THE BROOKINGS INSTITUTION

HEALTH CARE AND HEALTH INSURANCE

FOR CHILDHOOD DISORDERS

Washington, D.C.
Friday, October 23, 2009

PARTICIPANTS:

Introduction and Moderator:

HANNAH STORM
Anchor, ESPN
Founder, The Hannah Storm Foundation

Featured Speakers:

MICHAEL O'HANLON
Senior Fellow, The Brookings Institution and
Parent of a Child on the Autism Spectrum

LESLIE SINCLAIR
Program Director, Center for Autism
The Cleveland Clinic

LESLIE SMITH
Co-Director, Autism Outreach, Inc.

NICHOLAS SPARKS
Author, *The Notebook* and *Nights in Rodanthe* and
Parent of a Child with a Vascular Anomaly

DR. MILTON WANER
Co-Founder, Waner Children's Vascular Anomaly Foundation

* * * * *

P R O C E E D I N G S

MS. STORM: Hi, everybody. Good morning.

MR. SPARKS: Good morning.

MS. STORM: Thanks, Nicholas.

My name is Hannah Storm. I am not a scientist or a physician or a clinical investigator. In fact, you might describe me as an anachronism, a voice from the past talking to you about the future -- the past, because I was one of those children born with a vascular anomaly during a time when medical treatments were crude compared to what is available today.

But my parents, they did whatever they could. They made any sacrifice, without question, to see that their little girl wouldn't have to spend her life embarrassed by a port wine stain that sat under her left eye -- something that looks sort of like someone socked me in the face or gave me a black eye.

A port wine stain is a type of birthmark that you may have seen, even on a famous figure like Mikhail Gorbachev. It looks like somebody spilled part of a glass of red wine on your face. Well, that's what I was born with, over my left eyelid and below my eye. It's something that I spend a considerable amount of time every day covering with makeup before my job as a sportscaster at ESPN.

My parents spent their money and their considerable effort on a series of procedures throughout my childhood that actually left me pretty much like I was before, only with quite a bit of scar tissue, a tattoo and a lot of trips to hospitals and doctors. Although these outdated and, in the end, actually ineffective treatments were not covered by insurance, my parents made all the sacrifices necessary to get me treatment.

You know when a child is born with a birthmark, often their parents tell the little child: This is where the angel kissed you, up in heaven, before she sent you down to me.

In fifth grade, I underwent the first of two serial excisions. That meant a hospital stay under full anesthesia. As a young person, that's pretty traumatic. The surgeon would actually, I guess in the simplest forms, cut a slice of skin out where the birth mark appeared and then stitch the rest together. Sometimes, believe it or not, now I can still feel the pull of those scars. Also, this eye is a bit lower than the other because of it.

Later in life, I had a tattoo. A very well-meaning doctor said that it was flesh-colored, but actually it was, as it turns out, sort of a pasty white color that stood in very stark contrast to the red of the port wine stain.

In high school and college, there was a new solution. It was called the laser, only the laser technology at the time was such that it left third-degree burns, very painful, over the birthmark area. Finally, after the second treatment, when I erupted in a fit of uncontrollable teenage tears, I was done. No more treatments. I had had it.

Birthmarks not only affect the children who suffer from them but also their families. They can cause not only health problems but also emotional hardship and a considerable amount of heartache.

But what I really want to address today is the future. Today, we have much better treatments to take care of the thousands of children who suffer from vascular birthmarks and their related conditions.

We commonly refer to these as birthmarks. They’re actually vascular anomalies. Some of them are on the body surface. They have the potential to disfigure a child and potentially limit her opportunities in life. Others, though, actually extend inside the body with the potential to even cause a child to lose a limb or a vital organ. But this isn’t the end of the story.

Today, we have the treatments. We have the technology. So what is still in our future is to make sure that these extraordinarily important procedures are available to all children, in the earliest possible years of life, without the enormous financial burden to parents because they’re not covered by insurance.

These are not cosmetic procedures as the insurance industry often views them. These are critical surgical procedures that can help each of these children have what every child deserves, and that is a chance to start their lives on an equal basis with other children. Early intervention can have a profound impact if only the treatments could be accessed by families.

What we're talking about here are not rare disorders that could cost millions of dollars of health care dollars to provide treatment for a small amount of children, half a dozen children. That's not the issue here.

Last year, approximately 400,000 babies were born in the United States. Ten percent of those babies, forty-thousand babies, were born with a hemangioma. That's a benign skin lesion consisting of dense and usually elevated masses of dilated blood vessels. That's 40,000 babies.

Out of those 40,000, 4,000 required serious medical intervention.

And, out of those 4,000 babies, 9 out of 10 are girls.

So, what are all of these vascular anomalies? Well, roughly, 1 in 10 babies are born with a hemangioma. About 1 in 1,000 is born with a port wine stain, as I was. Venous and lymphatic malformations are also not uncommon, and some children suffer from arterial venous malformations. Those are clusters of arteries and veins with abnormal connections.

They can actually burst at any time during the life of that child. They can cause life-threatening blood loss, bleeding into the brain, irreparable damage to organs. They can even cause death.

Why are these so-called birthmarks serious, you might be wondering. After all, insurance companies, even the general public, think of these as cosmetic problems. Cover them up, and, if you want to have surgery, pay for it yourself.

Well, the problem is that these birthmarks, these vascular anomalies, can result in medical conditions such as blindness, congestive heart failure, respiratory failure, uncontrolled bleeding, problems with being able to learn normally, seizures and, yes, they can be fatal.

There are several syndromes capable of affecting all areas of the body. I'm going to quickly run through them for you:

KTS, a congenital vascular disorder, a limb affected by vascular abnormalities, varicose veins, too much bone and soft tissue growth. The limb might be larger, longer, warmer than normal.

You remember the golfer, Casey Martin, who successfully sued the PGA Tour for the ability to use a cart because he couldn't walk, he couldn't play 18 holes. He had KTS.

Symptoms can include bleeding from the limb, a skin infection, rectal/vaginal bleeding, pain in the limb, blood clots, anemia, seizures -- all part of this syndrome.

Sturge-Weber Syndrome, a neurological disorder indicated at birth by seizures, also a large port wine stain birthmark on the forehead and the upper eyelid of one side of the face, an overabundance of capillaries around the trigeminal nerve just below the surface of the face.

Sturge-Weber Syndrome: loss of nerve cells, calcification of tissue in the cerebral cortex of the brain on the same side of the body as the birthmark.

Symptoms include seizures that begin in infancy, and they worsen throughout the course of your life. Some children have developmental delays. They have mental retardation. Most will have glaucoma either at birth or they develop it later. Increased pressure within the eye can actually cause the eyeball to enlarge and bulge out of its socket.

PHACE Syndrome: the association of a large hemangioma usually on the face or neck, in combination with other abnormalities. The hemangiomas found in these patients are often associated with complications. If it’s near the eye, it may cause problems with the development of vision in that eye. The facial hemangioma on these infants is likely to break open and bleed, and when it does it’s very, very painful.

Infants that have this syndrome are at risk for migraine headaches, seizures, developmental delays, speech delays, ischemic strokes.

These are just some of the vascular anomalies that can affect a child for life. They can affect a child’s ability to speak, to breathe, to walk and to see. They do result in disfigurement which can have great emotional and psychological impact on these children and on their parents. This is something that can last a lifetime, but it can also have debilitating and deadly consequences.

The technology is there to help these children and their families. The resources are not accessible. Along with the lack of information and understanding is a lack of funding often due to the fact that these procedures are denied out of hand because they are determined to be cosmetic. Part of the issue lies in nebulous insurance codes -- that is something that we are trying to change as we speak.

Today's program will include perspectives on two really disparate problems, both of which have the potential to affect children throughout their entire lives, both of which require early intervention. We're talking about autism today, and we're talking about vascular anomalies.

Michael O'Hanlon will provide us with a parent's perspective about autism, how it affects the family, struggles obtaining treatment, issues with reimbursement. He is Director of Research and a Senior Fellow in Foreign Policy here at Brookings, where he has worked for 15 years. He'll come up in a second.

Leslie Smith, the Co-Director of Autism Outreach in Herndon, Virginia, is also with us this morning. She will be speaking, as well as Leslie Sinclair. She will provide us with an overview of the disorder, explain the benefits of providing the proper treatment, issues with coverage, and she's going to paint a picture of what success looks like as well, that's very important. She is nationally known for her service, for her achievement, service to individuals with autism. She has over 25 years of experience utilizing behavioral intervention with children who have pervasive development disorders.

