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COVER STORY

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Scientists study the allure of risk for teens.

COVER PHOTO BY ANDY TULLIS: A local snowboarder uses the roof of the Sunrise Lodge for a stunt, aiming his board toward a small remaining spot of slushy spring snow at Mount Bachelor.

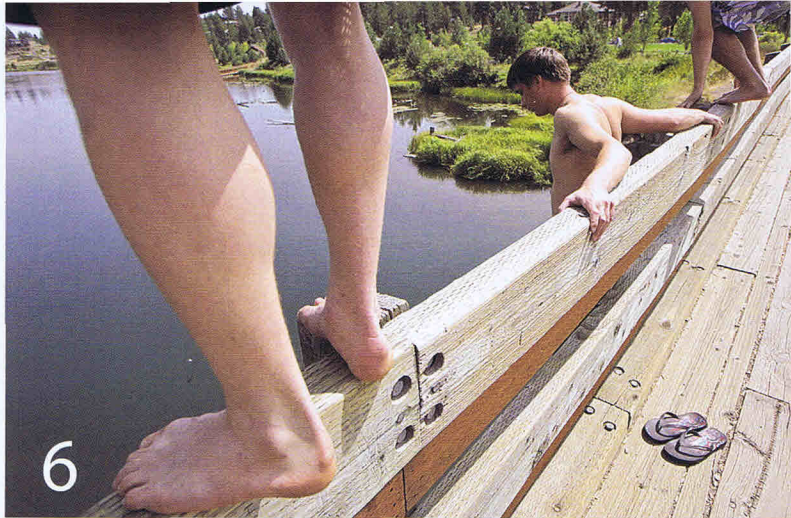
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PHOTOS FROM TOP BY ROB KERR, DEAN GUERNSEY, PETE ERICKSON, ANDY TULLIS





Jinger Cain and her 4-year-old son, Dylan, who has cerebral palsy, in the hyperbaric chamber at BMC.

Hyperbaric therapy: who benefits?

Though its healing potential is vast, only 13 uses are approved. Some local doctors think that should change.

BY LILY RAFF
PHOTOS BY PETE ERICKSON

When Jinger Cain's son, Dylan, was diagnosed with cerebral palsy three years ago, she became the kind of mother who ignores experts' advice in favor of whatever she believes could help her boy.

So when she heard a treatment called hyperbaric oxygen therapy — breathing pure oxygen under high air pressure — had helped other children with cerebral palsy, the Corvallis woman began searching for a facility whose doctors shared her independent streak.

A physicians group that oversees hyperbaric therapy in the U.S., the Undersea & Hyperbaric Medical Society (UHMS), approves use of the procedure to treat 13 specific health conditions. Cerebral palsy is not one of them.

Cain called all over Oregon to find a hyperbaric facility that would even consider treating her son. She found it here in Central Oregon.

Bend Memorial Clinic has Oregon's only medical-grade hyperbaric

oxygen chambers east of the Cascades. The clinic treats roughly 12 patients per day, and 5 to 10 percent of them have conditions not on the UHMS list. It is legal to treat patients with other conditions — often called “off-label” use of hyperbaric therapy — but insurance companies rarely agree to pay for it.

Some doctors, including the American College of Hyperbaric Medicine, caution against off-label hyperbaric therapy except in carefully controlled scientific studies. It carries some health risks, including seizures and ear damage. And because it is expensive, it could be prescribed for financial gain rather than a patient's health.

But doctors at BMC say the therapy has the potential to treat many other diseases, including cerebral palsy. And they say off-label hyperbaric patients are often less lucrative for the clinic than regular patients, because they require so much more time spent on research and preparation.

“We do off-label hyperbaric therapy because it helps things other than what's on-label,” says Dr. Robert Pinnick, a kidney specialist and medical director of BMC's hyperbaric unit.

Hyper-healing

Hyperbaric therapy increases the amount of oxygen in a person's blood. A patient lies in a sealed chamber where the air pressure is increased to nearly 2½ times normal atmospheric pressure. Instead of regular air, which is about 21 percent oxygen, the chamber is filled with 100 percent oxygen.

Google "hyperbaric oxygen therapy" and you're likely to get just as many celebrity photos as Web sites for hospitals and health clinics. The treatment's potential is often overstated.

Adding to the controversy is a set of cheaper low-pressure hyperbaric chambers that are advertised for home use. Home chambers cost much less and peak at a much lower level of air pressure that most physicians would not prescribe for effective treatment.

