

# The Pressure Point

Happy  
New Year!

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From CNN Health

## FAMILY KEEPS HOPE IN U. S. MAD COW CASE

Posted Wednesday, January 7, 2004

(CNN) – At 24, Charlene should be finishing up her master's degree or taking other steps to plan her future. Instead, she's become a statistic.

Charlene is the only person living in the United States with the human form of mad cow disease, according to the Centers for Disease Control and Prevention. (Her parents don't want the family's last name revealed for reasons of privacy.)

Her case has taken on renewed interest since the U.S. Department of Agriculture confirmed the first appearance of mad cow disease in the United States last month, sparking concerns about the nation's beef supply.

Doctors at the CDC said they are sure Charlene caught the disease while living in Britain.

She lived in England until moving to Florida 11 years ago at age 13. So far, 143 people in Britain have contracted variant Creutzfeldt-Jakob disease or vCJD, also known as the human form of mad cow. Six of them are still alive.

The disease – linked to eating infected beef – was first reported in the United Kingdom in 1996. There is no known cure for the degenerative, fatal brain disorder. This disease is not to be confused with classic Creutzfeldt-Jacob disease, which has been reported for decades. The National Center for Health Statistics show cases of classic CJD occur in about one in a million people and usually strikes people in their sixties and seventies.

According to the CDC, Charlene sought medical help for memory loss and depression in November 2001, and a month later she reported involuntary muscular movements, changes in her walking and difficulty in dressing.

Her condition continued to worsen. In less than a year, Charlene was bedridden, unable to eat by herself and no longer able to communicate with family members. Doctors had given her a few months to live when CNN first interviewed her family in October 2002.

Since then, her parents said Charlene has not gotten any better nor has she become any worse.

"She has stabilized from the last time we saw you," said Charlene's dad, Patrick. "They gave her three months at that time, and it's over 15 months now... and she is still here. She has not deteriorated."

### No cure available yet

How remarkable is it that Charlene is still living? U.S. and British health officials declined to comment about her condition, citing patient confidentiality. But a statement from the British Department of Health illustrates how little is known about variant Creutzfeldt-Jakob disease.

"It remains the case that there is still much that we do not know about vCJD," the statement reads. "For example, the route of infection, the incubation period, the level of exposure required to cause the disease and the possible role of genetic susceptibility. It is likely to be some years before we are able to make soundly based predictions about the future course of the disease."

Modern medicine has found no cure yet, but members of Charlene's family said they will not give up. They bathe and feed her, caring for her around the clock.

"How Charlene's mom does it, I don't know," Patrick said. "I'm amazed every day. It's tough on her – it really is to

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**Charlene receives constant care from her family, who do everything from feeding her to taking her to doctors.**



**Log on to CNN (below) to see a video of this young woman, who contracted the human form of mad cow disease in England and has outlived predictions.**

[www.cnn.com/2004/HEALTH/01/06/mad.cow.victim/index.ht](http://www.cnn.com/2004/HEALTH/01/06/mad.cow.victim/index.ht)

*Special Recognition***AWARDS PRESENTATION**

On December 13, 2003, The International Hyperbarics Association recognized contributions to the hyperbaric community by three notable individuals.

**1st Award**

The first award went to a remarkable woman whose exceptional organizational and leadership qualities led to the success of last year's 3rd International Symposium on Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child. Through her efforts, the symposium was attended by over 500, including 40 leading doctors, who presented cutting-edge data on Hyperbaric Oxygen. Considering that the event came close to being cancelled not more than 3 months prior to the scheduled symposium date, the fact that the event went off so smoothly and was so well attended is an accomplishment that few can meet. These meetings usually require a preparation lead-time of a year.

With her help, the symposium raised close to 40 thousand dollars—to be used toward equipping a Broward County Hospital with a hyperbaric chamber for the treatment of near-drowning patients.

The hyperbaric community will forever be better off because of her commitment to those children direly in need of HBOT.

The hyperbaric community owes their gratitude to **Shannon Kenitz** for making the symposium such a great success.

**2nd Award**

The next recipient's lectures and presentations on the effects of mHOBOT have gained him the highest reputation for master of his field. As a prolific researcher and writer, he has published over 60 papers in peer-reviewed, medical journals. His expertise continues to be in demand throughout the United States, Canada, Mexico and Australia.

His papers have included numerous studies detailing the advancements of hyperbaric medicine for various neu-

rological injuries, and most recently applications in immune function. He has also published his most compelling data illustrating the pre and post results of mild HBOT, using SPECT scans and neuropsychological testing.

His knowledge of toxicology has led him to pioneer safer protocols using mild pressure hyperbarics, and his research documents the dramatic positive effects of hyperbaric therapy on the brain—particularly for brain injuries like autism, A.D.D., stroke, cerebral palsy, and toxic encephalopathy. In the past year, his work has examined the anti-aging properties of mild hyperbaric oxygen therapy—improved immune function and decreased apoptosis (cell death). His current work explores a new hope for fertility issues.

The IHA recognizes **Gunnar Heuser, MD, PhD, FACP** for his Outstanding Research in the field of Mild Hyperbaric Medicine.

**3rd Award**

Our final award was fittingly presented by two parents, Mrs. Tracy Spracklen and Mrs. Bonnie Edwards, whose children have directly been impacted by the recipient's invention.

These remarkable mothers shared their emotionally charged stories—how their children were injured, how hyperbaric therapy changed their lives.

Mrs. Tracy spracklen first approached the IHA in July 2002. Her story so moved us to help afford a portable chamber, which could offer her son Robby a real chance at recovery.