We also turn to vascular anomalies then. We will hear a parent's story from Nicholas Sparks. He is the author of eight number one best sellers. He will share his personal perspective on vascular birthmarks and autism, the effect on the family, his journey towards treating his own children. And, of note, his novel *Nights in Rodanthe*, which was recently made into a movie perhaps many of you saw, there’s a key character in that movie who actually had surgery to remove a vascular birthmark, and that’s a very important part of the plot line that he worked into that novel.

Also joining us is Dr. Milton Waner, the world’s leading surgeon in this field. He has been responsible for the treatment of thousands of children, many of the treatments at his own personal expense. He is an internationally-recognized pioneer in the development of successful treatments for vascular birthmarks, author of over 70 major publications. He is Co-Director of the Vascular Birthmark Institute of New York, Beth Israel Medical Center and St. Luke’s-Roosevelt Hospital Center. He will share with us his personal account of just how powerful early intervention can be as an affirmation of why all children should be the beneficiaries of the treatments that they need.

Again, thank you for your time and attention. Now I’d like to turn it over to Michael O’Hanlon.

Michael?

(Applause.)

MR. O'HANLON: Thank you, Hannah. It’s a real privilege to be working with you and your fantastic team. It’s been a privilege to set up this event with the Hannah Storm Foundation, Dr. Waner's foundation, the Cleveland Clinic, Autism Outreach and other groups.

As Hannah has said, these ailments unify us in the sense that they are both currently being treated much better than they ever have been before, historically, and yet still very hard to access for families, and that's the unifying theme that I want to drive home. In the context of the ongoing national health care reform debate, it's a useful point, I think, to make.

But we have real experts following on my autism, and Nicholas Sparks will also give a parent perspective later. So I want to be brief and just mention a couple of things about essentially why I'm a lucky parent in the scheme of things.

Now, at one level, there is no such thing as being lucky when you're talking about autism. It's a very severe challenge even in cases that are well treated. But we're lucky. We have a wonderful daughter who is doing very well because of excellent treatment, who was diagnosed early, at age two, who has been receiving intensive intervention ever since that time, now about five years.

I can say that for my wife and I, our tears of sadness remain, but they're becoming more of a blend of tears of sadness with tears of joy as we see her now in first grade at Our Lady of Lourdes School in Bethesda, which is a wonderful place for helping with the flexibility we need. But she is in a mainstream environment, going to first grade like any other kid. She does have an aide with her a couple mornings a week, but she's doing very, very well. She's making friends. She's having play dates. The progress is extraordinary.

It would have been impossible without the kind of intervention that we've been able to access because when you watch these children, even the ones who are "milder" cases, and that word really should be banned from the lexicon of autism because there's nothing mild about any autistic condition. But, nonetheless, she's been relatively strong in a number of skill areas and, even so, building up the cognitive fundamentals to be able to see her do what she's doing now required step-by-step, deliberate training and education through a process of primarily one-on-one therapy, and that's what drives the cost. It's the one-on-one nature of it.

People in autism therapy are not getting rich, but they're working very hard, and they're doing it in this one-on-one way. If you do the math, the 25, 30 hours a week that the National Academies of Sciences say is appropriate for these kids, at a minimum, and you multiply that by a living wage for a therapist and you factor in the need for training and oversight, you're talking about costs that are typically in the general range of a thousand dollars a week, ballpark, and often quite a bit more.

Only in 15 states today, 15 states in the United States, are autism therapies generally covered by health care. This is largely due to the effectiveness of the autism lobby, Autism Speaks and other groups, which are working at the state level. It's a frustrating way to go, but they're having some success.

We hope, by the way, those of us in the autism community, we hope that the progress we begin to see with our challenge and our disability of interest also may have some positive effects for other childhood disabilities, including the vascular birthmark issue, the vascular anomaly issue and many others. So we really are part of a broader community here, dealing with a number of challenges that in our health care system today are not being properly addressed by insurance companies because they find reason or another to deny coverage.

Now, with autism, it's not an issue of claiming that it's a cosmetic problem, but the issues that people usually will cite, they'll say it's not really medical therapy if you're doing one-on-one tutoring because it looks a little bit like education. The schools should take care of that -- neglecting the fact that this has to start very early to be effective and that it's very akin to a lot of the therapies that are given to stroke victims, that are given to people with other kinds of neurological impairments and, therefore, really do have a lot to do with standard medical care.

A lot of autism therapy looks like speech therapy, looks like occupational therapy and can include those two things as well as its own dedicated methods.

Or, insurance companies will say the methods are not proven, that they remain experimental. This is, frankly, a nonsensical excuse at this point in history. We see 40 to 50 percent of children going through intensive early intervention, ultimately becoming mainstreamed in school today, despite their autistic challenge, and this used to be a figure around 0 to 5 percent. There is simply no doubting the evidence.

There is room for improvement in this field, and there are plenty of debates within the field about which therapy is best. One of the things I've been thrilled by is to watch our therapists learn from each other and constantly revisit their assumptions and their methods. I've seen this in the five years I've been involved in the field, and it's remarkable. But there is no doubt that we are already seeing methods that work much better, certainly than no treatment at all, and much better than they used to. Again, my daughter is a case in point.

The other reason why my story is mostly a happy story -- and I'll finish on this point before turning things over to Leslie Smith who is one of the people and one of the reasons why we're so lucky, because she is one of the people who has worked with my daughter -- is that we have been able to access this care. For one thing, we have two working parents making reasonable salaries, but secondly, and even more importantly, our employers have helped.

I want to thank Brookings again, publicly, for the fact that for a certain period of time, and it was not realistic to think that Brookings could do this indefinitely or at full cost, but for a period of time Brookings did help with some of the coverage. My wife's former employer, Discovery Communications, also has helped. Between the two, it's mitigated the cost, which has been in the low hundreds of thousands of dollars cumulatively by this point.

But our cost to us is probably, I haven't done the exact math, it's probably not a whole lot more than $100,000 to $150,000, and that's not small change. But, nonetheless, over a five-year period, by making that priority, we've been able to access this remarkable therapy.

This is a lucky story. Most parents in the United States don't have this kind of option or opportunity right now. Most parents don't live in the 15 states that now require some level of coverage.

By the way, I should also nod to the Department of Defense which is doing a better job with its Tricare health plan, also paving the way. I would encourage other insurance companies to ask themselves that if the Department of Defense can do this in a time of war, when it has so many issues on its agenda, why can't they try to do a little better, themselves?

Final word, in the course of the national health care reform debate, we are seeing some attention to this issue, but I'm not going to try to summarize this debate. I don't know enough about it because, frankly, things are a moving target, very fast. There are five bills before the Congress. Different bills have had different amounts of attention to autism.

I'm simply going to leave you with the note that there is some discussion of this, but there is certainly no assurance that we're going to see a mandate for health insurance to treat this kind of ailment like any other medical problem, and the therapies for it like any other medical problem. So far, they have not. They should. Again, thankfully, in 15 states, we're now seeing this kind of state-by-state mandate, but we've got a long ways to go.

Again, I'm delighted to have you all here. Thank you for your attendance.

Thank you, Hannah.

Thank you, everyone else on the panel, everyone who has worked with Hannah to set this up. It's a real thrill.

Just a personal note as I leave the stage and turn things over to Leslie Smith, I got to know Hannah Storm by talking about what I would call the Axis of Anxiety -- Iraq, Iran, Afghanistan and Pakistan -- when she was an anchor on the CBS Early Show. Her versatility is unbelievable, her commitment is unbelievable, and that's true for everyone else on this panel as well.

My own personal heartfelt thanks could not be more profound for the person you are about to hear from next, Leslie Smith.

(Applause.)

MS. SMITH: Thank you, Mike, and it is a pleasure to be here.

I'm a board-certified behavior analyst who has been providing services to children and teens diagnosed with autism for over 12 years now. I provide services for my population utilizing ABA or Applied Behavior Analysis. ABA is a scientifically-based intervention, and it is an evidence-based practice which consistently, throughout the years, has shown to be effective through scientific research.

Autism is a medical neurological condition which the CDC announced a couple of weeks ago affects 1 in 91 children and 1 in 58 boys. This is an epidemic for which most treatments right now, as you've heard, so far are not covered or reimbursed by insurance except for the military Tricare. The insurance companies say that ABA is an educational intervention and thus the responsibility of the school systems.

Behaviors that often occur in this population of individuals, the results of which are covered by insurance, are: Self-injurious behaviors, when the children hurt themselves or others, the ER visits are covered by insurance. Pica, when our children eat things that are not food -- rocks, dirt, feces, poison -- those things are covered by insurance when the children become ill. And, sleep and feeding issues are covered by insurance quite often.

