

## Interview with Shannon Kenitz: from a prognosis of death— to thriving via hyperbaric oxygen therapy

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### Abstract

Hyperbaric oxygen therapy, also known as HBOT, uses an increase in atmospheric pressure to allow the body to incorporate more oxygen into blood cells, blood plasma, cerebral-spinal fluid, and other body fluids. Mitochondria are responsible for processing oxygen and converting substances from the foods we eat into energy for essential cell functions. Shannon Kenitz's daughter, Grace, was diagnosed with a very rare mitochondrial disease: cytochrome C reductase. After virtually living the first three years of her life in the hospital, considered in a vegetative state, and blind, doctors refused to continue measures to prolong Grace's life. Shannon Kenitz took her daughter to receive hyperbaric oxygen therapy – the only thing that was changed – and Grace has progressed to, among other things, being off seizure and GI medicines and the feeding tube; and Grace is no longer blind, she is walking, she is thriving, and she has received normal EEG's and a normal muscle biopsy.

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*Hope and possibilities: something that every one of our children—more able or less able, on the spectrum or considered neurotypical, with or without health issues—needs their parents to believe in, and that is what Shannon Kenitz did for her little girl, Gracie. Degreed in psychology, Shannon Kenitz is the Executive Director of the International Hyperbarics Association, a nonprofit organization that promotes hyperbaric therapy through education and research. Shannon believed in hope and possibilities and brought her daughter back from a prognosis of death to the potential of life.*

*Shannon, thank you for being with us here today.*

Thank you for having me.

*Shannon, you also have a daughter, Lily. How old is she and how has her health history been?*

My daughter Lily will be turning 10 in September and she has had no problems with her health. She is a very healthy 9½ - year-old child.

*Gracie is 7-years-old this month, please tell us about your pregnancy, Gracie at birth, and how she was her first three years of life.*

My pregnancy with Grace, I did have some complications, but more just the typical problems with hyperemesis and being able to tolerate eating and so forth; and so they put me on a medication to help me through that. When Gracie was born, we thought we were taking home a healthy little girl and approximately a week after I brought her home, I knew that something was very wrong. Unfortunately, it took about three months for the physicians to listen to my instinct before being referred out

to any other specialist that may be able to help us find out what was wrong with Gracie.

And at that point Gracie was three months old and we went to an ophthalmologist and a neurologist in the same day, and we went to the ophthalmologist first and I noticed that Grace always had a lot of eye rolling and it was as if Grace always looked through me instead of at me; and when we were with the ophthalmologist and she did this eye rolling with her eyes he said to me, "You know Shannon, I believe your daughter is having seizures." And so instead of sending us to the clinic for our regular scheduled appointment with the neurologist they ended up taking us to the hospital and that is where our journey began. We did the EEG on Grace and sure enough Grace was having seizures.

*So when did you receive a diagnosis?*

Well a diagnosis, in the beginning, they thought that she had epilepsy that then turned into infantile spasms to the brain, but her true diagnosis did not come until a year-and-a-half into this whole process. We had been transferred from one hospital to another. By this time we had gone to Mayo Clinic, we had gone to New York Presbyterian, we had gone to Chicago Children's. They kept transferring us between all these hospitals because Grace's whole body was shutting down. She was having to have blood transfusions, albumin transfusions, platelet transfusions, she wasn't being able to regulate her temperature, so she was being kept warm under a heat lamp.

By this time she had gone blind, a feeding tube was placed because she was "failure to thrive," she was 1½-years old and barely weighed in at eight pounds. And we were at Mayo Clinic when she was 1½-years old having a brain biopsy done because they thought she had a different neurological disease, and when our muscle biopsy came in from Buffalo Children's Hospital,

that showed that Grace had a very rare form of mitochondrial, called mitochondrial cytochrome C reductase deficiency.

*This is awful. So that was at a year-and-a-half old?*

That was at a year-and-a-half old, and what was so heart-breaking about it was that I remember the day so vividly when they came in... it was a team of probably six to seven specialists and they said, “You know, we know what’s wrong with Gracie.” And I remember feeling so relieved and I remember almost like jumping up and down because finally we knew what was wrong with Gracie and in my mind, because we knew what was wrong with her, I automatically thought that we had a prognosis, then that all of a sudden we had the diagnosis. We now could have a prognosis and we can fix it and we can go home and we can be a family. But unfortunately for us in the same breath that they told us what Gracie had, they also told us that there had only been four other children in the world cited with this form of mitochondrial and they had all died before the age of two. And they gave us this news when Grace was a year-and-a-half old.

*That’s terrible. Well, tell us about mitochondrial cytochrome C reductase. What does it do?*

What mitochondrial does is that when you have a mitochondrial disease you lack the energy producing cells in your body. Everybody has to have the mitochondrial cells in order to survive, and what was happening with Grace is that in the mitochondrial chain she had deficiencies and there are six chambers and every one of them had deficiencies. However, her form with the cytochrome C reductase is the rarest of rare. Most kids have an oxidative form that can be helped. I mean the children certainly do not live long lives, they don’t live to be in their 20’s or 30’s from what I understand, but they have a better chance and a better outcome.

