, yes. Let me take those in order.

Where are we now? One of the disadvantages of being in one field for a long time is that if you go back and look at something you did 10, 12, 13 years ago and it's the same debate that you're having today, you get a little frustrated. So I went back and looked at some of the essays I wrote in 2003 and '04 about sharing data, about electronic medical records being used more in research, about getting patients more involved in designing clinical trials. That was in 2004, and that hasn't changed that much, which is really depressing.

The technology has changed enormously. So just as I said back when I was running FasterCures, it's the culture that's holding us back, not technology. And the technology for sharing, as an example, it far exceeds our cultural willingness to share. So we really need to stop this debate and start really acting on sharing data and enabling patients to have better access to their own data and the ability to easily share it with anyone they want to that they think could make good use of it.

In terms of where we are with the—with the budget in particular, the Trump budget is a—is a warning shot, and I don't believe it has a chance of going anywhere in the Congress. Let me just say that right now. But that's not the only important thing. What that budget does is it scares a generation of young people away from science. That's what it does.

And that is an awful outcome, especially when the President of the United States decides that he wants to scare a generation away from science and technology rather than expand their interest. You know, in the original moonshot Kennedy inspired a generation of people to go into engineering, science, math, and that decision and that inspiration gave us the technological prowess and advancement in any field you choose to look at. From dried food to computing, we became a much more innovative nation. We can't stop now, and the Trump budget is trying to put the brakes on getting people involved in science. It just cannot happen.

Andrew Schorr:

So, Greg, tell us about the Biden Cancer Initiative that you're the Executive Director of, because we understood the power, and we were all very excited about the commitment that President Obama had made and led to the moonshot, and now we're concerned what happens now, but you and former Vice President Biden and others working with you are still going forward. So what are you doing? And then tell us as patients and family members what can we do to help.

Greg Simon:

Great. So, yes, so the Biden Cancer Initiative is going to be—we're still doing the organizational paperwork—a free-standing 501(c)(3) nonprofit organization. We just now started raising money for the first couple of years of operation, and that will allow us to hire a staff to do many of the very same things we did in the moonshot in the White House. So number one is patient engagement.

There are public/private partnerships and private/private partnerships for that matter. There's communication, so people know what's going on and can be part of it. We will—we will be looking at hiring a technology expert, science policy and science expert, so we are in the middle of the organizational work.

The mission of the Biden Cancer Initiative would be to develop and implement creative solutions to some of the problems that hold back progress, like data standards, data sharing, better clinical trial design, more affordability and access to medicine and international collaboration since this is a global problem.

The—our mode of operation, if you will, will not be to give grants. We won't have enough money to give grants, but what we will want to do is convene the most important players in a given space around a set of solutions that we have reviewed with advisors and others from the world of solutions that are out there.

Just as an aside, there's no problem we've been dealing with on the moonshot to which there are not all kinds of solutions people have proposed. What's been missing is anybody to bring those solutions together, to pick the parts of each one that matter most and then implement them. So our mission will be to find those solutions, bring people together that can implement them and using Vice President Biden's convening power really drive to solution. So we're very excited about all that.

Now, it's going to take us a few months to get up and running, so I don't—I don't want to discourage people from writing me, but just know that we're not—we don't have a staff to do all the things we want to do yet, but we certainly will. And that will help us carry forward a lot of the work from the moonshot, and we're very excited about it.

In terms of what patients can do now, one thing is go read the Moonshot report if you've never read it. Go to Google, the Moonshot report. It's on the medium.com site, and it's on the archived White House site—that's a little harder to find—and read the blue ribbon panel report at the NCI, which is still on their website so that people understand what the—what the priorities are that may affect their lives or their loved ones' lives.

The other thing is it's never too late to start demanding that you have access to your medical records in a way you can share them. Companies are obligated to give you those records quickly, cheaply, and they will only respond if you ask. They're not out sending offers to send you your records. You have to really be an advocate for yourself.

Andrew Schorr:

Here in Southern California in San Diego County, I have one of the most conservative Republican congressmen, Darrell Issa, and I know we have concerns in this district about helping sensitize him to the needs of patients and that there's legislation and appropriations that support that. That's just one example.

What would you say that each of us could do in our districts so that cancer research can move forward, and we can have access to care?

Greg Simon:

Well, you know, unfortunately, the Trump administration so far has said nothing about cancer, the cancer moonshot, Alzheimer's, diabetes, epilepsy, rare diseases, I could go on. Whenever they talk health they only talk about money and insurance. That's not health.