However, ABA is not covered by insurance, and ABA is a proactive therapy and an evidence-based practice which would prevent any of these things from occurring and would actually save the insurance companies and society money in the long run.

Ironically, speech therapy is currently often covered by insurance, usually about an hour a week, when a child is diagnosed by autism. Speech therapy does absolutely nothing about any of the behaviors and health threats that were listed above. The large majority of studies stress the term, intensive early intervention, when addressing the needs of children with autism. An hour of speech therapy does not fit the definition of intensive or evidence-based in handling the needs of these children.

In the 1998 study by John Jacobson, Gina Green and James Mulick, it was estimated that when a child is diagnosed at an early age with autism and receives early intensive behavioral intervention, $1 million to over #2 million was saved over the lifespan. More recent numbers indicate that for a child who is receiving no services, who is diagnosed with autism, the cost for that child over his or her lifespan is $3.2 million.

As in any other treatment for any other severe child disorder, such as cancer, intensive behavioral intervention can be described as ingressive, intrusive, expensive and necessitating a high level of expertise in order for it to be successful. When the decision is made to invest in intrusive, intensive cancer treatments, for example, factors that are considered are the scientifically-based efficacy of that treatment versus using other treatments along with the consequences of pursuing other treatments versus that treatment or pursuing no treatment at all.

When looking at intensive treatment for childhood illness, cost is typically not the first consideration. Typically, there are various public and private resources that are made available to children and families who are dealing with a major disorder. Autism is such a disorder, and the same consideration must be given to these children and their families. In fact, at the end of the day, the most expensive interventions are those that fail to produce meaningful, measurable and lasting benefits, regardless of the cost.

ABA produces meaningful, measurable and lasting benefits to all children -- all -- who are lucky enough to be able to receive intensive ABA programming. In my 12 years of practice, I have never seen a child not positive affected impacted in some way by an ABA program. Studies consistently demonstrate that 90 percent of children with autism spectrum disorders improve with intensive intervention and 50 percent reach normal or near normal functioning level.

ABA is expensive for families to pay for out of pocket, as are most medical procedures. Why is it okay for our families to go broke, spend their children’s college funds, take out second mortgages on their home? And, those are the lucky families. The not so lucky families are declaring foreclosure and bankruptcy to be able to pay for therapy for their children. These events are the rule and not the exception with the families that I work with.

I recently had the opportunity and the privilege to speak to a mom whose son was diagnosed at an early age with autism. A year or so after receiving that diagnosis and navigating her way through the world of ABA, OT and speech and trying to figure out how to pay for all of it, her second son was diagnosed with leukemia. The son with leukemia is not in remission, and the son with autism is doing very well. However, this mom said if she had to go through it all again and choose she would choose leukemia.

In her words, “When your child is diagnosed with cancer, you are given a road map. You are told where to go next and who to see. You are provided with interventions that are medical, and you’re also provided with interventions that are educational both for the child and his or her family, all of which are covered by insurance.

“When your child is diagnosed with autism, you are told, it’s autism. I’m sorry. And you are left standing there and reeling and not sure what to do next.”

Autism is a medical diagnosis, diagnosed by a medical doctor. Insurance companies must be mandated to provide services to our children. Money will be saved by those companies and society when this happens because, again, the most expensive interventions are those that fail to produce meaningful, measurable and lasting benefits.

Thank you.

(Applause.)

MS. STORM: Thanks, Leslie.

Now we want to bring up our other Leslie, Dr. Leslie Sinclair of the Cleveland Clinic.

DR. SINCLAIR: Thank you very much. What an honor to be here at the Brookings Institution. I’m thrilled. Thank you for my invitation.

Of course, there are a few things that have already been said, but I have to start out with a story, as I usually do. It's a story about a mom, and her name is Sophia Ogea, and she would never mind me telling you her story.

This was approximately three and a half years ago when I met Sophia and Mark Ogea. They came to the Cleveland Clinic with their oldest child whose name is Marcel. He was approximately two years old at the time, and Sophia was nine months pregnant with her fourth child.

While we were in the diagnostic setting and we were doing the gold standard diagnoses, she turned to her husband and she said, oh, my God, Mark, our twins have autism too.

At that time, they were 17 months old. They were back the next week with their absolutely beautiful twin boys, and all three children got a diagnosis of severe autism.

I have had both the privilege and the honor of working alongside this incredible family. When their fourth child was born, which was a girl and she's neurotypical, an angel for the family, a light in the course of chronic heartache.

I will tell you there were no two parents that were more incredibly active in the process of helping their children than these two, and I know this because I've slept over in their house, been in their showers, gone in their bathrooms, eaten dinner at their family dinner table many, many times, doing intervention with their family in the course of getting treatment for their children, and they chose Applied Behavior Analytic instruction and intervention for all three of their children at the same time.

I cannot tell you the expense. There was expense not only fiscally, but there was emotional expense and marital expense. This is a heartbreak situation -- a lovely family, all like you, ending in tragic divorce, all three children with moderate levels of autism now. They probably spent an estimated $5 million second mortgaging their home, getting intervention for their children, MRIs that were not covered because a child did not have a seizure. This goes on and on, and now we have a tragic situation of a divorce.

This is one story, one story in thousands of those stories in the autism world.

I also start with one other story for you. Autism, as Leslie brought about, is a disease entity. We know autism is a disease. We actually understand much more about the genetics of autism now than we ever have. We have much research going on in the arena of autism. We need just incredible amount of more money to continue the research in autism.

However, we know that if we don't intervene, we don't do good assessment on our children, get them diagnosed and get them into intervention as quickly as we possibly can, that the disease progresses. So, without this intervention, it's much like untreated cancer. It gets worse.

This is really evidenced in children who do not receive intervention, children who are 18, 19 years old and are not yet toilet-trained, cannot sit in a chair for 30 seconds, have become so self-injurious that they are blinding themselves. This is because of a lack of good, solid intervention. It is absolutely, absolutely unforgiveable. Treatment is out there, and it needs to be accessed by all people who have autism spectrum disorder.

With that in mind, hopefully, I'll get this straight.

I am the Director at the Cleveland Clinic Center for Autism. I've been there for 10 years. We've grown a program from six children. We now have 109 full-time students with autism spectrum disorder.

I also want to just put a plug in for the Cleveland Clinic as well because the Cleveland Clinic covers Applied Behavior Analytic services to all of its employees, and that is 25 to 30 hours a week of intensive intervention for children, and they have done it for many, many, many years. I'm very proud to have been part of the process of establishing that kind of coverage and service through our wonderful institution. It's not a small shake because in the Northeast Ohio area, we have 38,000 employees, many of which have children with autism who access services through the Center for Autism.

We talked a little bit already, and I'm not going to belabor this, but you know autism has just recently had new diagnostic rates: 1 in 94 live births. You can't even wrap your arms around it. This is a tsunami. There's no other way. I want you to think of Indonesia. Unsuspecting people standing on the beach, giant wave approaching, no one is paying attention, and everything is wiped out.

Autism is approaching the United States absolutely at that level: 1 in 94 people with autism spectrum disorder, 1 in every 58 boys. It's impossible to imagine those numbers. It's impossible.

We are in real trouble because all of these children are going to be adults, and, if we don't intervene, we're going to have a lifetime of expense and service. If we intervene early, it's actually about a 60 percent return rate -- if we get our kids diagnosed at 15 months, which is absolutely 120 percent doable now. We have wonderful measures, wonderful evaluative assessments, and this can be done.

If we get kids diagnosed at 15 months, their tenure track in Applied Behavior Analytic Intervention, the average number of years is 2 and a half. There's much less expense associated with 2 and a half years of intensive early intervention than $3.2 million over the course of a person's lifetime. We're going to pay for it. We are.

So, what do we know about autism today? We have what we call the broad phenotype of autism, which means if you think about autism when you first heard it, you think about a child who might be nonverbal, who might rock, who is unresponsive, who cannot be reached.

That has absolutely been blown apart, and now we have a very wide range spectrum of people with autism spectrum disorder. We have children who are on the profound end of the spectrum, who may cognitive disability, but all share the core features of autism spectrum disorder which is deficits in communication, deficits in behavioral responding and deficits in socialization.

Our thinking and our paradigm about autism has certainly shifted over the years. One, we first started thinking about autism as its basis being much more related to communication. We know now that autism's basis is much related to socialization and that the socialization impairment in the areas of the brain where socialization occurs is actually what affects our people's ability to communicate well. So we know a lot more about what the brain is doing in terms of people with autism than we ever have, and this is very interesting news for us because again, like Michael was saying, we have come a long way in terms of treatment.