With Grace everything that is produced in those chambers—Grace wasn’t getting on her own. Her body wasn’t able to produce that. So what they did, they overloaded her with a lot of different vitamins and hoped that some of them would cross-over the barrier and get to her body and start picking up doing. But basically what happens is your body starts shutting down. Grace started to have a lot of problems with being able to regulate her own temperature. She wasn’t able to hold her head up at age one. She wasn’t developing. She was having difficulty eating. She was having difficulty swallowing. And it was basically, one by one, her body would shut down and they eventually tell you “enough is enough.” They told us when Grace was three-years-old that “enough was enough” and that we needed to take Grace home. They weren’t going to do anything more—life altering things—because Grace was so sick and they just felt that it was time that as a family we let Grace go.”

*They made that suggestion to you? That as a family, you should let Grace go?*

Yes, they told me, I remember vividly. I understand that if you look at the science end of things, no other child had lived past the age of two. However, Grace had; by this time she was

3-years-old. And was she a 3-year-old living a life that a 3-year-old should live? No, but she was still living and for me to take my child home and just let her die was not an option for me. I didn’t know how to do that, and I remember so vividly them going and getting counseling and saying that I needed to seek counseling then—I was being a bad mom because I was holding onto hope and possibility for one child, but they felt that I was taking it away from my healthy daughter. And so it was very difficult.

I had a very big challenge not only with the medical field, but I did have a lot of family and friends that felt that what I was doing was not right. And that’s very difficult when you’re put in a position where even your closest family members and your friends are saying “enough is enough.”

*Well let’s jump ahead and talk about Lily for a moment. Is Lily pleased to have Gracie around now?*

Oh my God, she is elated, and Lily is just an exceptional child in her own right and just is wonderful. I mean she and Grace are connected like no two sisters I’ve ever seen and that is something I had always hoped and dreamed for—that Grace would get that connection with Lily, that they would connect at some point because that maybe would give Grace the strength to hold on and the strength to say “wait a minute, my sister’s a little different than me and I want to do what she’s doing.” So it would give her that little extra push to do more, and Lily is just incredible. She’s very kind and loving and she has never, ever felt threatened by Grace, which is very difficult when you’re in this situation and you have a child with special needs, no matter what that special need is, it’s a fine balance—making sure that your healthy child is not left behind. And it’s a fine line that we parents walk to really know how to do that. I look back and there isn’t anything that I would change. I feel that I did everything that I could do at the time given and looking at Lily today I wouldn’t change anything for the world because she’s incredible, not only with Grace, but other special needs kids.

*So when Gracie was three-years old, was it the state or hospital or practitioners who, in essence, would you say suggested that life support be discontinued?*

Yes, we were in the hospital and we had physicians go in front of like a board and say that they were no longer going to do any life-altering measures and for Grace at this point, she had a PIC-line in that was giving her total protein nutrition—that was what was keeping her alive. She was needing food in her body because she was not able to eat on her own and the feeding tube just wasn’t enough to sustain the weight so that her body organs wouldn’t start to shut down.

*How much did she weigh at 3-years old, Shannon?*

Three-years old she weighed approximately between 12 and 15 pounds.

*Was she still having seizures and –*

Still having seizures with four different seizure medicines. So it wasn't even as if they were controlling the seizures. By all means they were a lot less, but she was still having breakthrough seizures with being on the four different medications.

*Was she on other medications as well?*

Yes she was. She was on a lot of different GI medications. She was on a protocol for the mitochondrial, it was about 17 different vitamin therapy medications along with all her seizure medicines and her GI medicine and then she did take things because she had a lot of blood issues at that point.

*Did she still lack eyesight?*

She did. By this time we had gone to New York Presbyterian and we saw a neuro-ophthalmologist, and I remember him telling me—for some reason the whole vision thing was very hard for me—I remember her main ophthalmologist back in Wisconsin saying to me later on in Grace's life, "I remember in your room, Shannon, and it was as if I told you that Grace was blind, but you turned to me and said, "will Grace ever drive? and I knew that you didn't understand what I just told you." And when I went to the New York ophthalmologist and I asked if there was anything that could be done, he told me that there really wasn't... That she had complete optic atrophy, that she was blind and I needed to accept it and try to work on the fact that maybe she could do something cognitive like Braille, but they thought that even that was a far reach for Grace because not only was she blind, but she had a lot of cognitive problems, and if you don't understand how to learn Braille, then you're not going to be able to do Braille. So she was still blind at this point at three years of age.

*Was she at any point, Shannon, considered to be in a vegetative state?*

Yes, and that's a funny word. They use that word not only for people that are in a vegetative state in comas, but they use that word for kids who lack development. When Grace was a year old and she wasn't able to sit up or hold her head up, or wasn't able to be in a crawling position, they considered that a vegetative state, or they say to you "this is what your child is going to be, she's going to be like a vegetable, she's going to be in a vegetative state where she looks through you and not at you, she doesn't hold her head up, she doesn't sit up," and I think that that's a really awful word *period* to give to anybody. But when you give it to a child like Grace—who at that time they didn't even know what was wrong with her—and to label her in that condition was just something that as a mom I couldn't accept. I couldn't accept that they were telling me that my daughter was going to live in this vegetative state.

