

McCallums hoping to improve son's way of life with a trip to Germany

Written by Chris Lee

It began with an article found in a Kansas newspaper in August. Now, members of the Gary and Andrea McCallum family are hoping to be in Düsseldorf, Germany in a little more than four months to help their son Blye undergo a stem cell treatment.

“My husband and I haven’t been able to sleep since we found out about this,” Andrea said. “It’s about to drive us both crazy because our heads just don’t stop spinning.”

Five-year-old Blye McCallum was born April 26, 2005 at Melissa Memorial Hospital. His stay in Phillips County didn’t last more than four hours before he was taken by Flight for Life to Children’s Hospital in Denver.

Upon arrival, it was found he had a subdural hematoma and a subgaleal hematoma. As a result, Blye was experiencing seizures and in order to stop them, was given phenobarbital. The treatment was effective and McCallum was able to return home with his parents.

Four months later, Blye began to get sick and was taken back to Children’s where he stayed for a week. During this second stay, he was diagnosed with cerebral palsy.

Cerebral palsy is an umbrella term encompassing a group of non-progressive, non-contagious motor conditions that cause physical disability in human development, chiefly in the various areas of body movement.

Five years later, Blye has become known by many around Holyoke and just began kindergarten. “He loves it,” Andrea said. “It’s been great.”

After reading the article in the Salina Journal about a child who traveled to the XCell-Center in Germany and had success, it didn’t take long for Gary and Andrea to think about it for Blye.

“I just started bawling,” Andrea said, after reading the article. “If this little boy can go and have this done, and have the possibilities of reaching for things, talking or his muscles not being as tight, it’s huge.”

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A website for the XCell-Center was listed within the article, and that is where the McCallums began their research.

Andrea called Blye's doctors to find out what they thought about the procedure and the next thing she knew, they were filling out an online application—one Andrea said was very detailed and in-depth.

Not even a month after the McCallums had submitted the application, they heard back from an XCell-Center contact in Houston, Texas informing them Blye had been approved for treatment of CP by lumbar puncture or endoscopy.

Along with the location in Düsseldorf, XCell-Center also has a clinic in Cologne, Germany. Since Blye is under the age of 18, Andrea said they have to go to the Düsseldorf location.

Andrea said there are many positives for choosing XCell-Center. One of the bigger ones will be no risk of Blye developing Graft vs. Host Disease (GVHD). This is possible any time a stem cell transplant involves a donor and a recipient such as with cord blood, fetal or embryonic stem cells.

"It wasn't as hard of a decision for Gary and I to make," Andrea said knowing the procedure would be autologous.

XCell-Center utilizes each patient's own (autologous) bone marrow stem cells so they have no risk of developing GVHD.

One of the perks of the trip will be Blye will not have to spend the night in the hospital. The entire procedure will be an outpatient one. The schedule is set to where the McCallums can go and rest in the hotel after therapy each day.

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The process will begin with blood tests, a physiotherapy consult and bone marrow collection on the first day. The following two days will entail lab processing and cell implantation.

The final day will be a mandatory rest day. Andrea said there is a risk of a spinal headache. The rest day will help decrease that chance.

Andrea said Blye is at the age where he is starting to get the white coat phobia. She said she talks to him before going into hospitals and it helps a little bit. Staying in the hotel instead of the hospital will be a big positive.

So, what will be different with Blye after the procedure has been completed? That's a good question. Andrea said they just don't know what to expect. Each child is different when it comes to the stem cell process.

Some of the families Andrea has been talking with saw changes with balance and motor skills. One boy even began walking on his own a little bit. Another child began saying words rather than the usual mumbled noises.

Andrea said they feel Blye is so close to talking and tries really hard. "You just feel like it's almost there, it's just on the tip of his tongue," she added.

Andrea noted all children are full-time jobs, but children with special needs need even more attention. She said it would be great if after the procedure, she could step back and say "look at what my kid is doing." Not having to be his arms and legs all the time would be somewhat of a relief for Blye's parents.

"We would love for him to run off the plane and just talk," Andrea said. "But our expectations are for him to just have something. Whether it is an ease in his muscle tightness or something else."

If the McCallums do see progress, there is always the option to go back for another round of

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therapy. They are hoping to have an MRI done before the trip and then roughly a year after the treatment to see any improvements.

One of the families Andrea has been talking with lives in Chappell, Neb. "It's been awesome to talk to them because we are looking at the same thing for us," Andrea said. "It's nice to be able to know what you're getting into."

Andrea nearly teared up thinking about all the Chappell family has gone through with their daughter Kendra, knowing she and her family have gone through the same thing. Kendra and her family are currently in Germany having her treatment done.

The McCallums are tentatively scheduling to leave Feb. 1, 2011 and arrive a few days ahead of time to adjust to the time change and do a little sight-seeing. They will also stay a few days after to make sure Blye recovers and is ready for the flight back home.

Appointments at the clinic in Düsseldorf can only be scheduled three months in advance—something Andrea said is very frustrating. She noted their contact in Texas said there shouldn't be any conflict with the February dates but won't know for sure until about three months out.

One of the concerns is Blye's ability to endure the long plane trip to Germany. Andrea said they will be speaking with their neurologist to see if there is anything that can be done to keep him comfortable during the flight. Andrea's parents, Paul and Sheila Gift are planning to travel with the McCallums for support and help.

Andrea said the trip probably wouldn't be possible if it weren't for her parents.

In a perfect world, Blye and family would be on a plane next week, but instead they are forced to wait. Andrea didn't want to try to take Blye through an airport during a busy holiday season so that is why February is tentatively scheduled.

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Andrea said she has been in contact with a couple different families who have gone or are planning to go to Germany for similar treatments. After talking with them, they each suggested the McCallums try to raise around \$25,000 to cover costs. Blye's procedure alone will run around \$13,000. The cost of airfare and other expenses will also need to be raised.

Gary and Andrea have set the goal of \$25,000 to have raised by the time of their trip.

The McCallums are planning a couple different fundraisers thus far and have dubbed the project "BlyesQuest." The first project will kick off right away with "Bushels for Blye."

Orange fliers will be placed at multiple Grainland locations and farmers will be given the choice to donate a portion of any grain to Blye. One hundred percent of proceeds from each donation will be deposited directly into an account set up at First Pioneer National Bank.

Plans are also in the works for a benefit to be held at Phillips County Event Center Friday, Nov. 12. A dinner by Allyn Robinson will be offered as well as both regular and silent auctions.

Andrea said donations both for the benefit and regular donations will be kindly welcomed. For more information on BlyesQuest contact Andrea at 466-0864.

Donations for BlyesQuest may be made out to Blye McCallum Benefit and sent to First Pioneer National Bank in Holyoke or Zion Lutheran Church.

For more information on the XCell-Center in Germany, visit www.xcell-center.de.

"It's a quest," Blye's mom said. "We're going to try and find him some freedom and give him that better chance of improving his life."