

Oxygen is Optional at IHA-Sponsored

“REACHING FOR THE STARS” CP CURE CONFERENCE.

By David Freels

Somehow a Paul Harch lecture on the use of Hyperbaric Oxygen Therapy for CP became “optional” at the first annual Reaching for the Stars Cerebral Palsy conference in Atlanta. The International Hyperbaric Association sponsored the April 16, 2005 event, produced by the Reaching for the Stars Foundation (RFTS).

Dr. Paul Harch, MD was not even listed as a speaker, nor was he allowed to lecture until after the conference officially ended. Dr. Harch has authored or co-authored over two dozen HBOT-related articles, numerous chapters in The Textbook of Hyperbaric Medicine, including HBOT for Cerebral Palsy and testified twice before the United States Congress on the use of HBOT for brain-injury.

Reaching for the Stars co-founder Cynthia Gray stated, “The reason [Dr. Harch’s lecture] was optional is that there wasn’t a possibility of adding another mandatory hour to the conference. No one else speaking was a paying vendor.”

In addition to the IHA, the conference was also sponsored by Children’s Healthcare of Atlanta (CHOA) and actually held at a CHOA facility--where CHOA had one of the largest, most prominent booths in the vendor area. Seven of the eleven speakers on the speaker’s roster were either CHOA doctors or therapists.

CHOA was the only sponsor singled out for additional appreciation, “We especially thank Children’s Healthcare of Atlanta for co-presenting this conference with us and for their outstanding support and assistance in making this conference a reality.” (reachingforthestars.org/sponsors.htm)

RFTS Founded by Parents of CP Children

Reaching for the Stars (reachingforthestars.org) was founded in 2004 by mothers Anna Marie Champion and Cynthia Frisina Gray.

Anna Marie’s daughter, Morgan Champion, is now five years old and the twin sister of Katelyn. According to her mother, Morgan can walk with a walker and is taking dance and/or ballet lessons.

Anna Marie was confined to bedrest the last two months of her pregnancy be-



Morgan Champion



Cathryn Gray

fore her twins were born prematurely at seven months (reachingforthestars.org/annamarie.htm).

Cathryn Gray is the daughter of RFTS co-founder Cynthia Gray. She’ll be five years old on October 25th. She was a “29 weeker” and weighed just 3 1/2 pounds at birth. Cynthia was also confined to bedrest for some 15 weeks before Cathryn was born (reachingforthestars.org/cindy.htm).

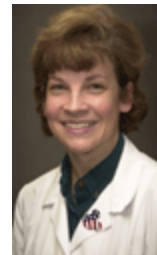
Mother Cynthia states, “Cathryn has progressed beyond our expectations and is happily thriving in school, taking ballet and one of the happiest children we know.”

The Reaching for the Stars logo features a child with the motor and balance skills to stand up, bear weight, and reach up for a star while holding a cane that provides minimal support.

Patients of Dr. Janice E. Brunstrom

Both Morgan Champion and Cathryn Gray are patients of Dr. Janice E. Brunstrom. Dr. Brunstrom is believed to be the only pediatric neurologist in the world who also suffers from cerebral palsy herself.

At reachingforthestars.org/annamarie.htm, Anna Marie wrote, “Coincidentally, my grandmother sent me an article she read about Dr. Janice Brunstrom, a pediatric neurologist who also had Cerebral Palsy, and I immediately called for an appointment.”



Brunstrom

Cynthia Gray wrote, “Somewhere between wondering ‘why Cathryn?’ and complaining that there didn’t seem to be any progressive research or treatments out there that I could find, I happened to run across an article about Dr. Janice Brunstrom, a neurologist with St. Louis Children’s Hospital, who happened to have CP herself and was in the process of working on a variety of unprecedented breakthroughs and research studies regarding children with CP. This really turned things around for us. I made an appointment for Cathryn that day and resolved that we would actively pursue the best medical experts dealing with children with CP, wherever they might be.” (reachingforthestars.org/cindy.htm)

Brunstrom Gave Two RFTS Lectures

Dr. Brunstrom was the first speaker at the first annual Reaching for the Stars conference.

Her first one-hour lecture was "Hope, Faith, and Help To Move a Mountain: Redefining the Future of Cerebral Palsy." Following the Medtronic-sponsored lunch break (Medtronic manufactures the Baclofen pump), Dr. Brunstrom’s second lecture was "Improving Strength for Enhanced Motor Ability: A Unique Perspective."

A Medline (ncbi.nlm.nih.gov/80/entrez/query) keyword search of “Brunstrom JE” yields twelve articles. Seven focus on the migration of neurons in the developing brain.