So fortunately our founding fathers and mothers created a system in which the Congress can have a huge say in the direction of the country if it chooses to. And I think it's really imperative that patients contact their elected representatives and let them know how important this is to them and point out that the cures bill was the only nonpartisan thing that happened in Washington last year.

It is a common problem. It is not a partisan problem, and it's up to Congress to appropriate the money that was authorized for cancer research under the moonshot. It's up to Congress to keep the NIH budget growing and the NCI budget growing, and it's up to Congress to make curing these diseases the priority. There's nothing more important, period.

Andrew Schorr:

One other thing I wanted to ask you about. So many of us with cancer, living with cancer, whether we're in current treatment or may have future treatment the doctors talk about exciting drugs and combining them, and these drugs are expensive. And so we're worried not just about research moving forward because some of it is, but as the research blossoms, can we afford it. So what do we do about affordability? You and I sat in on the President's cancer panel and on all quarters I think there's a real worry about the affordability of the medicines that science may bring forward.

Greg Simon:

Well, if I had one answer to that I wouldn't be keeping it a secret, so let me just tell you how I think about it and how I think we can approach it.

Number one, very few people in this country—if you go to a dinner and you ask people around the table how they are insured, the odds—unless everybody's working for the same employer, the odds are everybody has a different kind of insurance. Some are on the exchange, some through their boss, some through Medicare, some through the VA or the military. So people are in very different situations.

If you look at those different situations, some people, like me, I'm fortunate to have had good insurance, even though the cost of my drugs per monthly treatment was \$30- to \$40,000, my co-pay was very, very affordable. It was under \$3,000.

So that's the benefit of my insurance. In fact, it was even under \$1,000. If you are on Medicare you're in a different situation depending on whether you're part of the subsidy group or not.

The people in the worst situations are people with bad employer insurance or on Medicare, but they're not part of the low income subsidized group. They tend to fall through the cracks of our safety net, and they have the largest co-pays. And because so many cancer drugs fail on first attempt, the price for treating cancer is higher than most other diseases just because you have to pay for failures along the way to a success.

So what we're trying to do is identify which segment of the population is most vulnerable to drug pricing and has an access issue and come up with a solution that will affect them first because if we try to deal with the entire problem—should the government regulate drug prices, should we import from Canada, should we have different kinds of subsidies—those people that are most affected by the problem are sitting there waiting for a solution to the entire world.

What we really have to figure out first is how do we help the 600- to 800,000 people right now whose insurance leaves them vulnerable to ridiculously high co-pays for their cancer drugs. That's what we have to deal with first, and that's where we will—we, the Cancer Initiative will go out and solicit solutions that people have generated in different organizations at different conference settings and then try to put together a proposal that we can actually do that would help these people afford life-saving medicine.

Andrew Schorr:

Greg, as you know there's been a lot of discussion in Congress and criticism about the price of drugs, and the pharmaceutical industry is bashed all the time. You've been—you were an executive at Pfizer at one point, you've worked with the pharmaceutical industry, and you've been in Congress as a staffer as well, so you've heard all sides of it. What do you think the truth is, or is it somewhere in the middle? Are we going gouged, or does research really cost that much? And no matter what, what do we do about it?

Greg Simon:

Well, there are so many different categories. For instance, for rare disease and you only have a thousand people, the drug has to be expensive for the drug company to make any money on it, because the total spent on that disease is not that much. Even if a thousand people pay \$300,000 a year for a drug that has a huge impact on their life in a rare disease, compared to other blockbuster drugs that's not that much money, but it took years and years of research to get there. People devote their lives to that.

So—but just to give you a sense of the scale of the problem, an insurance executive told some friends of mine that met with him, he had 13 insured people who paid a total of around \$55,000 in premiums that cost him \$65 million because they had a rare disease. And he ended up having to pay a fortune from the insurance company to a very small number of people, but are we—what's the solution? Are we going to walk away from rare diseases because they're so hard to deal with? Of course not.

Now, in terms of whether this is gouging, there are certainly high-profile instances of gouging, where people take a drug that's at one price for 10 years and then up it a thousand percent. We can't make policy based on people who break the law, and I view that as breaking the law. I view that as fraudulent if nothing else but certainly unethical. Even if it's not illegal it should be.