So we started treating our kids very intensively in the social realm very early, and, by doing so, we begin to impact communication right away. So that's exciting stuff for us to know. It's important. It's very, very important. It leads the agenda for intervention. Without that, we really don't have platform to say that we need to have all this stuff covered, and that's where we need to continue to go.

The idea of having MRIs done on our children before intervention occurs should be an absolute given because in Applied Behavior Analytic intervention, and some other interventions that are given to our children, we do rewire. We rewire our little kids' brains, and then, if 8 months from then, we did another MRI you would see something very, very different. We have only a few studies that report that, and we need more of that because that's going to push our agenda much further.

So, what is the history of the insurance dilemma in autism?

Well, why did we have initial exclusion? One, it was a very rare condition. You know autism originally was 1 in 100,000 and 1 in 50,000, then 1 in 10,000, 1 in 15,000 live births. So we had a rare condition. Most people said, oh, I just love autistic kids. It must be really fun to be working with them.

That considerably has changed, certainly with the incidence and the prevalence rate. Autism is now a household word. It's been at 1 in 150 for well over 5 years now, and you hear about it all of the time. It is in all media. It is on television. There are movies about people with autism that far extend past Rain Man, though that was a good mosaic composite of autism.

But now why do we have these initial exclusions? One, it was low incidence population.

Two, it was seen early on, when it was first defined in 1944 by a doctor named Leo Kanner, much more in the psychoanalytic world. You may or may not recall that early on parents were blamed for their children having had autism. Mommies were called refrigerator mothers because they were not able to bond with their children. Then, in 1975, we had a change in the paradigm of autism, and we started to understand that this was much more of a neurological condition than an emotional disorder.

But if you will go back in time, in terms of the insurance industry, you understand that most mental health-related issues, most emotionally-related issues were not covered and have historically not been covered. Mental health issues are the stepchild of the insurance industry -- are the stepchild -- and they are often forgotten about and often ignored, which is why we have rampant mental health issues across our great nation.

It needs to be fixed, absolutely needs to be fixed. So we have a big problem here, but these are the historical roots of why we have exclusion.

So it was very easy for insurance companies at that point in time to say this is an educational issue. The schools need to treat it.

And the schools are throwing up their hands, of course, sand saying, how? What do you do with these children? We don’t know what to do with them.

So, in the fifties and the sixties, you know what we did with kids with autism? We put them in state-run institutions, and that’s where they were.

In the eighties, we had a national mandate to de-institutionalize people with developmental disabilities. I know that because I lived and worked in the group homes that these people were de-institutionalized to, and it was an honor for me, but it was a tragic event -- tragic because there was a mandate to de-institutionalize within a month.

People who had lived in state-run institutions for 30 years of their lives were now living in homes for the first time. It was an abysmal failure, but they weren't taken back because those institutions were closed. So many of the people who had mental health issues, who had developmental disabilities were living on the streets.

We have a major crisis. We have a major crisis. So, past ramifications are those social issues which affect the nation totally. Not only do they affect the nation, they affect states, they affect communities, they affect towns, localities, and they affect families.

So, what is covered? Well, as Michael was saying, we have a state-by-state issue, and each state covers treatments very differently.

For example, if you live in the State of Pennsylvania and you want Applied Behavior Analytic services for your children, you can only get them in your home. So, if you're running a center-based program that's a really center of excellence, that has great therapists, combined years of experience, you cannot get your child covered. But if you go in your basement of your house and you have a board-certified behavior analyst come in and lead the team in your basement, you can get coverage. Seems silly.

Other states cover certain aspects of Applied Behavior Analysis. Other states cover only evaluation of children with autism, and some states don't cover evaluation.

And, of course, it goes insurance company by insurance company. They have their own exclusions. I have been privileged to read a number of policies that actually are blatant, and they say no diagnosis of autism is covered, and the related kinds of services.

I have to tell you one quick insert story. Yes, time. A little boy in our program, dad is a physician. Got coverage at the Cleveland Clinic Center for Autism. His little boy is only three and a half years old.

When he left, the child is completely healthy. He just happens to have a diagnosis of autism. He is completely healthy. Denied coverage by the next insurance company, complete coverage -- no medical coverage, no psychological coverage and certainly no intervention for autism. Dad had to come back to the Cleveland Clinic in order to get insurance coverage for his child. It’s crazy.

So we have some medical services that are and are not covered. Many times, children with autism need MRIs because they think they might be having subclinical seizures that are not easily detectable, often not covered.

Psychosocial, for the most part, covered for initial evaluations. If you go back a year later for another evaluation, you’re probably not going to get covered for it.

Behavioral intervention, only covered in certain states across the nation. It is absolutely the premier and leading intervention for children with autism that has a scientific basis and evidence base. The insurance companies are usually very archaic in their thinking in regards to what Applied Behavioral Intervention is, and behavior analysts have to spend a lot of time doing education to insurance companies instead of education to children. So we have a lot of issues. We work many, many hours.

Educational interventions, usually not covered at all. Some of the alternate and alternative interventions that are really showing some good value and have some very nice studies behind them right now, coming, not covered -- not covered -- and there are a number of them now that will be very nice in terms of being compatible with doing things like Applied Behavior Analysis as your core and then having some of these alternative mechanisms around it that enhance treatment for our kids.

We talked about this already, if you are excluded and you don’t have dollars to pay. We aren’t supported our families. We have an impact on the child, on the family, and schools cannot support in *toto* by themselves. They just cannot. So we have all of these fragile systems that are somewhat out of balance, and they aren’t sharing. They are not equally sharing.

So it affects our schools. It affects our communities and absolutely, as a tidal wave, will be affecting our nation as it already is.

We have some current trends in coverage change. We have lots of good groups out there, really pounding the pavement. I worked in Ohio on House Bill 8. It has changed its name. We’re in it again. We’re in our third year of fighting for insurance coverage in the State of Ohio. I’ve spoken both to the Senate and to the Congress, and we are working very hard to get it through this year. So we really need a lot more work, of course.

I just want to say one final thing, and then I will absolutely be done. Our President of the United States came out, and the first pediatric condition that he talked about in terms of federal health care reform was autism, twice, very aware. It is absolutely, I think, the biggest blip on the radar screen right now. So many children are affected, and its ramifications are far-reaching.

Then I'll save questions for later.

Thank you so much.

(Applause.)

MS. STORM: Thank you so much, Leslie. As you said, autism is very well known. It is a household word now in our country, and I hope that that's a great thing and helps to effect change.

But something that people are unaware of, certainly the severity of, although we all know someone with a birthmark, are vascular anomalies. So here to educate us about those and the very severe consequences for the children of our country, Dr. Milton Waner, Co-Director of the Vascular Birthmark Institute of New York.

(Applause.)

DR. WANER: Thank you very much, and I must say I found that absolutely fascinating.

We’re going to switch over from the autism side to something that’s a lot more physical but nonetheless has severe consequences from a psychosocial point of view, and so we’re going to talk about vascular birthmarks that were just briefly introduced by Hannah Storm. What I’d like to do is take you through a journey of these birthmarks and show you what they are, what we can do and what some of the deficiencies are that have resulted from these birthmarks.

Now one of the first things that’s happened, and this is very, very important, is that we now classify, we now understand these very, very differently from what we used or from the way we used to understand them. In the past, these children were all told, or the parents of these children were told that this is a hemangioma. Go away. Live with it. It will eventually go away.

Some went away. Some didn’t go away. So, for instance, if you look at these two children, you’ll see that this child and the child next to her both have vascular legions of the upper lip. This child’s lesion is a hemangioma whereas the other child does not have a hemangioma.

So, what is the difference and when did we recognize this? The renaissance started in the mid-eighties. There was a chap in Boston by the name of John Mulliken who educated us as to what these differences were. He recognized two groups of lesions -- hemangiomas and vascular malformations -- and he taught us that hemangiomas were usually not present at birth whereas vascular malformations were always present at birth.

The difference was that hemangiomas grew and then regressed whereas vascular malformations never grew, never regressed. As the patient got older, the blood vessels that made up this disorder just simply got bigger and bigger and bigger.

We also know that hemangiomas are more common in females than males. The initial figure was given as 3 to 1, and, as Hannah mentioned, we now know that a certain type of hemangioma is 10 to 1 more common in females than males whereas there is an equal incidence of vascular malformations.