I remember a physician literally had a pair of keys and he rattled them and after rattling them, he dropped them and he said "that's your daughter—this is your daughter" and then he threw them on the table and they laid still and he said, "This is your daughter's future."

*That sounds cruel, you know?*

It was very cruel. But I think that they were trying to get a point to me. There was a time when I hadn't left the hospital for over four months. I didn't go see daylight, I didn't get out into the sun and I didn't leave Grace's bedside, but the problem with that is, yes, maybe I did need to go to counseling at that point; however, the one time that I did choose to leave Grace's bedside and go down to the cafeteria to get something, Grace coded. If Grace died, I needed to be the one that she was with. I wanted her to feel me. I didn't want it to be in a cold hospital bed. I needed to be the one that - even though she couldn't see - I could hold her to my chest and she would at least feel my love and feel my tears and know that it was okay to go. And so after that first time of leaving and having her do that and almost losing her, I didn't want her to die alone. So I could never get myself to leave again.

*Absolutely. I understand. So, obviously, Shannon, you did not accept what the practitioners told you, even after they said that the other rare cases didn't live past two, is that correct?*

That is correct.

*So you didn't accept what the practitioners were telling you. Had you tried all kinds of other therapy at any points in addition to the medications?*

I had. I mean we had Grace going through speech, she was going through vision therapy in the hospital, occupational therapy, physical therapy. She was doing all the traditional types of therapy that we could possibly think of. We were doing different types of brain testing on her and to see if there was any activity where we could focus on. We tried everything traditional—what they would consider to be traditional—we tried it all.

*So what did you do and where did you go?*

I looked into a therapy called hyperbaric oxygen therapy and looking back on it, I researched hyperbaric therapy for over a year. I had heard about Mom's United for Moral Support and it was for children that had cerebral palsy and autism and traumatic brain injury, but Grace had a lot of those same characteristics. And I felt as if maybe it would help. But all of my mainstream physicians were telling me it was a waste of my money and my time and I needed to let go, but finally when she was three-years-old and they said "we're not doing anything more," they pushed my hand and we tried hyperbaric therapy. We went to a clinic and we started treating and it was amazing.

We first went to Joe DiMaggio Children's Hospital and we had a SPECT scan done of her brain and the radiologist there said, "you know her brain is lacking in so many areas," that he still told me not to waste my money and to go home; but we had raised the money to try it, and so we wanted to go ahead and try hyperbaric therapy. And we did and it was amazing. After about 10 treatments, I felt I saw something after the first treatment. She just seemed a little different, but you have to realize this was our last thing. We didn't have anything left. I went there thinking, "If this doesn't work, then I do need to let Grace go." And so I was putting a lot of hope into something that I had no

idea if it was going to work, and after about 10 treatments Grace started to reach and she started to track, and after 40 treatments we went back to that same radiologist and did a repeat SPECT scan on her and it showed dramatic improvement. And I decided this is where we want to be, that we need to continue with hyperbaric oxygen therapy. No matter what we have to do, this is where we have to focus our resources because it was changing Grace's brain. Not only were we seeing it clinically, but now they were seeing it scientifically on the scan. And so we did hyperbaric therapy and it totally changed our family's life.

*That's wonderful. And let's go back a little bit for our listeners who don't know: Could you please explain what a SPECT scan is and also what, in summary, is hyperbaric oxygen therapy and how physiologically it works to help the patient?*

A SPECT scan is an actual scan, unlike what the traditional—now there's new MRIs, but the traditional MRIs and CAT scans will actually show masses or lesions, they show if you have an abnormality. The SPECT imaging is a scan just like that where your child would go into a machine and it circles around the brain, but it actually traces the flow of oxygen. So unlike the MRIs and the CAT scans, the SPECT scan can actually show the flow of oxygen, where it decreases and where there actually is none. And so it's able to show you that your child is lacking oxygen to certain areas of the brain that then may be able to be helped by administering hyperbaric oxygen therapy.

What hyperbaric oxygen therapy is, consists of going into a pressurized condition which then increases the oxygen. So there's different forms of chambers that you can go into, but the laymen's term is you go into a chamber and it is pressurized—you are giving oxygen. What is critical isn't so much the oxygen itself, as much as the fact that you're going under pressure. And so it's really important that when you get hyperbaric therapy, that you're going into a chamber under pressure and that even if you go into what they consider to be a mild hyperbaric chamber, you're still getting an increased flow of oxygen because of the pressure. And Grace would go into these chambers, and we did therapy twice a day, six days a week for the first year of Grace's therapy.

And so it would be like going into a chamber, lying down, depending on what type of chamber you're in; sometimes you wear a hood, sometimes you wear a mask, sometimes you just lay in the chamber and go under pressure with nothing added. So there's different forms of hyperbaric therapy, but for the lay person that's basically what it means: it is getting an increased amount of oxygen under pressure.

