

Testimony

**“A Report from Parents on How Their Children’s Lives  
Have Been Improved by Hyperbaric Oxygen Therapy”**

The International Hyperbaric Medical Association Foundation

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**“Autism Spectrum Disorders: An Update of Federal Government Initiatives  
and Revolutionary New Treatments of Neurodevelopmental Diseases ”**

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“Autism Spectrum Disorders: An Update of Federal Government Initiatives and Revolutionary  
New Treatment of Neurodevelopmental Diseases”

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CONGRESSIONAL TESTIMONY OF JULIE J. GORDON

Dear Chairman Burton and distinguished members of the Committee, thank you for allowing me to testify and represent the parents of this nation who want to share with you the remarkable results of Hyperbaric Oxygen Therapy for their children with Autism and brain damage.

When my daughter, Jessica, was born in 1973 her brain was damaged from loss of blood during delivery through a slit in the umbilical cord. She was born dead, resuscitated and given ice cold blood transfusions as was I. As her damaged brain swelled the seizures began. In those days babies like Jessica went to institutions, not home with their parents. In spite of the resistance from hospital staff, I chose to take her home. The Federal Law would not be passed for another two years even allowing a child like Jessica into the school system. We had many battles ahead of us and today I am fighting for the babies yet to be born so that they and their families are spared what we had to endure and are still enduring.

I gave up my teaching career to care for her. When she was four years old I gave birth to healthy, gifted twin girls. Divorce is much higher in families with children with disabilities and only the strong marriages survive. Mine did not. The girls and I were forced to go on SSI, welfare, food stamps and Medicaid. It was frustrating and degrading to have two college degrees and to be living below the poverty level and accepting government help with no alternatives. Disabilities in a family are devastating not only emotionally, but financially which in turn makes more people dependent on the government.

This all could have been prevented for our family for just \$3. 58 an hour's worth of oxygen. Loss of blood is one of the non-approved conditions for treatment with Hyperbaric Oxygen Therapy (HBO). I strongly believe now that if she had been treated with HBO immediately, she may have gone home perfectly normal. Instead I was sent home with a seizing, spastic, screaming infant with no referral for any therapy or for any support.

In 1979, when Jessica was six years old and the twins were two, I started a small support group for parents whose children had disabilities. We shared our hopes and sorrows and most of all we supported each other and knew we were no longer alone. We discovered we had power too. When a mother, Donna, with a two year old son who was blind and needed leg surgery called us because the hospital wouldn't let parents stay overnight, we met with the hospital administration and had the policy changed. She slept on a cot in her son's room that night. We grew in strength and number. New mothers knew nothing about the services we did, so a newsletter "*MUMS Matchmaker*" was developed to get information out to those who couldn't attend meetings. Thousands of parents now had a voice to share their emotions, problems and helpful solutions. Milwaukee Children's hospital reestablished the Parent Rooms on each floor because of our editorial complaint in the MUMS newsletter.

As parents of children with rare disorders joined, we established a matching service to link them with each other. Because of the uniqueness of this service, over the years MUMS grew to be international and now has over 19,300 members from 54 countries covering 3400 diagnoses. Over two thousand Professionals joined and refer parents to us for help.

In 1995, through the exchange of newsletters from England, I discovered that 500 children with Cerebral Palsy in England were being treated with HBO and were improving. One article told about Linda Scotson's 16 year-old son who went from being blind, deaf and in a wheelchair; to seeing, hearing and riding a two-wheel bike no handed. This seemed to me to be impossible so I called Linda in England and she said she had a large chamber in her living room in which she treated him and other children and verified their improvements.

After receiving more HBO information anonymously about people coming out of comas and "Idling neurons" becoming active in the brain using HBO, I decided to share this information with my Medical Board of Advisors and five parents to see what they thought. My Pediatric Neurosurgeon and two parents, Laurel & Diane, went to investigate Dr. Neubauer's clinic in Florida where he was treating off-label conditions. The parents each got 14 treatments for their daughters and saw amazing improvements. They were so excited when they returned that Laurel raised money and put a chamber in her home and Diane's husband tried to build one out of a propane tank.