Dr. Murray Goldstein, Medical Director of the United Cerebral Palsy (UCP) Research and Educational Foundation, strongly believes in-utero interruptions of neuronal migrations to be a primary cause of cerebral palsy. At the 3rd International Symposium on HBOT for the Brain-Injured

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Child (2003), Dr. Goldstein gave an impromptu, unsolicited talk for nearly 20 minutes on neuronal migration. At the same time Goldstein refused to answer a question asked repeatedly by audience members: What percentage of CP children have cerebral palsy as the result of an hypoxic-ischemic event?

As reported here earlier, UCP is financing and dictating the protocol of an HBOT-for-cp study designed to fail. See http://ihausa.org/newsletters/newsletter/pdf/2004_Oct_Nov.pdf.

Brunstrom: No To HBOT

An informal survey through Internet listservs of other parents whose children have been seen by Dr. Brunstrom revealed she's like nearly all pediatric neurologists: Dr. Brunstrom has never prescribed or even recommended hyperbaric oxygen for a CP child. In fact, she discourages families from even trying HBOT.

However, according to David Deister of the Kansas City, Missouri Hyperbaric Healing Institute (www.HHI-KC.com), a Brunstrom patient they treated made tremendous developmental gains from HBOT, but Dr. Brunstrom refused to acknowledge the improvements came from Hyperbaric Oxygen Therapy. Deister said he even attempted to speak personally to Dr. Brunstrom, but she was unreceptive and declined the opportunity to learn more.

Emails and in-person inquiries from several people asking if Brunstrom would be interested in trying HBOT for herself have gone unanswered.

At the Reaching for the Stars conference, Dr. Brunstrom chose to leave for the airport just as the conference ended. She missed the chance to hear Dr. Harch's lecture.

RFTS Purpose: Find a CP Cure

The goal of the Reaching for the Stars Foundation is to find a cure for cerebral palsy.

"Although cerebral palsy is not yet 'curable' in the accepted sense, training and therapy can help improve function and many promising therapies and treatments are currently being investigated.

RFTS, Inc. is a world-class research foundation started by and for the parents of children with Cerebral Palsy centered on the belief that leading-edge pediatric research can lead to cures and new treatments of CP." (<http://reachingforthestars.org/>).

Shannon Kenitz of the International Hyperbaric Association agreed to help sponsor the first RFTS conference. "The IHA is certainly supportive of anyone who wants to find a cure for cerebral palsy."

RFTS First Invited Neubauer, Kenitz

According to Anna Marie Champion, RFTS first contacted and invited Dr. Richard Neubauer to speak as a medical expert on HBOT. Next, RFTS contacted Shannon Kenitz to make a presentation about Hyperbaric Oxygen Therapy from a parent's perspective. Shannon's daughter Grace Kenitz suffers from an extremely rare mitochondrial disorder. At one time Grace was one of four known cases in the entire world. Today she is the only survivor, thanks to HBOT.

Because RFTS was a new organization started by mothers of impaired children, Ms. Kenitz, acting as an IHA Representative, also offered for the IHA to sponsor the first annual Reaching for the Stars CP Conference. Said Kenitz, "These were two moms with kids, trying to put on a conference. I could certainly identify with them. I knew what they were trying to do and how difficult it is. I wanted to do what I could to help."

In July 2004, with the help of the IHA, Kenitz produced the four-day, 60+ presentations Fourth International Symposium on HBOT for Brain-Injured Children held at the Hyatt Regency in Fort Lauderdale, Florida.

When Dr. Neubauer later withdrew from RFTS, the IHA immediately offered to replace the Neubauer slot with Dr. Harch. RFTS agreed, but it wasn't until the day of the conference itself that the IHA or Dr. Harch clearly understood the Harch lecture was an "optional" event that would take place only after the conference officially ended.

RFTS co-founder Anna Marie Champion said, "When Neubauer dropped out, his slot was filled by a speech pathologist." However, according to Kenitz, the IHA immediately guaranteed another speaker on HBOT the moment RFTS notified her Neubauer had withdrawn. Both Gray and Champion were asked repeatedly for an explanation of how a speech pathologist's presentation necessitated greater priority than hyperbaric oxygen, particularly in light of RFTS stated goal of finding a cure for CP.

No explanation was ever given.

Harch Not Listed as a Speaker

The IHA first guaranteed an HBOT presentation in late December or early January. Next, RFTS requested a copy of Dr. Harch's Powerpoint presentation before he was officially accepted as an RFTS speaker. He submitted a 100-slide Powerpoint presentation. There were four or five phone calls and an additional four or five emails between Harch, the IHA, and RFTS before Harch was accepted and finalized in early March. Even with all that communication, it was never clear to either Dr. Harch or the IHA that his lecture would only be after the conference officially ended.

