

JORDAINE'S STORY

Jordaine is a 5 year-old girl from Menasha, WI. She was diagnosed with Chiari Type 1 Malformation in March 2008. She had a brain operation in July 2008 to have this condition fixed. Chiari is a rare but common disease. Most people live with it not even knowing it is the cause of their headaches, nervous system problems, numbness in their arms and legs, or blurred vision. Chiari is a condition you are born with and goes unknown until it is found with an MRI. Chiari Type 1 Malformation is where the bottom portion of your brain is pulled out of the base of your skull. It clogs the flow of spinal fluid through your spinal cord. The average and most common chiari is 4mm in size, Jordaine's chiari was 28mm long. Meaning that 28mm of her brain had been pulled out of her skull and was blocking her spinal fluid from flowing properly. For children if the chiari is not treated soon enough they can develop paralysis, scoliosis, or many other nervous system problems. We are raising money through fundraisers to help Jordaine and her family with medical and travel expenses. We are also donating the remainder of the funds to the Chiari Research Center at The Children's Hospital of Wisconsin in Milwaukee, WI. Please help Jordaine reach her goal to help the doctors who are helping her and so many other children with this condition!!!

*Cracking
The Code*

JORDAINE'S
CHIARI BOWLING
BENEFIT

CONTACT INFO



JORDAINE'S
CHIARI BOWLING BENEFIT

DATE: October 26, 2008

TIME: Registration @ Noon, Bowling @ 1pm
Pre-Register by Calling 920-428-0448

WHERE: Sabre Lanes 1330 Midway Rd.
Menasha, WI. 54952

WHAT IS CHIARI?

There are thousands of people that go through life never knowing that they have Chiari and never experiencing any symptoms. Then there are those who have 2 or more of the symptoms and need an operation to try and relieve their pain and discomfort.

Definition: A serious neurological disorder where the bottom part of the brain, the cerebellum, descends out of the skull and crowds the spinal cord, putting pressure on both the brain and spine, and disrupting the normal flow of cerebrospinal fluid (CSF); also known as Arnold-Chiari, ACM, ACM I, ACM II, CM

If left untreated, Chiari can lead to the development of a fluid-filled cyst in the spine (syringomyelia) and cause permanent nerve damage and paralysis. Chiari is a complex disease which is poorly understood, and being diagnosed is an overwhelming experience. Patients are thrown into a whirlwind of medical jargon, tests, and surgery, all the while not knowing how things will turn out in the end.

CHIARI FACTS:

- ❖ Affects people of all races and ages; in fact, at least 30% of children born with spina bifida also are born with a Chiari malformation.
- ❖ Causes a wide ranging, diverse set of symptoms. Research has shown that 95% of patients experience at least 5 symptoms.
- ❖ Diagnosed using combination of MRI, neurological exam, physician's judgment, and other tests; patients often go 5 or more years before being properly diagnosed.
- ❖ A study of over 300 patients found that 57% had at one time been told by a doctor they were suffering from a mental or emotional problem.
- ❖ A world-wide survey of neurosurgeons found there is little agreement on how best to treat Chiari, leaving

9-PIN NO TAP BOWLING TOURNAMENT

1 OUT OF EVERY 1,000 PEOPLE IN THE UNITED STATES HAS CHIARI. If we raise \$1,000 in bowler registration each bowler will receive a free soda.

THERE ARE APPROXIMATELY 3500 CHIARI OPERATIONS DONE EACH YEAR IN THE UNITED STATES. Prize goes to every person that can raise 350.00 or more in personal contributions. (Must be turn in on the day of the event.)

THERE ARE 14 SYMPTOMS OF CHIARI. First 14 teams to pre-register by August 31, 2008. Get a free small (1 topping) pizza on the day of the event.

77 PEOPLE OUT OF EVERY 10,000 HAVE MRI FINDINGS OF CHIARI TYPE 1 MALFORMATION. Anyone with a score of 77 in the 7th frame of the 1st game wins a prize.

THERE ARE 4 KNOWN TYPES OF CHIARI. First person with 4 strikes in a row during each game wins a prize.

MOST PATIENTS GO 5 OR MORE YEARS BEFORE BEING DIAGNOSED WITH CHIARI. Anyone with a 500 series wins a prize.

patients in the position of having to put total faith in their doctor.

- ❖ Many physicians are not familiar with the latest findings, so treatment plans may be based on old, inaccurate data.
- ❖ Many patients undergo traumatic surgery in an attempt to relieve symptoms or stop them from progressing.
- ❖ Research has shown that surgery can improve symptoms for about 80% of patients, but fails 20% of the time; some patients end up in chronic pain, on disability, socially withdrawn and depressed.
- ❖ Chiari can place a tremendous physical, mental, emotional, and economic strain on patients and their families.
- ❖ *Chiari Affects Everyone Differently*

JORDAINE'S CHIARI BOWLING BENEFIT

\$10 per person up to 6 per team!!! All net proceeds go to benefit The Chiari Research Center in Milwaukee, and to help a local 5 year old girl. Please come and join us, learn a little about a rare disease and have a great time!!! Jordaine hopes to see a lot of people there to help the hospital that is helping her, and many others!!!

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Bowling at 1pm
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BOWLER INFORMATION

Each team may have up to 6 players. You may use the form below to fill out the names of each player on your team or you may pick up a form at the bowling tournament. Thank you for your participation.

Player One: _____

Player Two: _____

Player Three: _____

Player Four: _____

Player Five: _____

Player Six: _____

WE HOPE TO SEE YOU THERE!

For more information, please contact XXXX
Phone: [Phone number]
email: [Fax number]
E-mail: [E-mail address]