*So Gracie did this two times a day, six days a week--did you say for the first year?*

For the first year.

*How much time each session on those two times a day?*

She went into the chamber for one hour each time. So we'd go in the morning and it took us about five minutes to "get to pressure," we would treat for one full hour and then we would

"come back," and then we took four hours off in between the two treatments, and then we went back for our second treatment, but they were each one hour long.

*And what kind of chamber pressure and concentration of oxygen did Gracie use?*

Boy, we've been on the whole line of it with Grace. We started at 100% oxygen in a steel chamber. And so Grace went into a steel chamber and had 100% oxygen delivered to her. Then after we had so many treatments of that, then we went into a maintenance treatment program with Grace where we used a mild hyperbaric chamber, but we still followed the same protocols. And now she does both. Now she does mild hyperbaric and she goes to a center three times a week and gets a higher pressure treatment.

*What conditions does hyperbaric oxygen therapy help? I know you mentioned a couple earlier, but there must be more.*

Boy there are. There's many that it helps. Any type of neurological indication... whether it is stroke or it is chronic fatigue, lyme disease; and then in pediatrics you have cerebral palsy, traumatic brain injury, you have autism, you have ADD, ADHD, bipolar. You have kids like Grace with mitochondrial disorders. You have the traumatic brain injuries from car accidents. Anybody that has any type of neurological indication where they may have had a lack of oxygen, whether it was from a birthing incident or whether it was from a car accident or what the incident may be, hyperbarics can help with that. By no means is hyperbarics a cure, but it is an incredible adjunct therapy that is noninvasive that really makes a difference with neurological patients.

Vision is another one. A lot of ophthalmologists are referring to hyperbarics because of the visual improvements with kids that have cortical visual impairment—with adults as well. And then there's things such as the traditional, which would be like if you had a wound or carbon monoxide poisoning or the indications that actually are covered. Diabetics use hyperbaric therapy. MS patients use hyperbaric therapy. ALS patients, Parkinson's and so it's across the board. With hyperbarics it can really make a difference for neurological patients.

*Now, do all of the commonly used forms of hyperbaric—high pressure and mild—help all of these conditions that you've just mentioned equally well, or do you think that there are different indications for different pressures or concentrations of oxygen at different times?*

Well, I think that in my experience—I've been in this field now for four years—I believe that across the board they all help. I think that the key is going to be able to find what is best for the individual patient, and this is a question that when I go across the country speaking to parent support groups that I get, you know, "Should I go into a mild chamber versus a high pressure chamber? Should I be at 1.3? Should I be at 1.5? 100% or 40%?" And what I normally do to show parents especially because my heart lies obviously in the pediatric world because of my child, I bring some parents who have all done hyperbarics

with their children and I have each one of them speak and they all say the same improvements.

And then after they're done speaking, I then point out to the audience that every single one of these parents did hyperbarics in a different way. One of them did it in a mild hyperbaric unit in their home with a concentrator, the next did it in a clinic at a 1.3 with 100% oxygen, another did at 1.5 with 100% oxygen, and they all had the same improvements. And now we're getting more into the research end of it—especially in autism the key is going to be able to find what the safest pressure is for autistic children. And we do have some of the leading authorities in autism right now doing research to find that answer out for us.

*Well that's promising, Shannon, and that's encouraging to hear. You mentioned that you're not—and for lack of a better word—I'll say “promoting” this as a cure, and that's fine. People can, you know, use this as an “adjunct therapy,” but in Gracie's case, you are sure that this helped her, are you not, because this was the only thing you changed?*

Yes, and in Grace's case it saved her life. It saved her life and I have no doubt about that, and that's why I can so publicly speak about it because we made sure that when we did hyperbarics we didn't change anything else in Grace's life. We didn't increase any medicines, we didn't take any medicines away until after we got into hyperbarics when we could get off the seizure medicines finally, but the only thing that we altered in her life was we gave her the hyperbarics. And we have been in a situation where Grace wasn't around hyperbarics, we took her out of it for awhile because of obvious financial reasons and so forth, and Grace started to decline; but you have to remember that Grace has a terminal diagnosis and continued to die with her mitochondrial. So Grace probably will need hyperbarics for the rest of her life, but if oxygen is my drug of choice, I am the happiest woman in the world because we are off all of her mind-altering drugs as I would call them. All her seizure medicines we are off and her last two EEGs have been completely normal. We are off all of her GI medicine, her feeding tube is gone, she's no longer blind and she's thriving. And I know that the only thing that is doing that is the hyperbaric therapy.

*That's wonderful. And her seizures have stopped?*

Her seizures have stopped. We've been seizure-free for over two years—without any medication..

*That's wonderful Shannon. And how are Gracie's lab tests now? You mentioned two of her EEGs, has she taken other lab tests? Is she considered in remission?*

Before she had a big problem with her lactic acid, which is now normal. She's had a lot of problems with her H&H (hematocrit and hemoglobin) where now she hasn't had a blood transfusion of any kind in over three years.

*Wow.*

Her last muscle biopsy which is what is the most incredible, and we're going to be doing another one in the next couple months—but her last muscle biopsy, which is what tells you where your mitochondrial level is—her last one came back normal.

