

“The Ringside Show” interview, October 25, 2011 (host Jeff Crouere)

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Host: When we come back, we’re gonna talk about the pledge of parenthood. We’re going to talk to Stephen Gallup. The book is *What About the Boy? A Father’s Pledge to His Disabled Son*. Stephen Gallup holds a degree in chemistry and zoology, an MA in English. Prior to his son’s birth, he had written professionally and had done travel features—an interesting life story. We’ll talk about his personal situation and the book, when we come back.

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Host: All right, very pleased to have on a special guest now, Stephen Gallup. We talked about his background, what he’d been doing prior to his son’s birth. His life changed fundamentally with the birth of his disabled son Joseph. Recognizing the problem, he pursued answers that he felt must exist. He consulted with physicians, reluctantly concluded that they had no answers, and he found and implemented an intensive treatment campaign that resulted in dramatic improvements in his son’s condition. Facing the limitations of that course, he continued to educate himself on available options, and writing a book, that we’ll talk about right now, that explores the limits of what we can learn and do. The book is *What About the Boy?* and our guest Stephen Gallup is now joining us on the Ringside program. Stephen, good morning. Welcome!

Guest: Hey, Jeff. I appreciate your having me on today.

H: Um, so this is a first-person account, your family’s situation and what happened after your son was born. Tell us a little bit about your son Joseph.

G: Well, let’s start off with a rhetorical question that might illustrate where I’m coming from. I don’t mean to put you on the spot but what would you do if you had a little baby who cried literally all the time, and who was obviously in distress? And what would you do if time passed and that child wasn’t achieving any of the usual developmental milestones? You’d be taking him to the doctor, of course, but what if the doctors didn’t help? That was my family’s experience. We had a child with an acute problem, a mysterious problem. There was no diagnosis. And my wife and I discovered, over a period of time, that we were pretty much on our own when it came to finding out how to help him. That wasn’t good news, but the principle that kicked in, I guess, in our thinking, was individual responsibility.

One of the major lessons brought home to us by that experience—and I think this may be of particular interest to you and your listeners—was the discovery that nobody else had the same priorities that we did. Especially, the people connected with insurance and health maintenance organizations—the bean counters—

H: Right.

G: These people are not motivated to make sure patients get the best possible healthcare. These people want to keep costs down. So on the other hand, the families who are living with the consequences of

whatever decisions get made—we want whatever it takes to get the best possible outcome. And when we're talking about something really important, like the health of your kid, well by golly if insurance isn't going to cover what's needed we're going to find another way to pay for it. And that's what my family ended up doing for our son. I think this is relevant to the topics you normally discuss because, based on our experience, I *knew*, last year, that I did not like the idea of government bureaucrats being added to the mix of people who decide what kinds of treatment you can and can't get.

H: Right. Yes, definitely! I don't either. Now, your son was born in 1985?

G: That's correct.

H: And so he is twenty-five, twenty-six now?

G: He's twenty-six.

H: Twenty-six. OK. In your search for answers, and your search for solutions and in dealing with your son's condition, obviously with the medical profession you had roadblocks and problems. I mean, 1985 was before the Internet so you couldn't go on the Internet and search.

G: Precisely. That was the main difference between those days and today.

H: Did you go to your library?

G: [*Laughing*] Yes we did! The library was *so* out of date! Yeah, we came home with armloads of books and then realized these things were not helpful at all.

H: Was there a support group that you got involved in? Others that maybe had a similar situation in their families?

G: In due course, yes, we found some support groups. And unfortunately those folks were just about as clueless as we were. Of course, those who had been in the situation longer had experience and could tell us the best resources to turn to. But it was nothing like today. People today are so lucky to have access to all this stuff on the Internet.

H: Right. Now, just to let people know, your son was born with a condition called autism spectrum?

G: Well, let's say that's a convenient diagnosis. Autism—a lot of people think he does not have autism, but it's used because it gives us a basis for placement. He had more severe problems than that, because as a baby he wasn't learning how to crawl or walk, or do anything, really. So our first focus in trying to help him was to get him to where he could, you know, crawl and do basic things like that. And that's where our attention was for the first few years. And we succeeded! If we had not intervened he would probably be in a wheelchair today. But as it is, he walks with perfect coordination and strength.

H: Fantastic. Now, how does his situation differ from a typical case of autism?

G: Well, the outward symptoms are very similar. He has obsessive-compulsive behaviors and he does not speak now. He did speak earlier and lost that. Most people would say that his behavior is autistic.