Additionally, he was the only speaker not listed by name on the roster of conference speakers. Instead, his lecture time was listed as an "Optional Question and Answer Session with:

International Hyperbaric Association" and the "American Association of Pediatric Intensive Physical Therapy." (source: RFTS registration material)

The surprise discovery of the "optional" status on Saturday followed a Friday evening "Physicians Only" dinner given the night before where Dr. Harch was the only conference speaker not introduced.

RFTS co-founder Cynthia Gray later said, "Anna Marie and I were supposed to introduce all the speakers; however, a Children's Healthcare of Atlanta person introduced [some of] the out of town speakers during some opening comments. Immediately I stood up, apologized, and thanked Dr. Harch for attending and traveling from out of town to participate."

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CHOA Speakers: Botox, Baclofen, and Rhizotomies

While the stated goal of Reaching for the Stars is to find a cure for cerebral palsy, the overwhelming majority of conference speakers were conventional practitioners from CHOA who only advise parents to use conventional therapies and interventions. Only the last speakers in the conference spoke on alternative therapies, which was a brief, 55-minute period of short presentations by four different speakers on Hippotherapy, Aquatic Therapy, Suit Therapy, and Biofeedback.

Dr. Harch was allowed the very last five minutes to preview his lecture that followed the conclusion of the conference. In a post-conference email, Mrs. Gray stated, "We were able to squeeze in 5 more minutes for Dr. Harch once we knew he could attend. We were under no obligation of any kind to do so but wanted to. There is no gray area here. We were happy to have him and happy to have the IHA as a vendor."

Five Minutes for Harch, 20 Minutes for Champion and Gray.

After Dr. Harch's five minutes, the two Reaching for the Stars co-founders gave a lengthy 20 to 30 minute presentation on how the Reaching For The Stars Foundation came to be. Every parent in the room could certainly identify with the stories of their children, their heartache and disappointment, but most of the attendees already knew how RFTS started.

Next, Champion and Gray introduced members of the RFTS board of directors, which includes Tina Black (an occupational therapist), Tim Oswald (CHOA orthopedic surgeon), Noreen Scott (a physical therapist), Melanie Sudge (another mother of a CP child), and Dr. Barbara Weissman (a pediatric neurologist).

Dr. Weissman is also an outspoken critic of HBOT, and said a peer-reviewed medical journal published an article about a CP child dying from hyperbaric oxygen (personal communication) but could not provide a specific reference to the article. A Medline (ncbi.nlm.nih.gov/80/entrez/query) search on the keywords "palsy hyperbaric death" did not produce an article like Weissman described.

Dr. Weissman's RFTS lecture "The Baclofen Pump, Botox and Other Injected Treatments: Considerations For Your Child" followed Dr. Brunstrom's "Redefining the Future of Cerebral Palsy" lecture.

Leland Albright on Medical Advisory Board

In their concluding talk, Mrs. Champion and Mrs. Gray also discussed the creation of their medical advisory board. The one doctor they most wanted to lead the board was Leland Albright.



Albright

Dr. Albright is a neurosurgeon at Pittsburgh Children's Hospital and is often spoken of as "the guru of Baclofen pumps" (source: Medtronic). According to Dr. Albright's web page (www.neurosurgery.pitt.edu/faculty/albright.html), he's "published approximately 150 papers in refereed journals;" however, a Medline keyword search of "Albright AL" yields just 125 references. Of those 125 papers 16 are about baclofen pumps. When asked the usual fee for a baclofen pump implant, Dr. Albright responded, "Approximately three times the reimbursement fee of your predominant carrier."

According to Mrs. Champion and Mrs. Gray, they "researched all the most important people and decided the name Leland Albright should be at the top of

their list." Dr. Albright initially declined to serve on the Medical Advisory Board of RFTS; however, Champion and Gray persisted. Finally, they said, "Dr. Albright said 'he'd serve on the board if they [RFTS] contacted and got this person and this person and this person and this person to also serve.'"

The RFTS co-founders continued, "Dr. Albright hung up and probably thought he'd never hear from us again, but then we got "this person, this person, this person, and this person to also serve. We called Dr. Albright back, and he had no choice but to join our board because we did everything he asked us to do."

Leland Albright: "I will do everything I can to prevent HBO from being offered by [Medicaid] medicare in the U.S."