*Wow.*

Some of them will say she is cured and they won't say that she doesn't have it, but it is in the 80% range and to me that's normal. And it says right on her sheet, that no abnormalities found in mitochondrial.

*Wow.*

So as far as I'm concerned, I do feel like it saved Grace's life literally and I will continue to do this because I know that it is what she needs in order to thrive and to be a normal seven-year-old little girl.

*And she graduated, she went to her kindergarten graduation correct?*

Yes, she did. Last year we put her in school which was very traumatic for our family, to say the least. I have never been away from Grace, but I saw she was better and that maybe she did need to be around children and, being a psychologist, I knew that was an incredible component of Grace's rehab; and we put her in a school, we put her in a normal kindergarten class with an aide and it was the best thing that I could have ever done. All the fears I had about kids teasing her, being in a wheelchair and having, you know—cognitively not being a kindergartner—it was the best thing that I could have ever done for her and for me is to put her in a kindergarten class with other kids her age because she started to thrive even more.

*That's great. And you mentioned a wheelchair, but she started walking recently didn't she?*

She did. It has been now five weeks. I was away on a speaking tour, which I do, like I said previously, for moms and special needs kids—I talk about hyperbaric therapy and how it can help—and I came off the airplane and came down the escalator and I remember seeing a ton of cameras, but I was thinking “oh, my God something's going on,” never thinking that it was in relation to me, and I started to look at them. I started to recognize faces, and all of a sudden they kind of cleared a path and I saw my daughters Lily and Grace. And Grace got up and walked to me for the very first time in her life without her walker, her braces, or a teacher holding her, or somebody holding her. She just walked independently right to me.

*That's wonderful Shannon. So, is she considered to be in remission now?*

That's what we would say that she is in, yes. And some doctors tell me to continue doing what I am doing and the only thing I'm doing is hyperbaric oxygen therapy so I will definitely keep doing that therapy.

*And oxygen is considered as medicine?*

Yes, it is. Oxygen is a drug, therefore you need a prescription in order to have this therapy. When you go to a clinic you will need a prescription from a physician stating that you can undergo hyperbaric oxygen therapy because it is a drug.

*Well let me recap some of the wonderful accomplishments that Gracie has had as a result of your going forward and helping her with hyperbaric oxygen therapy, Shannon, and please, correct me if I'm incorrect about anything or add anything that I may have forgotten, okay?*

Okay.

*Okay. So Gracie crawled, she started to be able to feed herself, she talked, she walked with a walker and now most recently she walked independently, she went to her kindergarten graduation, she recovered her eyesight, she gained weight, she stopped her medications and her seizures stopped.*

That is correct. But most importantly to a parent and I can't say this enough, is that my daughter "knows." You've heard me talk about Grace always looking through me instead of at me, my daughter now looks at me. Her eyes look at me and she engages and she knows that I am her mom, she knows that her sister is her sister and that means more to Lily and me than any of the other accomplishments that she has gained with hyperbarics. The fact that she knows us, is what is so essential to Lily and me and to our family.

*Yes. Well, Shannon, can you tell us the bills for hyperbaric versus what the hospital costs were for Gracie for zero- to three-years old, I know that the most important thing isn't the monetary concerns just like you've just described, but what is this in comparison?*

Hyperbarics is nothing in comparison to what they were paying. Our private insurance dropped us when Grace was a year old, so Grace went on full disability, but her medication bill alone, her vitamin bill alone for the state to pay is over \$4,000, and when you added all those medications, you added the feeding tube, every little thing costs money right down to the tubing for the feeding tube, to the syringes that we had to have, and the hospital was paying over \$100,000 a month and that's on an easy month. When Grace was in the hospital—which she was predominately for the first three years of her life—she maybe was home a couple months here and there, not all together, but if we look at over the three years we had maybe 90 to 100 days where Grace wasn't in some hospital or clinic. And when you look at that, her bills were in the millions.

And hyperbarics compared to that is nothing. And I don't understand why they can't see that. Why they can't see that if hyperbarics can get these kids off of these medications, not just financially, but these medications end up causing problems to our children... unfortunately that's the way that business is and that's the way insurance is, that's the way state aid is—is that they look at the bottom line rather than the health. And I don't understand why they don't, because hyperbarics is very reason-

able. They'd be better off even to purchase chambers for these families and they still would have 90% less costs than having the children continue to do what they're doing. Grace's physical therapy, her OT, her speech, her vision, which she was going to need for the rest of her life—we are now on a limited schedule for that. We don't need intensive like we used to need it, and then you think of all the medications she's no longer on, you're thinking about all the hospital stays, the surgeries, the blood transfusions, all of that is gone.

And hyperbarics, in this country you can get hyperbarics anywhere between \$100-125 an hour up to \$250 an hour. And that is nothing compared to what we paid in hospital bills.