Their experiences made me decided to publish an article about Hyperbaric Oxygen in our MUMS newsletter in 1997 and the response was an amazement to even me. You see when your child has brain damage the doctors tell you there is nothing that can be done. Hyperbaric Oxygen Therapy gave us hope - our only hope.

Naive parents willing to pay cash started knocking on the doors of hospitals with chambers only to be turned away. We were shocked! Parents in the Military on bases with huge multi-placed

chambers were also turned away. Parents sent MUMS articles they found about HBOT and we developed a packet of information and started distributing it. Parents started going to England and Canada for treatments and shared their experiences – more information for our HBO packet. With the increased demand for HBOT from parents, existing free-standing wound care clinics and new clinics started to treat our children. Parents and grandparents whose children had improved opened clinics.

As parents reported back to MUMS of the existence of these HBO clinics we started a list of clinics to share with interested parents. MUMS became the clearinghouse for parents to find clinics and for clinics to get listed if they were willing to treat off-label. Parents from all over the world started contacting MUMS and sharing their experiences – the first to be treated in Germany and Malaysia and France. A group of parents in South Africa bought a chamber and were treating their children and shared their testimonials. Presently we have 131 HBO free standing clinics listed that will treat off-label conditions. In addition in England there are 100 clinics and 11 in Scotland treating Multiple Sclerosis for free through a charitable trust and they have opened their doors to children with brain damage for a small fee.

A letter to the editor in Exceptional Parent Magazine from two parents requested more information on HBOT. I wrote and the response with MUMS' address and phone numbers was published in the magazine so more parents called and letters poured in. The letter I had responded to turned out to be from Claudine Nadeau from Quebec and Debbie Nardone from Illinois. Debbie was a member of MUMS and met Claudine through the Internet. Debbie shared the information she had from the MUMS newsletter and the two of them decided to meet with their sons in England to get HBOT.

When Claudine brought her twin sons, Michel and Matheau, back from England, Dr. Marois, their pediatric physiatrist, was amazed at their improvements. Claudine and he approached McGill University in Quebec to do a study. As a result, the McGill Pilot Study took place Oct 15 – Dec. 15, 1998 in Montreal. The results were amazing considering the 25 children ages 3 to 8 years old with spastic diplegia Cerebral Palsy only got 20 treatments at 1.75 atmospheres. Results showed reduction in spasticity in hip adductors, hamstrings and ankle plantar flexors. Patellar tendon and Achilles tendon reflexes were found to be significantly reduced. It was reported that there was significant improvement in the children for walking and sitting as well as for knee walking. The study concluded that HBO improves function in children with spastic diplegia, Cerebral Palsy.

Following the results of this study, a group of parents from Quebec, spearheaded by Annie Lachaud, organized a Parent Movement to further research on HBOT. Because of the pressure put on the Canadian government by these parents, 1.2 million dollars was allocated for another McGill study which included 111 children at three different locations. The study was completed in August 1999.

As Dr. Paul Harch has stated, “The real story behind the McGill Pilot Trial is not the findings of the study, it is the story of a group of mothers organized and connected by the MUMS Network and Internet who became a force so powerful that they were able to overcome tremendous resistance and accomplish what a group of physicians were unable to achieve in over 50 years.”