In the 1980s, the therapy was becoming popular for hundreds of medical uses, some of which were dubious. The National Enquirer published photos in 1986 of pop star Michael Jackson lying in a hyperbaric chamber and claimed that Jackson underwent frequent hyperbaric therapy at his home as part of a plan to live to 150.

Alarmed by the apparent overuse of hyperbaric therapy, the federal government threatened to stop paying for the procedure through Medicare and Medicaid. As a compromise, the UHMS offered a list of 13 conditions for which there was indisputable proof that hyperbaric therapy helped. But many doctors, including Pinnick, argue that there is compelling evidence, if not ironclad proof, that hyperbaric therapy can help other diseases, too.

"We would like to see the (UHMS) number expanded to probably 25 or 30 diagnoses," Pinnick says. "In the 1980s, they were (treating) 173 diagnoses, which is way too many, and clearly something had to be done. In reality, 13 (diagnoses) is probably too few. But that's the way a pendulum swings; it goes way out to one side and then way back to another, and somewhere in the middle is where it should be."

BMC bought its first hyperbaric chamber in July 2008 and quickly expanded to three chambers. Each chamber cost about \$120,000. The program runs daily from 6:30 a.m. to 6:30 p.m. One of five doctors is on duty each day.

According to Pinnick, almost all of BMC's hyperbaric patients — including off-label ones — are referred to the program by other doctors in the area. In off-label cases, the referring physicians have usually come across a study that suggests hyperbaric therapy could help.

"There are lots of great testimonial papers and diagnostic papers that show the benefits of hyperbaric therapy" for various diseases including cerebral palsy, Pinnick says, "but no papers that clearly compare 1,000 patients with (the therapy) and 1,000 patients without (therapy) and definitively can say: 'This works.'"

Patients with UHMS-listed conditions are accepted into BMC's program with a referral and an examination by a BMC hyperbaric doctor. An off-label patient is accepted only if all five doctors agree that:

- Hyperbaric therapy would be safe for the patient.
- There is a reasonable scientific indication that hyperbaric therapy could help the patient.
- The patient has a legitimate medical problem.

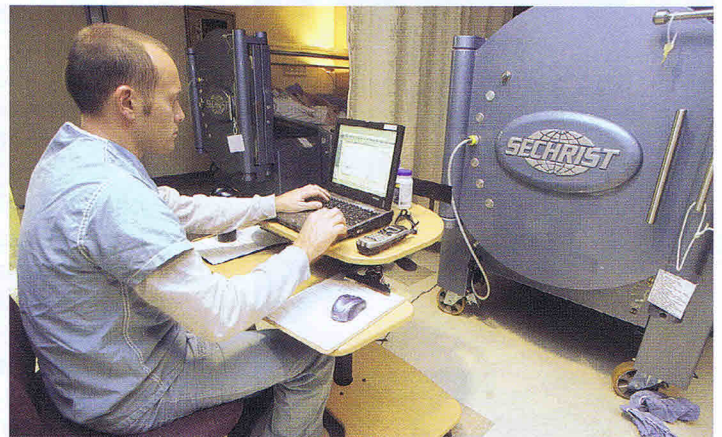
"The way our call schedule works, I might need to cover somebody else's off-label (patient), so that needs to be something that I'm comfortable doing," Pinnick explains.

For off-label patients, the doctors confer with one another about treatment strategies. How many sessions will a patient need? At what

THE 13 APPROVED USES FOR HYPERBARIC THERAPY

- Air or gas embolism (due to complications from surgery or trauma)
- Carbon monoxide poisoning and cyanide poisoning
- Clostridial myositis and myonecrosis (sometimes called "gas gangrene")
- Crush injury, compartment syndrome and other acute traumatic ischemias (inflammation or injury that cuts off blood supply to part of the body)
- Decompression sickness (gas bubbles in the blood, known as "the bends")
- Enhancement of healing in selected problem wounds
- Exceptional blood loss
- Intracranial abscess (infection and inflammation in the brain)
- Necrotizing soft tissue infections (bacterial infection that causes tissue death)
- Refractory osteomyelitis (bone or bone marrow infection)
- Delayed radiation injury (complications of anti-cancer radiation)
- Compromised skin grafts and tissue flaps
- Burns (from heat only; chemical burns are excluded)

Source: Undersea & Hyperbaric Medical Society



Technician Andy Dicus watches over the hyperbaric chambers at BMC. Doctors here and elsewhere say hyperbaric therapy — or breathing pure oxygen under high air pressure — has the potential to treat many diseases.

atmospheric pressure? For some off-label treatments, the doctors have little scientific proof to guide them.