The differences are in certain very subtle traits that had to be pointed out to me. I had not noticed them. But for example, he's unusually short. His legs are short in proportion to his body, and his fifth finger has a slight bend to it, and there are other minor things of that nature, which a geneticist tells me indicate there is some genetic error, which may be at the root of all of this. It's not necessarily autism. But autism is such a broad umbrella, covering so many probably different conditions, that it's not very useful. You hear about treatments for autism—and that's great, I'm glad people are being helped—but it doesn't mean everybody who has that diagnosis is going to benefit from them.

H: Does Joseph live with you and your wife, or does he live in another facility, or how does that work? Is he able to live on his own?

G: Well, no, he's not able to live on his own. He lived with us until he was twenty, and we'd all be happy to have him still with us, but the point was made that when people get to a certain age it's time for them to step out and get away from the family, away from *my* overbearing influence. He moved into a licensed residential facility with three or four other guys. And he's there, and they have people who make sure they're in good shape, and he comes home with us on weekends.

H: Are you pleased with that facility?

G: I am. It was recommended to me by a friend, a coworker, whose son was already there, and we have never changed.

H: My heart goes out to you and your family, Stephen. Parenting is something that is already difficult. I mean, I am the parent of two children and it's already quite a job. But you and your wife have had other incredible challenges along the way as well.

G: That's true. Parenting is never easy. And we didn't intend to sign up for this, but you never know what you're going to get.

H: By writing this book, what you're trying to do is just let folks know the process you went through and everything, all the various roadblocks that you all had to face in caring for Joseph?

G: Well, this would be a good point to say that the book I wrote is not a how-to book. I'm not trying to sell people on any particular treatment regimen, partly because what *we* did with our son may not be the least bit appropriate for somebody else. It so happens that Barnes and Noble displays this book in their "Family and Childcare" section. I'm not sure that's the best category, because it's not meant to be instructional. I call the book a *memoir*. Ultimately, it's a story. It dramatizes my family's efforts to help our child. It shows consequences of an unconstructive doctor-patient interface. And it's about the broader experience of pursuing a goal when you don't have reliable guideposts. Now, families who are grappling with developmental disability, or chronic health issues of any sort, can certainly draw lessons from my story. But so far, most readers that I am aware of do not even have a personal connection with disability. *They're* describing this as "an emotional mystery novel," and they say that it reminds them to go hug their kids. They see it as a—well, as a reminder to appreciate the small things in life that we sometimes take for granted.

H: Stephen Gallup is with us. The book is *What About the Boy?* It's a first-person true account of a family that refused to accept limitations when they were told they had no choice. And—the medical professionals that you dealt with, were they *all* disappointing? I mean, were there *some* who stepped forward and provided help that did ring true? Or was it just a string of problems?

G: As long as we were going to regular pediatricians and neurologists, they were pretty disappointing. There were some who had heart, who had compassion, but they really didn't have arrows in their quiver for the problem we were dealing with. They wanted us to get counseling. They wanted us to get treatment for ourselves, so that we didn't go crazy. And I said, "We are not the patients. Our kid is the patient. Let's talk about him. If we can fix *him*, then *we* won't need counseling." We did finally get some guidance when we went off the reservation and saw some alternative providers. And I did that very reluctantly. I did not think—I said if the alternative people had something to offer they would not be alternative, they'd be in the mainstream. But my wife led the way on that. She was determined to get to whoever would give us the help we needed. And although some of them did not inspire much confidence, some really did turn things around for us.

H: What were the ones who were most helpful, Steve?

G: There was an osteopath who practiced something called cranial therapy. She said that a large part of his problem was due to birth trauma. My wife had been in labor for about 24 hours, and then he was delivered with suction, which is basically like a bathroom plunger on his head, pulling him out. And this compressed the plates of his skull, and he had been in pain for the first year and a half of his life. He'd been crying constantly, and she said that the poor kid had never been comfortable, didn't even know what it was like to be out of pain.

H: Wow.

G: And she was able, with manual pressure, to relieve that. And he was able to tune in and be in touch with us for the first time.

H: Stephen Gallup, fascinating. As we deal with the situation today, how is Joseph doing?

G: He's healthy, I think happy. I describe him in the book as like a quiet fishing buddy. He and I take comfort in each other's presence, and I'm always happy to be with him.

H: I really appreciate your sharing this story with us, and for joining us here on the Ringside program. We're going to link to the site, where people can go and get a copy of this book. I think it sounds like something that would be a great upcoming holiday gift for folks. The book is *What About the Boy?* Stephen Gallup is the author. Stephen, thanks for being with us.