Because of the studies and requests from Canadian parents more clinics opened in Canada. In 1999 a new HBO clinic with a 10 person multiplace chamber was opening in Coquitlam, British Columbia and offered me free treatments for Jessica when they called to get on our HBO clinic list. I had never really thought about getting her treatments because I couldn't afford them and I truly felt at age 25 years old it was too late. But how could I turn down this wonderful opportunity? Parents had shared the names of organizations that provide free airline travel to children for medical purposes and I contacted one and we were approved. Amy, a friend from Palm Springs flew with her 11 year-old son, Ari, who has severe Cerebral Palsy and Autism also and the four of us shared a hotel room. Our children each got 40 treatments with a protocol of 1.75 ata twice a day. We know now this was a dangerous protocol because 1.5 ata is safer and more effective, but we were all experimenting with our children and we followed the protocol used in England. During his second treatment, Ari's tight arm easily could be raised above his head. His speech became clearer and his legs more relaxed and his Autistic behaviors lessened.

The noticeable changes in Jessica occurred after about the 20th HBO treatment. Her muscle tone became much more loose especially when she was in a relaxed state. Her posture in her wheelchair became straighter and her head control much better. She used both her hands together much more. She even lifted a towel off her tray with both hands to wipe her mouth off. She used to slide off the bench in the chamber, but now with her relaxed legs she could sit with ease and with only slight assistance from me.

Her alertness and attention span increased. One technician noticed she seemed "more animated". She enjoyed having me read books to her which she never had the attention span to enjoy before. The sentences she spelled out on her communication board were more complicated as are the words and phrases and ideas she uses. She initiates conversations now instead of needing prompting.

Prior to HBO Jessica could only make the "M" sound and say "Mama". Jessica has started to talk and can now say 5 words including saying her sister's name, "Abbie". She can say "Hi" and delights in hearing the new sounds come out of her mouth. Overall she just seems smarter and more alert and happier.

Jessica was evaluated at Central Center in Madison, Wisconsin before and after her Hyperbaric Oxygen Treatments. Previous evaluations showed her getting more spastic. When stood Jessica's legs scissored (crossed severely) and she was up on her toes. After 61 HBO treatments her physical therapy report says, "Significant changes (+/-) in the following: hip extension (10° to -15° right) and (5° to -10° left), hip internal rotation (35° to 50° right and 35° to 55° left), left shoulder abduction (135° to 145°) and her right wrist extension (55° to 65°). Jessica also had an improvement in her hamstring flexibility on the left as evidenced by improved straight leg raises (45° to 55°). When placed in quadruped (on all fours), Jessica was able to weight bear on both hands with hands open. She was able to accept the weight more evenly on all four extremities and even began to weight shift back and forth with assistance. She had attempts at moving her legs and also advancing her left arm. During her previous admission (before HBO), Jessica had difficulty keeping the weight back over her hips and kept her hands more fistled and required maximal assistance so this was an improvement. Movement into tall kneeling also improved." Her improvements were documented! Now when I stand her, her legs are apart and her feet are

flat on the floor. I only need to hold the back of her head for support. A recent report said her ankle flexibility improved 20%.

In the Coquitlam clinic there were 30 children a day getting treatments. I met two children who had been seizing all day long and both completely stopped with HBOT even though the parents had taken them off all medications. A seven year-old Canadian boy, Brett could walk, but had such low tone in his hands he could not even hold a crayon. After HBOT, his favorite thing to do was to color. A five year old French Canadian girl walked alone for the first time in the waiting room as we all applauded. Nineteen year old Adam from Texas not only got more relaxed and responsive, but his severe psoriasis almost disappeared! Two year old, Mitch, who was a shaken baby from Minnesota scooted off his blanket for the first time since his injury and stopped seizing totally.

In July 1999, Dr. Neubauer, a pioneer in treating off-label with HBO, had *The First Symposium On Hyperbarics and The Brain Injured Child* in Florida and parents came from all over. This gathering fueled our excitement. Listservs started and parents shared their children's improvements and others joined wanting to know more. At the symposium we met a man, Tom Fox, from Alabama who ran a free-standing Hyperbaric Wound Care clinic and he was so touched by what he saw, he offered five of us free treatments if we would come to Alabama. To his surprise a few weeks later we were all on his doorstep.