Each of the UHMS-approved uses for hyperbaric therapy relies on the super-dose of oxygen and air pressure to help the body form new blood vessels.

But some believe the therapy has other regenerative effects, too. All humans produce stem cells, which have the potential to regenerate tissue. Some studies have shown that a patient who undergoes 40 days of hyperbaric oxygen treatments for about one hour each day ends up with eight times as many stem cells circulating through the body. That stem cell boost is what piqued Cain's interest in hyperbaric therapy.

High hopes

Five years ago, Cain was working a full-time, high-tech job in Corvallis while happily pregnant with her first child.

On Dec. 16, 2004, she gave birth to Dylan, who was born with the umbilical cord wrapped around his neck. He came out blue and not

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breathing. The doctor whisked him out of the delivery room. According to Cain, minutes passed before Dylan took his first breath.

Four months later, the Cains learned Dylan was blind. One year after that, he was diagnosed with cerebral palsy, a brain disorder caused by the lack of oxygen at birth. Symptoms include blindness, poor motor control and speech disorders. Dylan has a particularly severe case, and the Cains say doctors told them their son might never walk or talk.

Since then, Jinger and Mark Cain have dedicated their lives to proving those doctors wrong. Jinger was laid off from her job and has been taking care of Dylan full time. The family flew to Pennsylvania and learned intense physical and cognitive therapy techniques at a private organization called the Institutes for the Achievement of Human Potential.

Founded in 1955 by a physical therapist and an educational psychologist, the group advocates a treatment for brain injuries called "patterning," which involves the manipulation of a child's limbs. The technique has been criticized by the American Academy of Pediatrics, among other experts. But Jinger Cain believes the treatments have helped Dylan. The Cains still spend four to nine hours each day using the group's techniques. Dylan has learned to crawl. His vision has improved. He speaks a few words.

Before Dylan was born, the Cains made arrangements to save the blood inside his umbilical cord. Cord blood is highly valued for its abundance of stem cells. There are several universities and private companies that "bank" cord blood in the U.S., although its use is regulated by the federal government.

Last year, the company storing Dylan's blood called the Cains about a Duke University study on children with cerebral palsy. Doctors there take banked cord blood and inject it into the patient it originally came from. The stem cells, they believe, could help repair some damaged or dormant brain cells.

Treating cerebral palsy with stem cells is not a new idea. In China, doctors have reported success with stem cell transfusions using donated cord blood. In fact, the Cains were considering traveling to China for treatment before they heard about the Duke study.

In early June, Dylan was infused with 500

million to 600 million of his own stem cells. Doctors at Duke said it could take six months to see any improvement. But by August, Jinger Cain was noticing what she described as breakthroughs in Dylan's movement and speech. The boy's right leg and foot seemed less rigid. And Dylan began speaking a new word almost every day, which Jinger reported at the bottom of her daily e-mails to friends and family.

Now Cain wants to amplify the stem cells that already seem to be having an effect.

Shortly before the Cains left for Duke, Jinger began searching for a facility to administer hyperbaric therapy to her son. First she tried hospitals near Corvallis, but was told they would only consider treating conditions on the UHMS-approved list. Then she called private clinics, including BMC. A receptionist at BMC asked Cain to send a fax explaining her request.

"I ask you to please consider what it would be like to be a 4½-year-old who couldn't walk or talk," she wrote in the fax. A few days later, Pinnick's office called Cain.

Holes in the research

Marian McDonagh is the principal investigator at the Oregon Evidence-based Practice Center in Portland, a group affiliated with Oregon Health & Science University that conducts systematic reviews of various health care topics.

In 2001 and 2002, McDonagh reviewed hyperbaric therapy's effect on cerebral palsy patients. She looked at all the relevant published studies, then weighted the results depending on how scientific and thorough each study was.

The cerebral palsy results were inconclusive, McDonagh found.

One problem with hyperbaric studies, she says, is that the treatment is so obvious it is difficult to develop a convincing placebo.