*Could be less even some places?*

Oh, in some places it can be less and then if your doctor feels that you should have a hyperbaric chamber, they can write a prescription for you to have the mild unit in your home. And I know the most expensive one of hyperbaric units are I think around \$22,000, maybe \$23,000, and that's it. You have your chamber then and that's all you're spending. So of course it can be so much less expensive for insurance companies and state-aided programs when these kids go on disability to implement hyperbarics than to do what they're doing.

*Right and of course as you said they're looking at the bottom line versus health and of course the child's health and quality of life is always the most important consideration along with the quality of life for their family. But in addition to that, Shannon, I would say that they're looking at the bottom line now versus the bottom line down the road. You know they're kind of looking with a very narrow gaze at the bottom line.*

They really are. I mean my daughter three years ago, her case was heard in a Congressional hearing and afterwards one of the senators came up to me and said, "Do you know the ramifications that this could mean for long-term?" I said, "absolutely." Do you realize how much money is spent on a stroke patient in rehab 10 years out or these kids that have cerebral palsy or even our autism population, when you're looking at long-term, you're looking at therapy costs, you're looking at special aids in schools. If you look at long-term, hyperbarics is viable and a smart financial way to go. And I think that it's going to just take more education and getting to the right people to show them that we're going to have a crisis in the Medicaid and Medicare system down the road to start with. This is a way that it can certainly help alleviate that future cost and that future damage that's going to happen. I just think it's getting the information to the right people and by all means they need to look at long-term, because every child that is special needs, their long-term cost is an incredible amount of money.

*Yes, and you would think that (I hate using this word with regard to each child who's precious) they'd want to reduce the caseload per practitioner....say in a hospital setting you would think that they'd want to alleviate some of that for the medical systems and social service systems and things like that.*

You would think that; and coming into this, I'm not a physician, I'm a mom. You know I say I'm a mom on a mission because I know that this therapy can help so many families. I know so many families that did lose their children that maybe they could have had them longer, and to us families that have special needs, quality of life is everything. If we can get rid of one of their disabilities, that's a huge thing for us, but it's such a fine line in the medical field. I haven't quite figured it out yet, what's it all about. Does it really come down to pharmaceutical companies versus wanting to make sure... I mean if for some reason, you know, hyperbarics or any other type of therapy alleviated having to be on drugs for so many people, then what's going to happen in that industry? That industry brings a lot of money into the country and I just haven't figured it all out what exactly it's all about. But as a mom—all it should be about is health. The money should never ever come into play. And that's why I took this job with the International Hyperbarics Association (IHA)—is that I never want a parent not to do hyperbaric because of money. That should not be an issue. If that is an issue, then contact the IHA, I will help you get it. It is a shame that we do not get a therapy, especially a therapy such as this that is noninvasive, it's non-harmful, it's not like going into a surgical room and Grace having a brain biopsy done, and if it's something you're looking into, money should not be an issue as to why you're not getting it and that's my goal. My goal is that every person that looks into this should have an opportunity to try it regardless of their resources available to them, and that's what the IHA does, we help get that done for those families.

*That's excellent Shannon. Yes, our children are beloved flesh and blood, they're not income-generating-units.*

They're not.

*Well, are you at liberty to share any other remarkable success stories such as from patients in the Wisconsin clinic?*

Oh, absolutely. The Wisconsin clinic is being setup as the standard of care clinic. It's not only a hyperbaric clinic, but it's an educational clinic where parents can come once a month and physicians are brought in from around the country that specialize such as in autism or cerebral palsy or whatever the specialty may be, gluten/casein-free nutritionists, so forth. But we have had incredible improvements at this clinic in Wisconsin.

They shared with the IHA some testimonials and I actually happen to have them in front of me because they gave them to me because we're going to be putting them into the next IHA newsletter. But we have probably 10 of them that are autism or on the autism spectrum and the stories have been incredible. We have a little boy here who started hyperbarics, he's five-years-old and at about a year-and-a-half he had a seizure that had left him with reduced central vision and had no function in the right arm and he has had only 17 treatments to date and he is already starting to speak and he is saying words such as "papa," and instead of saying "ahdah" for "daddy", he is now saying "daddy". He's saying the word "purple," which he never could do the "P's" before, he's able to move much better, he's being cognitive—that is the biggest thing that we see is with the cognition, especially in our autism patients.

We have a two-and-a-half-year old autism child who really never spoke much. He maybe would utter here and there, but now is actually being able to say "mama let's go" or "I would like to ride in the car" instead of just saying "car" and that seems to be the gist of it with autism—the speech is what has been incredible for these parents and then the cognition. And the fact that they pull up in the driveway and the mom says "Papa Dave," who is the technician at the clinic and the children say, "hyperbaric treatment." They're able to put things together and the teachers are calling in and saying "wow, the kids are being more cognitive at school, their concentration levels..." parents are finally having children go through the night not having accidents in the bed or they're getting rid of their stimulation machines and the children are now having bowel movements on their own. And it's been just incredible.