While there I told Tom if he could bring a mobile chamber to Wisconsin, I would help him find interested parents to bring their children for treatments. For fear of having the FDA stop us, we parked the unit on an Indian Reservation outside of Green Bay. Because so many parents in Wisconsin were interested in HBOT we had no trouble finding willing parents. Billy's mother drove 1 ½ hours one way to get the treatments. Billy has a Chromosome 9;11 Balanced Translocation and is Autistic and had very crossed eyes. His mother, Lynette said because of his sensory issues, he would never wear a hood and she had trouble getting him to go in the chamber for the first treatment. After one treatment, Billy's eyes straightened and after seven treatments they were permanently straight. He became so much calmer and loved crawling in the chamber. Billy would try and put his own hood on even before we were at pressure.

Another man from Oklahoma, Mike, bought a mobile chamber because he had a niece with Cerebral Palsy and a sister who had a stroke. He also brought his chamber to Wisconsin. Now Jessica and many more children in Wisconsin were able to get HBOT on a regular basis without having to travel.

Jessica to date has had a total of 215 treatments and she is a totally different child. Another MUM, Sherri, who brings her son's companion dog once a year to demonstrate at Jessica's adult program called me and asked what I had done to Jessica. I asked her why. She said, "Well last year I saw Jessica and asked her a question three times before she answered by pointing to "yes". This year she drove up to me in her powerchair and asked how my dog was. This demonstrates the new Jessica. The most profound change in her is the lessening of her autistic behaviors. Her thought patterns are more mature and complex. She wishes she could get married and that she would like to "try" and drive a car. She initiates conversation, is so aware of her surroundings we have to be careful what we say in front of her, where before she was in her own little world.

Her father wanted to make her a CD of music and I told him she never indicated an interest in music, but I would ask her. She spelled out, "Walking on Broken Glass", "Sit Down, You're Rocking The Boat" and "Uptown Girl" I was astonished! She listens to her music CDs all the time which is more age appropriate.

She can problem solve now. Recently she spelled out she wished we had an elevator so she could go down in the basement. Her sister just moved out into an upstairs apartment and when I told her I cannot show her the apartment because of the stairs, she asked me to make a video of it for her to see. She likes to watch "Sex In The City" (how normal do I want her to be? :>}) and reminds me a few minutes before 8 o'clock every night to turn on "Larry King Live". She never even watched TV before HBOT. She tells me when she has a headache, is sick or if her tray is dirty. She even laughed and called me stupid!

Another new development which prior to HBOT she was unable to do is that Jessica has a job making personalized stationery and envelopes and brings home a paycheck ! She never had the interest or ability before. Throughout her years of schooling a constant goal that was never reached was for her to tell me what went on in school. Now she voluntarily tells me she went to the museum, or that they had "Take Your Daughters To Work Day". Her communication and social skills are becoming near normal thanks to HBOT. Although she has been G-tube fed for the last ten years she is eating more by mouth and even eats corn-on-the-cob without difficulty.

Every parent fears for the future and worries who will take care of their child when they no longer can. With Jessica's new awareness and communication skills I feel more confident she will be able to communicate her needs and will better be able to fend for herself when I am gone. It is so amazing how the brain can improve after 25 years with Oxygen and a little pressure.

**I have gathered 100s of cases but I will present just a few, but please read the other documentation I have brought for your review:**

- In 1998 a five year old little boy in Texas, Edgar Gonzalez, who was hit by a car and had a traumatic brain injury was in a coma for three weeks with a score of "7" on the Glasgow coma scale. A hyperbaric doctor in Galveston, Sally Robinson, tried Hyperbaric Oxygen treatments on him and he is now back to normal except for a lumbering gait when he walks! One of our MUMS in the Galveston study triggered by the success with Edgar told us her daughter's vision went from cortically blind to 20/20.
- Shortly after his daughter Rebecca's complicated birth and cardiac arrest for 35 minutes, Ed Nemeth of Sacramento, California and his wife were presented with the unspeakable, yet strongly suggested single choice for their first-born child: discontinue life support or allow their child to continue brain dead. Devoid of options the Nemeth's discontinued life support; Rebecca rallied and lived. Five years later through their indefatigable efforts the Nemeths found HBOT and after a short course of HBOT their daughter experienced a quantum leap in neuro-cognitive function and significantly improved movement and coordination. Ed is now involved with two hyperbaric clinics and funded the Second First Symposium On Hyperbarics and The Brain Injured Child in Florida because of his interest in furthering HBOT for children like his Rebecca.