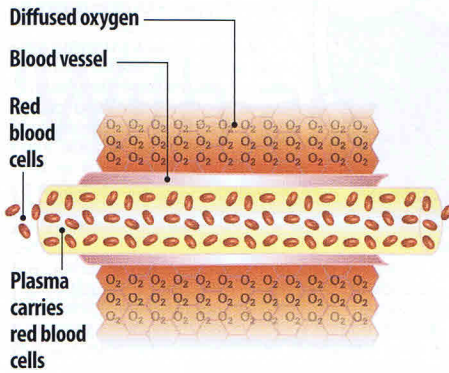
"A blind, randomized, controlled trial (is) the highest standard," she says, describing a study that includes a broad group of patients where each patient does not know whether he or she is receiving the actual treatment or a placebo, also called a control.

In the best hyperbaric study she and her colleagues found, the control group lay in chambers containing pressurized room air instead of just pressurized oxygen.

HOW HYPERBARIC OXYGEN THERAPY WORKS

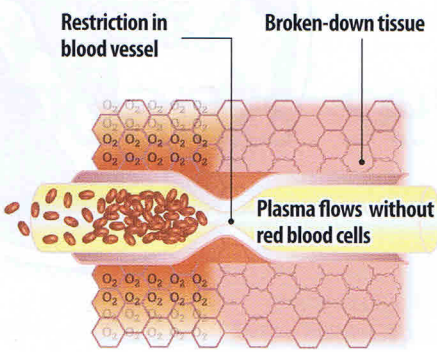
Normal blood flow

The air we breathe is about 21 percent oxygen. Red blood cells, which are suspended in plasma, carry oxygen through blood vessels all over the body. Oxygen gradually diffuses into the surrounding tissue.



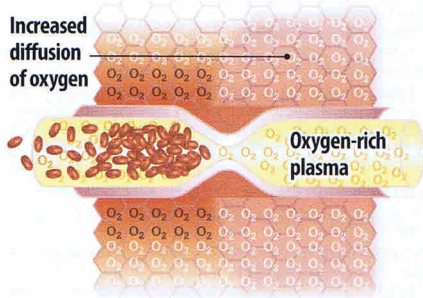
Restricted blood flow

Surgery, illness or injury may cause a restriction in blood flow. Plasma passes through but red blood cells are blocked. Without oxygen, the tissue on the other side of the blockage begins to break down.



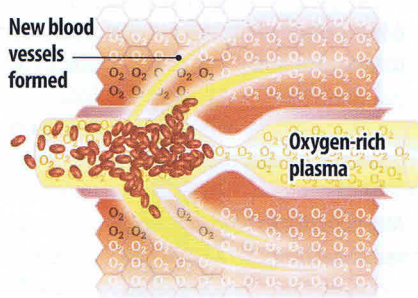
Hyperbaric oxygen therapy

Breathing a high concentration of oxygen under pressure causes oxygen to not only attach to red blood cells but diffuse into the plasma itself. This oxygen-rich plasma is able to travel past blockages, where oxygen may then diffuse into the damaged tissue.



The healing process

Tissue that contains a high concentration of oxygen is more likely to generate new blood vessels. Oxygen-rich red blood cells start to flow through these new vessels, delivering even more oxygen to the damaged area.



Source: www.hyperbaricworx.com, Bend Memorial Clinic

GREG CROSS

"The control group improved (their motor control) just as much as the hyperbaric oxygen group," McDonagh says of the study. "They both got better."

It is possible, she adds, that even pressurized room air yielded some benefits.

Better studies are also needed, according to McDonagh, to gauge risks. Patients, especially children, are prone to seizures and ruptured ear drums in hyperbaric therapy, although the rate of complication has not been clearly defined.

"All of the studies we found mentioned harms as an afterthought," she says.

McDonagh found other problems with existing research, too. Studies tended to test patients before and after treatment for changes in motor skills, for example, and define improvements as a positive outcome. But McDonagh found that the parents of cerebral palsy patients defined any improve-

ment whatsoever as a positive outcome.

"One mother said that her daughter smiled once after hyperbaric therapy. She had never smiled before and that, to this mother, was worth it," McDonagh says. "Well, how do you design a study to objectively measure outcomes when (any change) is considered a positive outcome?"

Funding is a major hurdle for hyperbaric studies. Oxygen cannot be patented, so there is little incentive for a drug company, for example, to invest in testing. McDonagh says she has tried to update her review on hyperbaric therapy research, but few new studies have been published in the past eight years.

BMC's hyperbaric unit is not a research facility, so off-label use there is not contributing to the body of scientific evidence. All five doctors in the unit are board-certified

Continued on Page 34

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Ashli Jones, 21, fainted at a track meet when she was 12 and was diagnosed with a heart condition three years later.