I went to a fundraiser of this little girl with a very sad story. Her mom bled during birth, the little girl was born basically with no blood and she was born not breathing and on the ninth minute of trying to resuscitate her, they said they were going to do one more minute. Well they got her and they saved her, but they told the parents that obviously under the conditions she was not going to be anything, told her the same thing about the baby would be in a vegetative state the rest of her life, that she suffered severe brain trauma, and it totally tore their hopes and dreams apart for their daughter. And they started hyperbaric treatment, they've had 78 treatments and now this little girl who had absolutely no chance in life is lifting up her head completely on her own, her dSATS and oxygen when sleeping are completely gone, she is stronger, she can grasp and she's tracking. And they have now done a fundraiser to continue doing hyperbaric therapy because they have a child that laid there and was not doing much and now is doing, and the only thing they changed in their daughter's life was hyperbarics.

And I get letters like this from people across the nation to the IHA that call me. And right now you do see a surge of it with autism. I probably would say about 75% of the calls and the letters I am getting are from families whose children who have been diagnosed with full autism or on the spectrum or have ADD, ADHD and they've been doing hyperbaric and the improvements have been incredible. It's wonderful when you hear these parents say, "I heard you talk Shannon, I know what you meant when you said your child looked through you and now they're actually looking at you. It's the most incredible feeling, or when your child for the first time instead of just saying like "ma" says "I love you mommy" and is engaging and is aware of your surroundings.

We have a mom who said she considered her child a runner. The minute they got out of the car, he would be gone, having absolutely no idea about the danger that lay around him. And how traumatic for a parent to know that they have to get over to that side real quickly and to make sure they guard their child because they have no idea that another car coming could hurt them. Now he gets out of the car, he waits, he takes the hand, he knows not to go in the street, a car can hurt you. Those are the things that when parents live with these diagnoses every day they not only impact the child, but they impact the family unit. And hyperbaric therapy is changing the family unit and that's what it's all about—making families become more of a family. What most people may take for granted, parents of special

needs kids—no matter what the need is—don't take that for granted. Anything that we can grasp onto to be what we would consider to be normal in a family is incredible. And changing a family unit gives people so much hope and so much possibility, and it brings people together.

When you have special needs children, it's incredible how high the divorce rate is. I feel that somewhat hyperbarics impacts that and brings people closer because it changes the family unit. It's allowing them to be more family. So there's a lot of ramifications in the positive end of hyperbarics, not only with helping the child, but helping the family become a stable family unit.

*Yes, and how do parents find a reputable hyperbaric oxygen therapy clinic or other provider?*

What I would highly recommend is what we have done through the IHA. The International Hyperbarics Association is a nonprofit association. Not every person that has a hyperbaric chamber can become a member of the IHA. There are many clinics that we have turned away because we felt that they were inappropriately using hyperbaric therapy. We definitely are not a regulatory board, but we do have an incredible physician advisory board on hyperbaric therapy and we know what the standards are and we do expect a higher standard. The other thing is with IHA clinics, is that we do ask them to keep their prices at a price the families can afford, and then by being an IHA clinic, we're able to fund treatments. So if a family can't afford hyperbarics, they can sometimes apply through the financial aid program at the IHA and receive funding, and we pay the clinic directly and then we're able to work with that clinic and say, "this person's going to need about 40 or 80 treatments, but obviously they can't pay \$120 an hour, even \$100 an hour." So I can get them to come down to \$50-60 an hour and we're able to monitor it. So I would highly suggest going through an IHA clinic.

Like I said, it's not everybody that has hyperbarics is an IHA member clinic, and it doesn't necessarily mean that those people that aren't, are not necessarily a good clinic. It's just there are so many people getting into hyperbaric therapy right now that we just can't get to all of them or they contact us, and before you become an IHA member clinic, one of us has seen the clinic or has gone to the clinic or we know the physician and we know that they're following the proper protocols as we feel the protocols are, and that is following what has been done for the last 20 years in neurology.

The biggest thing I would get from parents is "it'll be cheaper for me just to go purchase a chamber." I do not recommend that. I'm very vocal about that. I do feel that home units are eventually maybe necessary and if a doctor writes a prescription for it, then I feel that that's okay. But I do feel that you need to do hyperbarics first in a clinical setting: that it needs to be under the direction of a physician. And what was happening especially in the autism world, we seem to get a little bit of resistance where the parents are so educated and so in tune with their children that they state, "You know what? We're just going to get the chamber." So we kind of alleviated that problem. What I did is, I went to the manufacturer and I said, "Listen, this is a problem. I don't want these parents to just go purchase

a chamber, can we work something out?" And so we do have a program that if you go to an IHA clinic and you spend so much money at that clinic in hyperbarics, that then can be taken off the price of a chamber. Therefore you're not out any money and yet at the same time you are getting the hyperbarics under the direction of a physician and that's what I preach all the time.

*That is so nice giving parents a break.*

I'm able to do that through the IHA member clinic. Then we're also starting another program up—where I probably will be announcing it in the next couple months—but it's another program like that, where if somebody wants to purchase a chamber, they're not sure how they're wanting to do it—if they get the chamber through a certain manufacturer and so forth—they are allowed to buy these coupon books and then these coupons are redeemable for hyperbarics in a variety of hyperbaric clinics around the country, because my goal is to have that parent do their initial set under the direction of a physician.