➤ Shannon Kentiz of Wisconsin called me crying that her two year old daughter, Gracie who had Cytochrome-C-Reductase Disorder and was on life support. This is a very rare mitochondrial condition (there are 40 types) that destroys the brain and the doctors told her the five children they knew about all died by the age of 2 years. They were pressuring Shannon to remove the life support and she said she could not watch her baby die. Shannon was given no options. I explained to her that no one had tried Hyperbaric Oxygen Therapy on Mitochondrial Disorders, but maybe it was worth a try. Since she had nothing to lose, she brought her daughter to Florida by ambulance. Gracie was lethargic and blind and in a coma. After hyperbarics she is walking, pulling the pens out of her doctor's pockets and can see. Her mitochondrial disease is totally gone and they now think with more HBO she will be normal. I spoke with her ophthalmologist in Madison who was so amazed he is doing a study using HBO for visual problems. Carlos Ponte, Gracie's pediatrician was so impressed he has changed his career direction, has moved from Wisconsin to Florida and is studying to be the medical director of a Hyperbaric clinic there.

➤ Michelle Divino from Illinois has two children with Autism. Her son age 9 years was somewhat verbal before treatments, but echolalic (repeating what others said only), had obsessive behavior with self-stimulating behaviors as a norm. He would typically play obsessive games to amuse himself, screaming to vocalize his needs, and only used nouns to communicate. After 40 HBOT he properly uses pronouns, is using prepositions, conjunctions, and will repeat his sentences over and over until he is satisfied with how they sound. He has shown real emotion, and even told a lie! He is now able to tell what is wrong when he is upset. He says "good night" spontaneously. Once he said "Look at that green car, it's beautiful". without any prompting at all and said he a certain game he was playing. Her daughter is 2 and a half, nonverbal, and somewhat aloof showing very little interest in her mother before treatment, preferring her father. Her daily routine consisted of watching videos all day and "reading" her magazines and books. After the first few treatments her daughter said, "bye-bye" and "mama" and began to seek out her mother to play. She showed more interest in her siblings as well. Her interest in videos slowed down and she began playing in the sandbox which was taboo before HBOT. She began to run (which she was unable to do before HBOT) and attempted stairs one foot over the other versus one stair at a time. Overall she became more aware, less aloof and will look at her mother and smile when she says hello 2 out of 10 times versus not at all.

**<http://www.netnet.net/mums/AutismHBO.htm>**

➤ One of our fathers whose son had a near-drowning episode while he was visiting his sister in California knew about Hyperbaric Oxygen Therapy before the incident. He told me he literally got down on his knees, crying and begging the doctors at Loma Linda to treat his son. They refused.

➤ Debbie, a MUM in Wisconsin, was pregnant with twins, and had her leg amputated because of flesh-eating bacteria. When this failed to stop the spread of the bacteria she was given HBOT which totally killed the bacteria. Why was HBOT not the treatment of choice before amputation? The twins were 24 weeks premature and both have Cerebral Palsy. Her other child has Achondroplasia dwarfism.