So that was the start. This crystallized our ideas, our thought processes. We began to understand that there were these different birthmarks.

But things have gotten a lot more complicated, as they always do, and we've gotten a lot further in our understanding. We now classify these as vascular tumors and vascular malformations. Hemangiomas are indeed vascular tumors. There are lots of other vascular tumors, as you can see, whereas vascular malformations are classified according to the type of vessel that they make up.

Now let me show you some pictures of some of these lesions, so you'll be able to see what we're talking about, and take you on a journey of discovery about these lesions.

Firstly, hemangiomas, which are the most common, one in ten children have hemangiomas. If you look very carefully at this child's forehead, you may see an area of blanching, of lightening. Now, pretty soon, the hemangioma will develop, and that's a very typical hemangioma.

If you look at both of these children, they seem to be fairly normal, a slight blemish on the first child and virtually nothing on the second child. But, within a short period of time, these very, very large hemangiomas develop, and very disfiguring lesions develop, and they grow very rapidly. It's probably one of the most distressing things.

A child is an extension of one's self, and your child is born with this tumor which grows and grows. Nobody really knows what it is, and nobody knows what to do, and it's probably one of the most distressing things.

Did I do anything to cause this? Did I eat anything? Is it something in my genes or my gene structure? All these questions and all this guilt and all these emotional feelings which come to bear upon these children, upon the parents of these children and their families -- this is a family disorder.

We now know, and this is some of the work that I've been engaged in, we now know that hemangiomas are stem cell tumors, and this is very interesting. They're tumors made up of stem cells where the signal to stop making blood vessels is not turned off as it's supposed to be. We've even identified the gene that we believe that is responsible of this.

There are different types of hemangiomas. There are the ones we call focal which grow as tumors and the ones we call segmental which grow much more diffusely. The segmental ones are much more destructive and can lead to very many more problems for these children than the focal ones, and these are some of the ones that we've concentrated on early growth.

Complications are numerous. We see children who fail to thrive, who go into congestive cardiac failure. The function of the heart is to maintain pressure within the blood vessel system. The hemangioma acts as a shunt. It's like punching holes in the tube, and the heart has to work harder and harder to maintain this pressure, so some of these children will go into cardiac failure.

Ulceration, a huge problem, the pain associated with this is profound, much more profound than, say, a simple sore. We're not quite sure why this is so, but we know that these children cringe every time an adult approaches them because manipulation, movement, is associated with pain. So mother picking the child up or changing the diaper or doing anything to help this child will cause or will be a painful experience. This ulceration, left untreated, can persist for months and months and months -- so chronic pain, a huge problem.

Tissue destruction, you can see ulceration which developed, and this ulceration developed virtually overnight, and this will destroy the nasal septum, the columella, et cetera. You can see the other child had had some ulceration. So ulceration, tissue destruction are huge problems.

Then we see some children with a small number of fairly benign-looking hemangiomas, but these children can be in imminent danger because many of these children will have liver disease. If they do have liver disease, this can be fatal. So this must be diagnosed early. Unfortunately, very often, it is not, and many of these children in the past have not survived as a consequence of this.

Here’s an example of a child’s liver. The liver is normally a uniform organ. You can see each of these is a hemangioma. So this liver is riddled with hemangiomatosis. The liver has virtually been replaced by multiple small hemangiomas. That was the child that you saw earlier.

Blindness is another problem. Any child whose eye is covered for a period of time will develop a lazy eye, and a lazy eye is simply blind eye. This is very important because we know that the cornea is responsible for focusing an image on the retina.

Now, if a hemangioma develops in the upper or lower eyelid, what will happen is as it expands it indents the cornea, and so this perfectly symmetrical structure is no longer able to focus the image on the retina. The focal point moves off, and so the image that the child sees is fuzzy. This is known as astigmatism.

If one eye sees fuzzy and the other eye sees normal, the brain will ignore the fuzzy image, and so that optic track, the connection between the eye and brain, will not develop. It will atrophy, and so that child will develop a lazy eye. A lazy eye is simply a blind eye.

So, early intervention, absolutely important -- we can save the child's vision, and we'll show you some examples of children in whom we've been able to do this.

Psychosocial consequences, these are profound. This child was homeschooled because every time she went out people would stare at her, people would ridicule her. She was sent home from Sunday School because a lot of the kids were grossed out by her.

So these are some of the problems that we come across.

The medical community believes that all hemangiomas involute. In fact, I remember as a medical student looking at this and saying, oh, well, this is not important because they all go away.

It is true that some involute, but many do not. At least half do not. The consequences and implications and complications that these children go through or experience are profound and certainly worthy of treatment.

Here's a picture that I pulled off the internet. There are many sites. This mother, very religiously, photo-documented her child's journey. At 15 weeks, you can see the hemangioma. Four years, it was still there. Seven years, it was still there, a little smaller. At nine years, it was certainly still there but somewhat smaller. So this means nine years. For nine years, this child had to put up with some form of physical disfigurement.

Here's a child whose hemangioma had involuted, and that's what was left.

Another example, the nasal hemangioma which didn't quite go away, but this is what she was left with.

And, this is an adult with a similar condition, an example of a hemangioma before and after involution. It shrank, but that's pretty much all it did.

So we know now that involution simply means shrink. What's very interesting for us is that if one was to take a piece of skin from the affected area and look at it under a microscope, it would be as if that skin was taken from a person much older than the patient really is. There's no collagen. There's no elastin. The hemangioma destroys these structures, and so as it regresses it leaves aged skin behind.

Now, cosmetic surgery -- one of the problems that we have is that the insurance companies will call this cosmetic surgery, and this was just an example. This child came to me from Florida. Her mother was told that this was cosmetic surgery and that the insurance would not pick up the cost of surgery, and so I said, well, just come anyway and we'll figure it out. Sure enough, we figured it out, and we were able to cover the cost of the surgery.

We have various foundations, various groups of people who are willing to help. I do a lot of pro bono surgery, and we've never turned any child away who has not been able to afford treatment.

We have found that early management is of the utmost importance, and I have to credit Dr. Fran Bly sitting in the audience here, who worked very closely with me on this. We have found that with early intervention, within a few months, we can get these children looking normal.

Here's another example. With early intervention, this child will look normal with a very short period of time.

There's someone else sitting in the audience whose child was also treated very, very early, and she is responsible for forming the Waner Birthmark Foundation, and her child was also treated early.

This is a child who was not treated early. This child came to me too late. The Steri-Strips were used to hold the child's eye open, so that he was using this eye and would not go blind. This child faces virtually a lifetime of surgical procedures to correct whereas with early intervention, with Propranolol and some laser treatment, the child by six, seven, eight months is totally normal. So early intervention does make a difference.

Here's a child born with a small hemangioma in her right check, which got bigger and bigger and bigger and very, very large, and that's when they came along for treatment. So this is the type of thing that we must prevent. Early intervention could have prevented that. Some

Propranolol and some laser treatment could probably have had this child looking totally normal.

So, what of the child whose parents were told that this was cosmetic surgery? Well, we operated on her. I devised some new operation to try and fix this up. Sure enough, it worked, and here she is today with a fairly normal-looking nose.

The child who was homeschooled, yes, she looks pretty good. She's going to school. This is her at two weeks. I just recently saw her. This is her a few months later. I'm going to have to give her a normal nostril, which I can do in a few months time, but she will look normal. Once again, her surgery was not covered by any insurance company.

This is a child who is about to go blind. I was on my way to go on holiday, and this child walked in, and I was about to leave in a few hours for the airport and be gone for two weeks. Of course, I couldn't because by the time I got back this child would be blind. So, holiday got cancelled. The child got surgery. There she is immediately afterwards, and there she is a few weeks later.

So the results are very, very good. We can do lots for these children. Propranolol is a drug that we've begun to use, which really shrinks these hemangiomas, even without surgery.

Here's a child who underwent surgery and some laser treatment, and you can see the orientation of the lip is normal. By paying attention to details, we really can help these children.

Vascular malformations are the other group of disorders. These are classified according to the vessel type. This is a port wine stain which Hannah spoke about. This is also a port wine stain, a little older. As the child gets older, the blood vessels that make this up get bigger and bigger and bigger because the muscle surrounding the blood vessels doesn't work. The muscle has no innovation.

Eventually, the port wine stain will thicken, and here's one, or a child in whom the port wine stain was not treated, and this became tremendously thick. This child came to us from Iran. She also arrived with no insurance, no money, and we found a way to help her.