But what I'm more concerned about are the—you know, trees don't grow to the sky, so when new immunotherapy drugs come out that cost \$100,000 a year, well, what's to stop it—and these are drugs for thousands of people—what's to stop the price from being \$500,000 a year? Isn't there a normal, natural limit to how much any drug can cost? If you're making hundreds of millions of dollars because there are thousands of people taking the drug versus a drug in which there are only hundreds of people taking the drug, I think you have a very different calculation.

And the other side of this should be that you don't just buy a drug whether it works or not. I think we've got to start doing value-based pricing, and several companies have started saying, we will charge you X for the drug, but if after three or six months, whatever the timeline is, the patient's health has not improved or their outlook improved, then we will not charge you for the drug. That's—that's in the absence of a diagnostic test.

So part of the answer here is we've got to do a better job with diagnostic tests, which will help exclude people who should not be taking a drug, because right now the only way we do that is by giving it to them and see what happens. And that's expensive. It's not good for patients, and it's not good for the healthcare system.

Andrew Schorr:

One last thing I wanted to ask about relates to that. So diagnostic testing is developing, particularly in some areas of cancer, what we might describe as precision medicine tests, blood tests, genomic tests. But still in America many people don't get those tests, or there are reimbursement issues, and so they may not get the existing or clinical trial treatment that could help.

It seems like we really need to push ahead on that so people know, and their doctor, they know what they're dealing with and match up with the right therapy.

Greg Simon:

Well, when you think about how hard it is to get people to go to a physical and how hard it is to get people to take their medicines every day, it's going to be really hard to get people to go to the doctor for precision medicine tests in advance of being sick. But that's the best advantage of precision medicine is to see the signs in an individual, that they may have a disease that they have yet been tested for. So I think we have a real behavioral problem here.

Precision medicine cannot scale if doctors don't know what it is and how to use it and if patients don't know to ask for it and if insurance companies don't reimburse for it. So we're in this loop where we need more information to validate the assumptions behind precision medicine, but we don't have the incentives of giving people or the doctor or the testing facility for reimbursing the doctor or the patient for their time and effort around precision medicine.

So, in my view, if we're going to make a mistake, here at least the mistake we should make is to spend more money than we might like to reimburse a lot of these precision medicine tests so we can find out the data which ones are worth it and which ones are not. The alternative is to just keep kicking the can down the road for another five or 10 years and lose lives that could be saved, which is not an acceptable solution.

Andrew Schorr:

Boy, I agree with that. Greg, we've covered lot of ground so just to tie it all together. There you are in new offices, you're no longer at the White House. Joe Biden and Jill and the others working with you seem to be still very committed to leadership in this field. Are you hopeful that we can make progress? You have to go to work every day, how do you feel about it?

Greg Simon:

Well, you know, Rick Pazdur, the head of cancer at the FDA, has a great saying, "You can't be in oncology if you're not an optimist. It's just not possible." So, yes, I'm always hopeful that we can make progress, and I'm—you and I both are examples of progress.

You know, there was a time 10 or 15 years ago when my diagnosis of CLL would have been incredibly life-threatening, and as it was there are so many new solutions now for CLL that if the first thing didn't work, there were five other things they could have tried on us. So, yes, there is progress.

And I think there's progress both medically but also socially. People's awareness, people's understanding of what it means to be a cancer patient, people's understanding of how we can have better behaviors to prevent cancer, people taking responsibility as caregivers and taking responsibility to help caregivers who need their own help, I'm very optimistic that we're making a lot of progress on that side of the equation.

And I thought we made—and I still do—a lot of progress under the moonshot last year in the White House. And even if this White House doesn't do anything on cancer, the rest of the world is moving ahead at lightning speed, and this is not the last administration we'll have in America. So even though I'm not optimistic that the current administration will do as much as

we did in the Obama administration, I am optimistic that the agencies, the military, the FDA, the NIH, the NCI and the entire private sector are going to continue to accelerate cancer progress.

Andrew Schorr:

Wow. Well, I want you to know our audience, me personally, we're very committed to working with you, with the Biden Foundation, Greg, and you've had perspective working on Capitol Hill at the White House and now continuing with the Biden Cancer Initiative. All the best to you, and we're always here to help. Thank you for being with us today.

Greg Simon:

Thank you so much. I really appreciate your interest in what we're doing.

Andrew Schorr:

All right. Well, we'll keep working on it together. I'm Andrew Schorr. Remember, knowledge can be the best medicine of all.

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