"I liked the idea of it because there are no medications, no risks of side effects, and it just seemed different."

Ashli Jones, who suffers from Postural Orthostatic Tachycardia Syndrome and looked forward to trying hyperbaric therapy at BMC

"We were fairly excited and, subsequently, fairly disappointed."

Dr. Michael Feldman, Jones' doctor

Continued from Page 25

in another specialty and are working toward board certification in hyperbaric medicine. When certified, the clinic will be eligible to participate in hyperbaric research.

In the meantime, BMC's off-label use of hyperbaric therapy goes against the recommendations of the American College of Hyperbaric Medicine, which discourages hyperbaric treatment of all non-approved conditions except in scientific studies.

Pinnick says he understands the theory behind that recommendation. But in practice, he says, it does not always make sense for individuals to wait for conclusive medical research.

"What if it works?" he says.

Disappointment

For 21-year-old Ashli Jones, it didn't. Jones was 12 when she fainted for the first time, during a track and field meet. The episode was dismissed at first. Jones had overexerted herself. And besides, doctors said, some little girls just faint.

Three years later, Jones was diagnosed with Postural Orthostatic Tachycardia Syndrome, or POTS.

When a person stands up, gravity pulls blood into the lower body. To adjust, the brain triggers a process that speeds up the heart, increases blood pressure and constricts upward-pumping blood vessels. When all goes well, it takes just two heartbeats to redistribute the blood upon standing.

When a person with POTS stands up, however, the upward-pumping vessels fail to constrict. The heart races and blood pressure rises. But with inadequate blood flow to the brain, the patient feels dizzy and light-headed.

There is no cure for POTS, but most teens and children with the illness outgrow it by their early 20s. Meanwhile, doctors treat the symptoms with various medications, exercise and custom-made compression stockings.

Today, Jones is 21 and her health is steadily improving. The worst part of the disease, she says, is the migraines that strike four or five times a week.

Jones takes classes at Oregon State University in Corvallis, but frequently travels to Bend to visit family. Whenever she drives over the

pass, she gets a migraine.

"Elevation is a big trigger," she says. "Flying, traveling by airplane, is not really an option for me because (my migraines become) terrible."

This gave Jones' doctor, Dr. Michael Feldman, an idea. Feldman is a kidney specialist. Although POTS does not affect the kidneys, Feldman was intrigued by one young patient who had severe symptoms and no doctor willing to treat her. He now has about 20 POTS patients.

"Many of them give a very similar story, which is that they seem to do better when they get out of Bend and drive to Southern California or some other place at sea level," Feldman says.

Because patients feel a slight improvement descending to sea level, Feldman reasoned, perhaps they would feel similar improvements in a hyperbaric chamber. Jones signed up right away.

"I liked the idea of it because there are no medications, no risks of side effects, and it just seemed different," she recalls.

She noticed a slight improvement in her migraines while she was in the chamber. But the headaches resumed as soon as she got out. Even after weeks of daily therapy, Jones noticed no other benefit. Another POTS patient tried hyperbaric therapy and felt a decline in her overall health.

"We were fairly excited," Feldman says of the experiment, "and, subsequently, fairly disappointed."

But BMC has enjoyed success with off-label treatment, too.

'It gave her a life back'

Summer Stiers was Pinnick's patient for almost 10 years until she died in June, at 32. She suffered seizures, eye swelling, intestinal bleeding, kidney failure and muscle atrophy. Doctors could not figure out what was causing her body to deteriorate. Last winter, specialists at the National Institutes of Health examined Stiers with the hope of eventually helping others. They believe she is the first person to suffer a particular genetic disorder, which has not yet been named.

Here in Bend, Pinnick used trial and error to manage her complex symptoms. "Summer was completely off-label," he says. "There was no label for Summer."

He noticed that biopsies revealed lesions as if Stiers' tissue had been irradiated. Pinnick does not believe Stiers was exposed, but he decided to try hyperbaric therapy, which is an approved treatment for radiation.

Putting Stiers in a hyperbaric chamber was not simple. One year ear-

lier, she had a nerve stimulator — like a pacemaker for the brain — implanted under the skin near her collarbone. Every three minutes, the device emitted an electronic signal that traveled along her vagus nerve and into her brain to prevent or disrupt seizures.