These are children with venous malformations. Here's an arteriovenous malformation, one of the chin and lower lip, one of the upper eyelid, and these children all have lymphatic malformations. These are malformations of the lymph vessels. So the various vessels can be affected, and these are the disorders that result.

We can help these children. Here's a child with the lymphatic malformation before and after surgery. This child was advised to have her eye removed. Nobody really knew whether she would be able to see again. We operated on her, and she now has normal vision. This is her today.

This is a gentleman who came to us with an arteriovenous malformation. He was not born this way, but this is how he looks today. We've not cured him, but we've given him a new lease on life. We've given him the ability to function normally, and I believe everyone has the right to look normal.

Thank you very much.

And, this is a patient who, incidentally, we've just commenced treatment on. He came to me from Poland. He was surviving on a small pension. He was not able to work. He lived in a single room. He's actually mentally normal, but this has been getting worse and worse, and I believe we can get him looking normal.

Thank you very much.

(Applause.)

MS. STORM: So I bet you learned a lot. I think one of the beautiful things about us partnering together is that our world grows, and we learn about it, about an entire group of people who need help. But we also have such important things in common, like the need for early intervention, the difficulty in accessing that, in a large part because both of these conditions are largely misunderstood, and the needs of the patients. So I hope that today has gone a long way towards broadening that understanding.

What we want to do is a bit of a panel discussion with the two of you, and I would like for you to start with where we stand with today's health care, what the proposed health care, how that will affect treatment for these families and these children, and sort of what needs to happen down the road here.

DR. SINCLAIR: You know in studying what's going on in terms of health care reform and where we are, we now have 14 states and another 10 states pending insurance mandate for coverage for treatment specifically for Applied Behavior Analytic intervention for children with autism. So we've made some course towards making sure that all children are covered.

But children with autism are in the same pool as all children in the United States, and that is that all children in the United States are not covered under health care. As we get into more sub-specialty kinds of issues that we're talking about today, we have even less coverage available to children.

There is a huge push, because of the incidence and prevalence rate, to make sure that children with autism do get insurance coverage. The organization, Autism Speaks, has done yeoman's work in terms of making ad campaigns available to people in the United States to understand what autism is. It isn't anymore about autism awareness. I think we're beyond autism awareness action now. Now we're into autism action.

Our President is fully aware of autism. He has a very good understanding of autism spectrum disorder. Before he actually became President, he put a statement out about the need. There has been an enormous amount of money actually now given in terms of scientific study of autism just recently.

So I think we are on the way. There is progress. But with the amount of children that are being diagnosed, the progress and the volume of children, there’s a huge discrepancy between that. So we have a very fast pace that we need to kick up in terms of getting kids covered.

MS. STORM: Dr. Waner.

DR. WANER: Yes, in terms of children with vascular anomalies, many do have insurance, but many don’t. Or, many are covered, but many are not covered. It’s kind of a mixed bag, and it’s a constant fight.

For instance, laser treatment very often is not covered. Some insurance companies will, and in some states it’s mandated. So it’s a case-by-case fight, a state-by-state fight. Eventually, we will prevail, and we will win.

But so many or so often these children are told this is cosmetic and it simply will not be covered. For instance, a birthmark on the body or on an arm or a leg is not usually covered. Something on the face most often will be covered, but once again it depends on the insurance company, the policy. There’s no uniform policy for this, and we have to fight on a case-by-case basis.

MS. STORM: Can you talk about the issue that exists with insurance codes and how that might help the problem?

DR. WANER: This is a problem. There is no CPT code. Whenever, in America, we like to put everything in a little box and tick it off, and everything belongs, and if you're not in this box you're in trouble. This is what's happened to children with vascular anomalies because there are no CPT codes for many of the treatments. So they fall under the 99 code, which simply means a procedure for which there is no code, and that immediately gets kicked out by the computer that runs the insurance company.

So anything with a 99 code is not going to be paid. It gets kicked out, and it gets contested. Some lady sitting on a computer screen will say, oh, we're not paying for this. This is a 99 code. It doesn't exist.

So without CPT codes, we really cannot move forward. One of the actions which Hannah started is to get CPT codes going for these children. In fact, Hannah has made this possible for us to move forward in this direction. We're having some pretty high-level meetings later today, and things will hopefully move forward. We believe we will be able to get CPT codes, which means we'll now be a little blip on the map somewhere and somebody will be able to recognize these children and say, oh, yes, that's what they have. Now we can treat them.

DR. SINCLAIR: I have to put my two cents in on CPT codes and autism. If you put the 299 diagnostic code down for autism, it's rejected almost 100 percent of the time because it says autism.

If you put PDD NOS, it’s also rejected because it says PDD NOS which is pervasive development disorder, not otherwise specified.

If you put encephalopathy, you may get covered, which is a generic, certainly a generic code for you have a problem in your brain.

So we have some really huge billing problems for people with autism and also bill it as a communication disorder instead of an autism spectrum disorder -- so, really a very, very thick miasma of coding.

MS. STORM: Right. That’s part of what we’re trying to do is awareness and education is such a big part of this in terms of doctors properly coding and in terms of making insurance companies aware, again, of the seriousness of these conditions and not coming in as some sort of nebulous number that gets rejected out of hand.

What is the road map, if you could each summarize, for a parent who has a child and is so overwhelmed by the financial cost, the lack of information, the misunderstanding?

Maybe they’re not getting a proper diagnosis from their own pediatrician. What do you tell a parent who is looking at a child who needs treatment but who doesn’t have information, who doesn’t have the funds and literally either doesn’t have insurance or their insurance company cannot cover this condition?

MS. SINCLAIR: For autism treatment, the first thing that a parent needs to do, that I always say, is get to whomever is considered to be your local expert in terms of autism intervention and autism treatment and go where there is an evidence based for what is happening, that has a scientific basis, that has a proven record, that treats many children. Usually, there is a person within that confine that can help a parent move through the multiple parallel systems that they have to because it isn't just a medical system for children with autism treatment. It is also an educational system, a home system, a wraparound services system.

So you need to get to somebody who has a knowledge base, or a team of people that have a knowledge base of those systems. It's such an overwhelming map.

MS. STORM: How do you advocate with an insurance company as an individual?

DR. WANER: You know the same thing, the same sort of map is applicable. The first thing that the parents have to do is get to the local expert, get to somebody who really understands how to diagnose these conditions and what forms of treatment are available.

I think the internet has been an absolute godsend because there's a wealth of information out there. Some of it is good. Unfortunately, some of it is not good. But I think people can sift through the good and the not good quite easily. Anybody with a reasonable amount of intelligence can navigate the internet and find out what to do and where to go.

Once you get to your local expert, they'll be able to help you. Most of them will have advocates who will be able to fight for your cause, and you'll go through appeals and additional appeals and so on and so forth. Eventually, we prevail because at the end of the day there's always a panel, and there are one or two doctors sitting on that panel, and if they see a photograph of the child their heart will go out to the child, and they'll eventually overcome their ability to ignore this condition and pay more attention.

MS. STORM: But should it really come to that? Because in the meantime, if you're saying that early intervention in both cases is key and you're talking about appeals and panels and steps and finding experts and surfing the internet, this is all extremely time-consuming.

DR. WANER: Very much so.

MS. STORM: Meanwhile, this child, the conditions are getting worse and worse and worse, to some extent, beyond a point of really helping the child. So time is of the essence. These families don't have that kind of time.

DR. WANER: Very much so. In fact, time is of the essence, and we do have to get going, and we do have to move along.

MS. SINCLAIR: Certainly, two of the major problems in autism are: Our kids don't have any discerning features; that's number one. The second problem in autism is that if we early diagnose our children they have much more softer and subtle signs because the chronicity of the behavior has not solidified yet. So making the case for our kids becomes doubly difficult.

DR. BLY: I want to thank everyone for organizing this, and Hannah and everyone who worked so hard. I've learned a lot, and I think there are some similarities that are really very telling between these two disorders.

A question I have, or I'll say a comment I have is that many patients are referred. Many patients are referred by physicians. Many patients, they're referred by the physicians too late. Many families are the ones who push to find physicians who have the expertise.

Even when you get to that point, even if you are in the plans and these are families who have insurance, oftentimes what happens is the insurance will bump the patients to physicians in their network for surgery, for this, that and the other thing. Many times, those physicians are wonderful at what they do, but they may not have the knowledge base and experience in vascular anomalies. That is a huge problem, and it ends up being cost ineffective because many times they still have to go to those people.

Then it's the parents who end up really trying to work with us to say the parents don't feel comfortable. Then, ultimately, they get the insurance company to agree or don't, and they just have to pay on their own.