As readers will remember (Oct. 2002 Pressure Point), her son Robby, at 20 years of age, was in a tragic automobile accident. The doctors told Tracy that Robby would not make it. It has been four years since then, and Tracy has been there by his side documenting how mild hyperbarics continues to help Robby through this time of recovery.

From Left to right:

Dr. Elfriede Gamow,  
Dr. Igor Gamow,  
Ms. Shannon Kenitz,  
Dr. Gunnar Heuser,  
Mrs. Sylvia Heuser



Our second parent, Bonnie Edwards is the mother of a spirited 14-year old darling, Marion (Mo, for short). Mo's story was covered in the September 2003 issue of *The Pressure Point*. Mo has suffered with severe Cerebral Palsy since birth, as well as severe spasticity in her arms and legs for most of her life.

Both parents presented the final award to an individual with quite an extensive background in so many subjects. His invention was featured in *The Pressure Point, August 2002*.

This recipient holds a PhD in Microbiology Biophysics and is a Chemical Engineering Professor at The University of Colorado.

In addition, he has danced with the National Ballet Company, scaled the mountains of Nepal and has received praises from such notables as Sir Edmund Hillary for the development of a device that Sir Hillary refers to as "the stuffed cobra". Not to be overlooked, this recipient's famous father helped develop the 'Big Bang Theory.'

Dr. Igor Gamow, inventor of 'The Gamow Bag'—Portable Hyperbaric Chamber—graciously and humbly accepted this award.

In his speech, Dr. Gamow spoke of his father who would never have been so "practical" in his inventions as to name a device after his surname.

On a more serious note, Dr. Gamow told those in attendance, in particular both parents who had shared their stories and presented him the award, that it brought him a certain satisfaction to know that his chamber had affected the lives of so many.

Congratulations to all three recipients!

## Continued Family Keeps Hope in U. S. Mad Cow Case

(Continued from page 1)

be in this room every day. Because you can't leave. Sometimes she might need help breathing..."

A neurologist who saw CNN's original report on Charlene's condition was willing to try something new. He offered to give Charlene hyperbaric treatments – pumping pure oxygen into her lungs – which may help the brain function better. She gets treatments three times a week.

"When she first came in, she was virtually comatose, nonreactive," said Dr. Richard Neubauer of the Ocean Hyperbaric Neurologic Center in Lauderdale-by-the-Sea, Florida. "[She] could not obey commands, did nothing."

Neubauer said this procedure is no miracle treatment. He said he felt it was worth a try with Charlene since the treatment has alleviated other brain disorders.

"After 192 treatments, she's not only alive, but she's trying to talk," he said. "She's responsive and trying to respond to simple commands. [But she]

still [has] a long way to go."

Charlene's dad agrees that the treatments have helped.

"She has put weight on. She looks brighter. She moves around a lot more. She murmurs a lot more," Patrick said. "So yes, I would say that there is some physical difference."

Charlene's family members said the recent announcement that a cow in Washington state tested positive for bovine spongiform encephalopathy, or BSE, concerns them.

"I was very upset that lessons have not yet been learned," worried Sharon, Charlene's aunt.

Patrick said, "It's like being in England all over again, reliving this BSE thing and being told the meat is safe to eat. If... we believe our government on meat safety, if we [had been] told any differently, my daughter would not be lying here right now."

Charlene's father and aunt said they aren't against the beef industry, but

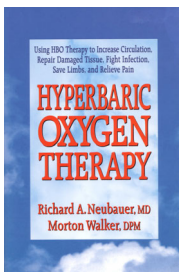
**"Dr. Neubauer said this procedure is no miracle treatment. He said he felt it was worth a try with Charlene since the treatment has alleviated other brain disorders. 'After 192 treatments, she's not only alive, but she's trying to talk,' he said. 'She's responsive and trying to respond to simple commands. [But she] still [has] a long way to go.'"**

they said they do worry that some other parent's child could fall victim to variant Creutzfeldt-Jakob disease.

"I am not giving up on my daughter, not for one moment," Patrick said. "I think if we've come this far, we can go further, and I hope one day and pray she'll walk off this bed. I have no doubt."

CNN's Miriam Falco contributed to this report.

## Books now available from the IHA

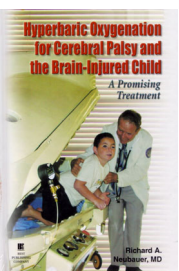
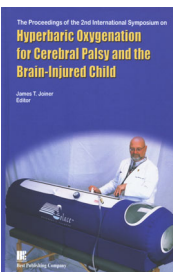


Hyperbaric Oxygen Therapy by Richard A. Neubauer, MD

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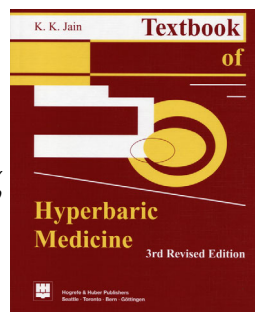


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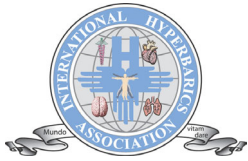
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# INTERNATIONAL HYPERBARICS ASSOCIATION



*The International Hyperbarics Association is a coalition of doctors, parents, patients, corporate chamber-industry professionals, hyperbaric center owners, and above all members who are committed to the cause of medical hyperbarics.*

*Our members come to us from all geographical areas with one common goal— to share their knowledge and information regarding the latest hyperbaric news.*

*Our driving force is our members, who are committed to do all we can "to give life to the world."*

— "Mundo vitam dare"

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