➤ I called a doctor that I heard from parents was treating children with Cerebral Palsy-sneaking them in the chamber. He told me he would treat children with brain injuries, but



that I should not publish it. He said he was seeing the same improvements in the children that was documented in the MUMS' newsletters. He then told me that he had a 51 year old friend who had suffered a viral encephalopathy and had been in a coma for five weeks. All the tests they did on him, MRI, EEG, showed no brain function and that he was clinically dead. The ventilator was removed but he did not die. He told the family that before they made the final decision to stop feeding him, he wanted to put him in the chamber. After the Hyperbaric Oxygen Treatments his friend walked out of the hospital, not well, but of his own accord!! I asked him why he wasn't shouting this from the rooftops? He told me he would lose his job for treating off-label. What state is our medical system in that our government allocates millions of dollars for research each year, yet doctors are afraid to come forward with the truth about HBOT for fear of retribution?

➤ David Freels of Georgia has a 10 year old son Jimmy who has Cerebral Palsy. HBOT improved Jimmy tremendously so David asked his state Medicaid to pay for the treatments. When they refused he sued and won. He based his claim on the language of the EPSDT statute that states in paragraph (5) 139d(r) that States provide "such other necessary health care...treatment and other measures...to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan." The state has appealed.

Ga. Dept't of Cmty. Health v. Freels, 576 S. E. 2d (Ct. App. 2002). Held that the EPSDT statute required only that a treatment be necessary to correct or ameliorate physical or mental conditions, not that a treatment be an acceptable standard of medical practice.

➤ Finally I present you with the story of Kevin Fickle who I consider the poster child for Hyperbaric Oxygen therapy. Kevin Fickle of Slidell, Louisiana was 11 months old when a viral encephalopathy put him in a coma. He was on life support, had five infarcts to his brain and all his organs were shutting down. His doctor knew about HBO, but because of the off-label ban on using it for brain damage he had to wait until Kevin developed the typical meningitis sore on the back of his head eleven days later. This was the ticket he needed to justify use of the chamber for wound healing. After three treatments Kevin fought the ventilator and after ten he was crawling around the chamber. His parents are members of MUMS and update me with pictures periodically. The only side effect he still has is a speech delay otherwise he is a normal boy. If he had been able to be treated earlier his speech would probably not have been affected.

His story was featured on Lifetime's Beyond Chance with Melissa Etheridge.

[http://www.musa.org/Stories/kevin\\_fickle.htm](http://www.musa.org/Stories/kevin_fickle.htm)

I get calls almost daily from parents with questions about HBOT. They cannot ask their doctors who have no training in this field. Dr. Harch, who is on the MUMS' Medical Advisory Board has been kind and dedicated enough to respond to many of them personally. He and I cannot keep up with the demand and there needs to be a better system for dissemination of information. Without studies we do not have the answers. We can only guess from our experiences and those of others.

With our nation in an economic crisis we cannot afford to ignore the possibility of HBOT reducing not only the medical costs, but the excruciating, life-altering pain and suffering

experienced by so many. The parent movement has taken on a life of its own. Desperate parents are going to continue to get HBOT for their children no matter what you decide today. Some are even talking about treating their children with scuba gear and 100% oxygen at the bottom of their swimming pools. We are crawling into chambers in the back of semis hidden on Indian reservations and in warehouses and having chambers installed in our homes. Parents are second mortgaging their homes and taking out huge unrepayable loans. Nothing can stop parents from getting HBOT for their children, but you can help us make it safe and available. We need studies to determine the safest and most efficacious protocol.

The question is not whether Hyperbaric Oxygen Therapy works. The exciting question is what other conditions will Hyperbaric improve or cure.

With your help, the testimony you have heard today could help revolutionize the medical industry and put hyperbaric oxygen as a treatment of first choice rather than a last resort. Infants born with severe brain damage could be sent home as normal babies. People involved in accidents suffering from traumatic brain injuries and those who have strokes could have the damage to their brains reversed or eliminated if treated immediately.

You know in your heart, after what you have heard today, if a loved one of yours incurred brain damage you would be desperately looking for the closest hyperbaric chamber too.

Thank you so much for your valuable time.

Julie Gordon