MS. STORM: So how big of an issue is this for children who have to actually travel out of network? There are very few places that can actually treat these vascular anomalies. There really isn't such a thing as a local expert in a lot of communities.

DR. BLY: First of all, in many of the patients, it's not just one physician; it's many. Sometimes they're at the same institution, sometimes they're not, which is really irrelevant because they would still work together.

But there may be some advocacy for centers of excellent that could just be the rubber stamp to be the approved centers, that just send them there. It would be so much more time effective and cost effective for everyone, and maybe that's how the negotiations can go.

DR. WANER: Yes, I think what Dr. Bly is saying is true, that insurance companies are obviously into cost or cost effective and saving money. In so doing, they have established contracts with certain physicians who are their network. With these physicians, they get discounted prices. So when somebody who is insured by them has one of these conditions, they will send that person to their local expert who may or may not have any experience in this, and that's what happens.

So time is of the essence. The child gets referred. The hemangioma is growing. The physician says initially he thinks he can treat this, but then discovers that he cannot, and the child needs to be referred out of network. This all costs time, and time marches on, and it's a huge problem.

MS. STORM: So what needs to happen?

DR. WANER: What Dr. Bly said -- We need CPT codes. We need centers of excellence where the treatment is rubber-stamped, and these should be recognized places around the country where children can go.

DR. SINCLAIR: Well, in autism, you know we have a few things that we need to certainly hammer out in terms of making sure that kids are getting equitable treatment because they're not.

First of all, I think it's really important. Number one, we have inappropriate CPT codes for our kids. So they get diagnosed with all kinds of different disorders. They're being then shuttled to different kinds of specialists.

MS. STORM: It's very difficult to pull back when you have an inappropriate diagnosis.

DR. SINCLAIR: I mean if you don't have an autism diagnosis that's driving your treatment course, you're going to places that don't have specialists in autism treatment.

So the delay between getting a diagnosis, even if it is an appropriate one, and a child with autism getting into treatment right now is about 18 months, from diagnosis to treatment. In those 18 months, 1 can only imagine what happens to a developing brain. So if you're 15 months and you're waiting 18 months, what if you're 18 months and you're waiting 18 months? And then you're 24 months and you're waiting 18 months?

Each time that goes by, each month is a year, each day is a month, each half a day is a week in that developing brain. We have missed all of those. We have missed those opportunities.

DR. WANER: One of the problems is that parents may recognize that this is what their child needs and may start the therapy and cover it themselves, thinking that when the appropriate diagnosis is made and when everything, they'll get reimbursed. Not so. They won't get reimbursed because the insurance company will say you didn't have approval for this, so we're not covering that. We're only covering from this point onwards.

QUESTIONER: I just have a few things I wanted to add. We need to also recognize, as with autism, when you take a parent and you put them in a room with a newborn that's three weeks old and you start talking about blindness, cardiac deficiencies, severe disfigurement, psychosocial development, all of a sudden the fact-finding, normal process that a parent is able to function, on even a high-functioning adult, goes out the window.

I just want to say, from an insurance fighting standpoint, it is a very involved process. Each insurance company, you have to know the ins and outs from each one in order to really accomplish your goal. By losing six months for the kids that have vascular anomalies, you're now repairing damage that's occurred instead of treating a condition.

So, as far as the insurance company and what needs to be done, I think, Hannah, the CPT codes really are an answer for us, but also we need to make this a household word. When I heard that one in ten children had hemangiomas, I was shocked because I didn’t even know how to pronounce the word, and they had to explain it to me.

But I want to bring to the attention that these are parents with feelings and emotions. Even though most of the people in this room are extremely intelligent adults, high functioning, you suddenly can’t make your grocery list because you don’t know if your child is going to survive their condition and you don’t know what kind of quality of life they’re going to have, as what you’re discussing.

So I think that it truly needs to become something that is a common word among parents in order for these patients to reach out. At this point, we go on the internet. We spend hours finding parents, talking to them, answering their questions, helping them navigate who they can talk to get the valid information that they need to fight their conditions.

MS. STORM: Sherry brings up a good point, and you touched on it, Leslie, about the high divorce rate among parents with children with autism. Can you both talk about the very, very serious emotional consequences for the entire family of having one child in this family? The family you talked about was absolutely heartbreaking, but how the entire family suffers.

DR. WANER: Yes, it is. It’s a family disorder. For instance, a child is born with a vascular anomaly. The child is disfigured. There is tremendous guilt amongst the parents. What did we do?

The child is an extension of oneself, and so if your child has a severe disfigurement it's your fault. You did something. Something was wrong. Something happened. Why is it me? Why is it my child?

So tremendous emotional turmoil ensues, and the parents become overprotective towards their child because every time they go out in the supermarket people stare at the child. And the first question is what did you do to your child?

I've had one parent who was on a bus with his daughter, going to school. When he got off the bus or the bus was stopped by a police patrol car, he was taken to the police station and had to call me so that I could tell the police officer, no, he did not beat his child. This was not a bruise.

MS. STORM: It happens quite often.

DR. WANER: Yes. This was a birthmark. So there are these tremendous emotional problems.

The siblings are affected because the parents will naturally be overprotective towards their child. And what happens to the siblings? Do they fall by the wayside or many, many things?

So this is a family disorder. This is something that affects the entire family, and we find this time and time again. All too often, divorce is something which we see from time to time, and this is a problem. The strain, the tremendous strain which some of these families come under can result in divorce.

DR. SINCLAIR: Well, one of the things about the impact on the family with autism, I think, and there are so many similarities here. I mean there are twin similarities in that, one, children with autism can often have very chronic behavior that occurs very frequently throughout the day and impacts the family.

One, our families are fatigued often. They're very, very tired, and that has a huge impact on the wellness of the family because children with autism have sleep disorders. They can sleep like cats. They take a five-minute nap, and they're up for four hours.

And guess what? Because they don't have the judgment about safety concerns in the home, mom or dad are also up with them. It becomes a very fatiguing situation for our families. So we have a physiological impact because no one is sleeping.

Then dinnertime can be a nightmare because so-and-so wants to eat this or he wants to roam or he wants to graze. Then we have other children who are decompensating because they don't want to bring their friends over because Johnny has such unusual behavior in the house. So we get an isolationism effect often with autism.

So we have a lot of issues that impact the family, and then the chronic nature of it too, and the parents getting very tired of having to do intervention with their children. Then they forget about themselves, and they forget about their spouses because I'm overwhelmed by taking care of this particular child. Then everybody else is okay, but I've got to super-focus on this.

And it does. I mean over time it can have a very, very hard impact on the families.

MS. STORM: These children are often made fun of by their peers. Their parents are often second-guessed by adults.

I just want to say before we have to get Nicholas Sparks here, but we do have another author here in the back. Evan, could you stand up for second?

Evan Ducker, when he was 12 years old, wrote a book called *Buddy Booby's Birthmark* which is now in 10 countries. Is that right, Evan?

He actually just received a big award in Ireland, but Evan wrote a wonderful book as a child for other children, with animals, and it promotes understanding of one kid to another about how to treat people who are different. Anyway, Evan is a very special guy. So, if you guys get a chance, stop by and shake his hand later.

(Applause.)

MS. STORM: And one day perhaps, Evan, you will be a *New York Times* best-selling author.

We do have one with us, a dear friend actually from Notre Dame, Nicholas Sparks, who is probably the perfect person to wrap up our day as a parent who has dealt with both autism and vascular anomalies.

Nicholas?

(Applause.)

MR. SPARKS: Yes, thank you, Hannah, for inviting me and thank you, everyone. I learned quite a bit here, certainly more than I ever knew about these things.

And it's funny. Boy! Boy, could I relate. I related to you, and, boy, did I relate to you. It was quite amazing. So let me just tell you a couple of stories because that's all I can do, because I'm not as smart as everyone who was up here before.

Let me tell you my older son had to have his tonsils out one time, and at that time in my life I was selling pharmaceuticals. So I brought him in to meet the doctor the day before he was getting his tonsils out. I brought Ryan in and my wife in, and we were in there. He was a good friend of ours -- just so my older son wouldn't be afraid of what was going to happen in surgery the next day.

And the doctor says, okay, who's this?

I said, well, this is Ryan.

Ryan was about three years old at the time.

He said, oh, hey, Ryan. How are you?

And he didn't answer. We just kind of laughed. We said, oh, he's not going to answer. You know. He's out little mute child. He just doesn't talk.

So he says, okay.

So he went through what was going to happen with my older son, and he said, hey, would you mind if I talk to Ryan for a little while in my office?

I said, no, no, go ahead. You just have at it.

I figured he was going to go show him one of these little skeleton hands, right, and maybe give him the secret lollipop stash that doctors usually have.

He was in there for maybe five minutes. He was an ENT. He was just a regular ENT. He came out, and he said, I hate to have to tell you this, but I think your son is autistic.

Those were very scary words to hear, very scary words to hear. At that time, this was about 1996. This was a long time ago. We didn't certainly know as much. We were still in autism awareness back then. We weren't in what to do.

Very scary -- we didn't know what to do. We said, well, what do we do? Is he going to be okay?

Well, we have to go. I recommend you go ahead and bring him for an evaluation.

So we took I think it was two months to get him evaluated, then another week to get the results. They said basically, well, yes, we're pretty sure he's autistic.

We're like, oh, my gosh, what do we do? You know. Is he going to be okay?

Well, we don’t know that, but a few things didn’t check out. We think he probably should get another test.

So we said, okay, schedule another test.

Another two months pass, living with this every minute of every day. He comes in, and two months later this is what they said to us: Oops. Sorry. We think we were wrong. Now we’re not sure it’s the severe autism. We think it’s somewhat PDD NOS. We don’t know what it is, but something is wrong.

We’re like, oh, well, what do we do? Is he going to be okay?

We don’t know, but we recommend that you get another test.

So we go in. This one was a hearing test to see if there was something wrong with his hearing, some internal ear thing. You guys know. I don’t know what it was.

It took a while to get it. They tested him. They came back to us, and they said, oops, we were wrong. Your child doesn’t have PDD. The problem with your child is that he’s profoundly deaf.

We’re like, why does he turn when the air conditioner clicks on?

Oh, he does that? Well, let’s get another test.

Another couple months go by. We get another test. They say, well, you’re right. Your son can hear. We’ve proven that. The problem with your son is that he’s profoundly retarded and ADD.

We’re like, I don’t think so. He’s pretty smart, even though he doesn’t talk.

It was a very stressful period for my wife and I. This was the same year that -- I had already lost my mother -- the same year that my father suddenly died in a car accident. It was the same year my sister was re-diagnosed with a brain tumor which would eventually take her life.

This was a very stressful year. It was the same year as *The Notebook* was being published, my very first novel. Big issues going on all this year.

So we were going through this, shunting from test to test. All we wanted to do know was what do we do? I don't care which. What are we going to do? We were in a small town in the South, and nobody ever really had an answer to that.

Anyway, I go on my book tour for that year. It's like 50 cities. So it was very stressful for my wife. She still doesn't know what's going on.

At the end of this period, I knew my wife was literally at the end of her rope. So I gave her a gift that I thought she would very much like. For Christmas, I gave her a trip to Hawaii without me. Right? It had been very stressful.

You might figure, you know, why would I do that? I will tell you. Who's going to watch Ryan? Who? Who? Nobody. There was nobody else. If I want my wife to relax, then go off with a girlfriend to go to Hawaii.

Well, it was very stressful on the marriage. While my wife was in Hawaii, we get into an argument on the phone. We get into this argument on the phone, and I'm arguing, and she's arguing.

She finally says, look, let me tell you what my life has been like the last year. I wake up every morning, and I wonder if Ryan is going to be okay. I wonder if Ryan will ever have a friend. I wonder if Ryan will ever go to school or drive a car or go to the prom or get married. I wonder if he's going to do anything.

He's four years old. We've been running around for a year. All that's happened in this year is he's fallen another three years behind his peers. That's all.

I don't even know if he loves me.

So I felt very petty about my little fusses at my wife, and I said, you know I'm very sorry. I didn't know that that was what your year was like.

I said, well, I'll tell you what. I promise to cure our son.

Big bold words, right?

Because while she was stressing about this, I was reading. I was reading. I was fortunate. So the next day I bought this little plastic table and chair from Wal-Mart, got this particular model because it had a seatbelt -- because it had a seatbelt on it. Buckled him in. Buckled him in.

He loved these little Nerd candies. He didn't say a word, but he loved these little Nerd candies. So I held out this little piece of candy, and I said, apple. Apple. Apple. Apple. Apple.

Oh, probably after about two or three minutes of that, he was getting pretty bored. After maybe five or six, he was beginning to fuss. Maybe after eight or nine, he was really this. After 15 minutes, he begun to scream and claw at his arms, trying to get out.

I said to him, apple. Apple.

After two hours of that screaming, two hours of nonstop screaming, my kid could say, ah.

After four hours, he said, app.

And after six hours, he said, apple.

I've had a lot of good things happen in my life. I consider my life very blessed. But, to this day, it's the happiest moment of my life because it was the first time I knew my kid could learn. He could talk. He could do it. And I knew it.

I remember I took his little face in my hands, and I said, son, you got dealt a crappy deck of cards. You got a bad hand in life. Well, we're going to fix that, and I'll be with you every step of the way.

So, the next day, I worked with him another six hours. My wife is still in Hawaii, and I call her that night and talk to her. I put my older son on the phone. She talks to him.

I get back on the phone, of course, playing her. I said, oh, by the way, Ryan has something to tell you.

Remember, she's not heard him speak. I put the phone up to his ear, and I mouthed what I want him to say, what we worked on for six hours. He says into the phone, I wuff you.

Now, I did not have the Cleveland Clinic in my backyard. I did not have a doctor who knew bupkis about what to do. There were books out there saying cure your kid with autism with hug therapy, eat bananas, all this crap.

I did what she did, but I didn't know how to do it. I wasn't trained. Why did I have to do that? Because insurance wouldn't have paid. Nobody would pay. So I had to strap that kid in that chair for three to four hours a day, two and a half years. Two and a half years, I had to work with him.

How's Ryan now? A little socially behind. But you know what? He's in high school, college-prep, a very rigorous school. I know this because I founded the school. It's not for autistic kids. It's for people who want to go to Harvard. It's tough. I think he got four As, a B and a C his last semester.

Right now, today, he's in Peru, hiking around Machu Picchu without his parents. Last year, he went to Costa Rica and Mexico, again, with the school. He's traveling. He's my son, a good kid. You'd like him.

All that's good, right? Boy, what else can happen?

A few years later, 2001, I had twin daughters born -- twin daughters. First was Lexie. Second was Savannah. Lexie came out with a little pencil hemangioma -- a pencil eraser, this big, right here -- and it began to grow and grow and grow.

My life has been very blessed someone in my little town said, you need to take her in now.

We didn’t know where to go. They did. They told us to go see Dr. Denque in Norfolk, Virginia.

Well, the problem was it had continued to grow. It was the size of a softball beneath her chin, and, if you touched it, it ulcerated and gushed blood.

I’m on my book tour. I’m talking to my wife. I say, yeah, we’re talking, da da da. Our daughter is smiling for the first time. It was so painful.

Six weeks go by. Lexie sounds funny. She sounds funny. So we bring her back in. The hemangioma came back. It was growing inward, into her trachea and her esophagus. It was going to kill her.

We got it fixed. If you see Lexie today, a teeny, tiny scar right there, right in that curve where you never, ever, ever see it. She also had one on her back that we had removed.

Now, despite these things, I consider myself very blessed because we could pay for it. We could pay for it. It didn’t matter to me. I was going to do it. I had read a lot, and I had researched. But that’s my nature, and I’m not everybody else.

CPT codes and insurance coverage and education and centers of excellence, I would have loved those things. I was going to do it, come hell or high water, but that's not most people. Most people lose themselves in the fear. That's what we're here for, and that's why it's important, and that's what -- anyway, that's my story.

MS. STORM: I don't think there's much more that can be added to that, and we're blessed to have so many wonderful people, wonderful minds, caring people here today.

Thanks to all of you for being here: Leslie, Leslie, Milton, Nicholas. Michael, thank you so much for providing us the forum of Brookings. Thanks to all of you for your time, your attention and your caring. God bless.

(Applause)

* * * * *

CERTIFICATE OF NOTARY PUBLIC

I, Carleton J. Anderson, III do hereby certify that the forgoing electronic file when originally transmitted was reduced to text at my direction; that said transcript is a true record of the proceedings therein referenced; that I am neither counsel for, related to, nor employed by any of the parties to the action in which these proceedings were taken; and, furthermore, that I am neither a relative or employee of any attorney or counsel employed by the parties hereto, nor financially or otherwise interested in the outcome of this action.

/s/Carleton J. Anderson, III

Notary Public in and for the Commonwealth of Virginia

Commission No. 351998

Expires: November 30, 2012