“Nobody with a vagus nerve stimulator had ever, as far as we know, been inside a hyperbaric chamber before Summer,” Pinnick says.

The high concentration of oxygen makes a chamber’s contents — especially metals and petroleum products — highly flammable. Patients must be careful not to wear makeup, lotion or jewelry, which could spark an explosion. The company that manufactured the nerve stimulator sent BMC one of the devices, which was placed inside a chamber and tested several times.

Stiers signed a long legal disclaimer and arrived at the clinic one morning in August 2008 to try the therapy. Her parents — adoptive father, Doug Ward, and stepmother, Kim Plummer — came, too. Pinnick and the technician were visibly nervous as Stiers climbed into the chamber.

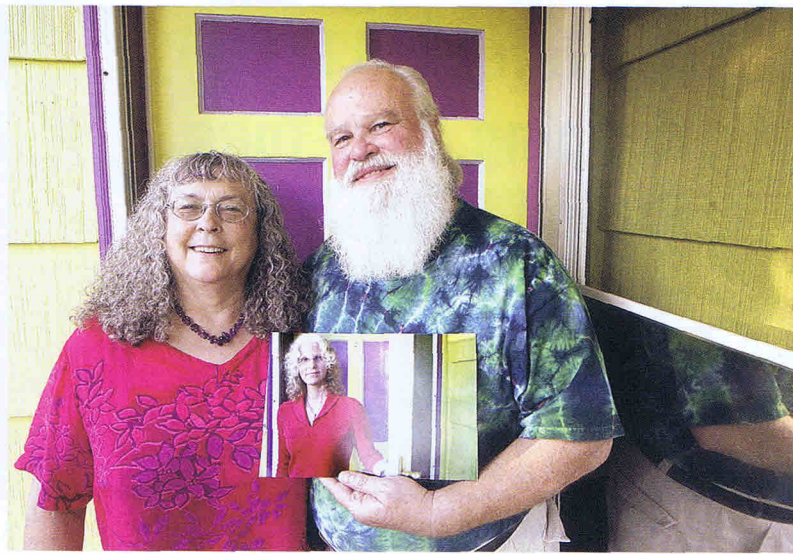
It went smoothly, so Stiers came back each day for about an hour. Within a week, the swelling in her eye was drastically reduced. Her vision improved. Her stamina and strength increased. At her weekly horseback riding lesson, Stiers could trot four times as far without her legs giving out. She could read the tiny print in paperback books again.

“It gave her a life back,” Ward says.

Then, in January, Stiers’ insurer, the publicly funded Oregon Health Plan, denied payment for more treatments. Stiers and Pinnick appealed the decision, claiming the therapy saved money by preventing the need for costlier procedures. In March, the insurer relented. But the month of therapy she missed coincided with a steep decline in her health that continued until her death in June. Stiers’ parents do not blame the missed treatments for Stiers’ demise. Her body was failing in almost every way, they say. And they remain grateful for BMC’s willingness to treat Stiers even though she did not meet the UHMS requirements.

“I think they look at (hyperbaric therapy) differently than other doctors,” Plummer says of BMC’s physicians. “They see its potential.”

Dylan Cain started hyperbaric therapy at BMC in early September. After a few treatments, doctors determined he needed ear tubes to ease the effects of the changes in pressure, said his mother, so treat-



Kim Plummer and Doug Ward are raising money in memory of their daughter, Summer Stiers, who died in June from an unknown genetic disorder. They hope to purchase a hyperbaric chamber that will be dedicated to charitable use.

ments were suspended for several weeks.

At first, the Cains are paying for the treatment out-of-pocket and through fundraising efforts. The charge for each of Dylan’s one-hour sessions is just more than \$500, according to BMC. Many patients have two-hour sessions costing twice that amount. The actual amount paid can vary depending on insurance negotiations. After an initial period of daily therapy, if the Cains see improvement, they plan to appeal to Dylan’s insurer, the Oregon Health Plan, to pay for more.

Ward and Plummer recently started a nonprofit in Stiers’ name. They aim to raise \$120,000 to buy a fourth hyperbaric therapy chamber for BMC, to be dedicated for charitable use.


“I’d love to see the chamber used not just for people who are uninsured or underinsured,” Plummer says, “but who have (conditions) that insurance companies do not recognize as being treatable with hyperbaric therapy.” ■

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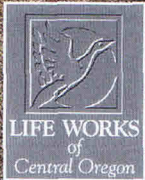
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