And you hear all the time that "hyperbarics isn't rocket science" and that "we can do this and so forth," but you know what? It needs to be respected, and oxygen is a drug and things can happen. Your child can have ear discomfort and we're parents, we're not physicians and we need to remember that. We need to remember that we might not necessarily agree with our physicians who many times I have fired doctors left and right on Grace's team. I'm the first one to let a doctor go. However, I'm also the first one to respect the fact that oxygen is a drug, that it needs to be treated like one and that you need to go and you need to have it under a direction of a physician first and then do it.

So hopefully with this program, it helps alleviate that. It helps the fact that "okay we did go, we saw no complications." You do have to have a prescription to purchase a chamber. So I have talked to physicians that were writing scripts before the children had the opportunity to have hyperbarics administered under the direction of a physician first. These physicians did that because they knew hyperbarics worked, but they didn't have a hyperbaric chamber in their clinic. Well, I solved that problem for them. I got them a chamber for their clinic. And so I've been able to implement hyperbarics in a lot of different clinics, especially a lot of the DAN! doctors and put them on a program where they can afford to have a chamber in their clinic to start these kids out with and then write the script if that is what they feel is medically needed for that child.

So I definitely highly recommend parents going through the IHA, contacting the IHA clinic, because not only is it going to be beneficial for them physically to have their child seen, have them go into a chamber with somebody putting them in, monitoring, even teaching them how to use a chamber and then if the doctor feels, then they can get it—not only do they have it physically, but it also will help financially because out of the monies spent at an IHA clinic, there's a certain percentage that will be deducted from the cost of the chamber.

*All right, I really appreciate that point, Shannon, facilitating, giving parents that monetary break—that's really nice and, yes, I agree. I felt more comfortable going through a provider first, going through a practitioner's office at first, and I would*

*feel more comfortable, of course, seeing how to properly operate the equipment.*

That’s exactly right, and you need that. At the end of the day we’re moms and dads and, yes, it may not be rocket science and you may know how to zip the bag and you may be able to know how to do all those things, but at the end of the day, it’s still your child, it’s still medical, and it is much better for not only you as a family, but for the medical field in general to have your child first be seen under the direction of a physician. The other thing is that it gives us data. These doctors then can follow those children and they collect data. They give that data back to the IHA and I’m able to take that data and go to different grant companies, go to the NIH and say, “Listen, this is the preliminary data that is coming out of these clinics. We need a bigger study. We need you to fund this. We need this to be a therapy that in five years is just a traditional therapy that is covered by insurance.” And I can’t get that done if I have people going in a hundred different directions and doing it and not getting any of that feedback. So really it all comes full circle and it helps future generations and that’s what I’m doing. It may not help me right now, but it certainly will help a mom that is in my position five years down the road and I never want them to go through what I had to go through.

*Right. Another thing that I appreciated about doing this in a practitioner’s office was initially you want to have your child’s ears checked. You want to make sure that it’s just that they’re, feeling discomfort and not that anything negative had actually happened. So I appreciated being able to be in a practitioner’s office and have my son’s ears checked when he seemed uncomfortable—to make sure that everything was fine. And his ears were fine.*

Yes, exactly.

*Okay. And what is the most important take home message that you’d like to share with all parents today?*

With all parents I would encourage you that if you’re in a situation that you are with doctors that are giving you no hope or no possibility and they’re telling you to go home and to enjoy your family as is, that you need to get a second opinion and

you need to get a third opinion. You have to remember at the end of the day, physicians are only physicians. Everybody can be wrong. If I would have listened to Grace’s doctors—and there were two of her doctors that I felt were family—I know that Grace would not be here today... that she would be in Heaven, and I believe that we at some point take control and know that our gut is right. That never to give up hope. If you give up hope, you don’t have anything and that’s just one thing that was driven in me, is that if I gave up hope on Grace, then she was going to die because I didn’t have anything to live for. Anything is possible in our world, everything is possible when given the opportunity. And so never close doors, get second opinions, do research, talk to other parents. The IHA has an incredible networking list of parents that have tried, not only hyperbarics, but a lot of other different therapies and I can connect you with those families because I also truly believe that talking to another parent in your situation is the best thing that you could possibly do because that parent is never going to lead you wrong. That they don’t have any financial interest in what you do, all they’re doing is telling you what worked for their child and they give you the most honest and blunt and you relate to them. So just don’t give up, anything is possible and look at Grace and look at everything that she’s been through in her life and she is here for a reason and I believe that reason is to reach out to other parents to say “wait a minute.” When everybody’s telling you that there’s nothing you can do, that’s when you need to remove yourself and find people and surround yourself not only with family and friends that are positive, but find those physicians that have an innovative look at life. And there are incredible physicians out there right now that are just extraordinary doctors, but even more extraordinary human beings. So put yourself in a position where you surround yourself with that and all the hope and possibility will come your way.

*Well, Shannon, thank you for that message and thank you for sharing your time and Gracie’s heartwarming and inspiring story. Gracie is fortunate to have you as a mom, and thank you for your hard work in trying to get the word out to help other children.*

Well thank you and thank you very much for the opportunity to be here today.