On September 3, 2002 Dr. Albright first contacted this author in an unsolicited email:

Subject: HBO
Date: Tue, 3 Sep 2002 12:21:39 -0400
Thread-Topic: HBO Thread-Index: AcJTZknBGf1AC1NBecKbJp845eEHg
Received: from chpexch4.chp.edu ([151.195.6.208])
From: "Albright, Leland" <Leland.Albright@chp.edu>
To: <dfreels@mindspring.com>

Dear Mr. Freels,

You do parents and patients a disservice by not knowing the results of the Canadian HBO trial. It was the best designed and conducted study I have seen in the past 20 years and showed conclusively that HBO is not effective. It's "benefits" are reported by numerous parents and owners of HBO clinics, just as there are with placebo treatments of many incurable disorders.

I will do everything I can to prevent HBO from being offered by medicare in the U.S. It drains dollars from treatments that have the potential to be truly helpful.

Leland Albright, MD
Chief of Pediatric Neurosurgery
Children's Hospital of Pittsburgh

Email Correspondence with Albright

In good faith, this author made a number of efforts to more fully explain to Dr. Albright what really happened in the second Canadian (Collet) study. These included The Lancet's acceptance letter to Collet--conditional upon Collet deleting all references to placebo. Dr. Albright

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was also sent a literature review of every double-blind, placebo-controlled study for any treatment modality in cerebral palsy--which showed no placebo group ever experienced improvement--except in the second HBOT-for-CP paper published by Collet and Hardy in *Developmental Medicine and Child Neurology (DMCN)*. DMCN is the official peer-reviewed medical journal of the American Academy of Cerebral Palsy and Developmental Medicine (AACPDMD).

Statements from Dr. Pierre Marois and Dr. Michel Vanasse (a pediatric neurologist) were also sent to Dr. Albright. Marois and Vanasse were both original investigators in the Collet trial but have never been allowed to review the raw data gathered in the study.

Over a year later on September 29, 2003, Dr. Albright finally replied:

Priority: normal
Subject: RE: HBO
Date: Mon, 29 Sep 2003 15:45:26 -0400
Thread-Topic: HBO
thread-index: AcOCwHP /yx8KWDaeQouf64HB8F/uwEAO qac
Received: from chpexch3.chp.edu ([151.195.6.207])
From: "Albright, Leland" <Leland.Albright@chp.edu>
To: "David Freels" <dfreels@mindspring.com>

Dear Mr. Freels,

My belief, like yours, is the same. I have read the articles but come to a different conclusion than you. In the opinion of the leaders of the AACPDMD, the Canadian study provided definitive evidence that HBO has no long-term benefit. For most of us, the issue has been decided. If HBO were of therapeutic benefit, some physicians in the AACPDMD would be championing it.

Leland

RFTS Founders Disrupt Harch's Lecture

After Mrs. Gray finished her presentation of "What is Reaching for the Stars," she announced the conference was officially over. There was no reminder of the upcoming Harch lecture, and none of the nearly 200 attendees were encouraged to stay. As a result, only 20 to 30 people stayed to see the only brain scans presented during the entire day that showed functional improvement in the brain after any intervention.

Even then, Cynthia Gray and her husband were both actually disrupting the presentation. Mrs. Gray was engaged in a loud conversation at the doorway to the room. An audience member finally got up and closed the door. Mrs. Gray's husband was busy packing away audio and visual equipment. This author actually suggested to him that he sit down and listen. Several audience members commented later that it was unbelievably rude not only to Dr. Harch, but also to the audience members who had stayed.

RFTS: Oxygen Shortage as CP Cause Ended in 1897

The CP Facts page at reachingforthestars.org/facts.htm states, "Because it seemed that many of these children were born following premature or complicated deliveries, [English surgeon William] Little suggested [in the 1860's] their condition resulted from a lack of oxygen during birth. He proposed this oxygen shortage damaged sensitive brain tissues controlling movement. But in 1897, the famous psychiatrist Sigmund Freud disagreed. Noting that children with cerebral palsy often had other problems such as mental retardation, visual disturbances, and seizures, Freud suggested that the disorder might sometimes have roots earlier in life, during the brain's development in the womb. 'Difficult birth, in certain cases,' he wrote, 'is merely a symptom of deeper effects that influence the development of the fetus.'"

IHA Demands Sponsorship Refund

As a result of the optional, after-conference placement of the Harch lecture, IHA Representative Kenitz requested a refund from the Reaching for the Stars Foundation for IHA sponsorship of the April 16th conference.

So far, no check from the Reaching for the Stars Foundation has arrived in the IHA mailbox.

In the final communication with RFTS, Mrs. Gray said, "We are doing our best for all children with CP and despite the offensive and untrue accusations put out there, your own children will end up benefiting from what we are trying to accomplish in the way of research."

A click on "Research" at the Reaching for the Stars website (reachingforthestars.org/research.htm) yields the following page:

