By Bill Kirk

SPRING VALLEY—Expectant mothers can be forgiven if they haven’t heard of Intrahepatic Cholestasis of Pregnancy (ICP).

Hilary Boyer, who’s devoting time to spreading the word about ICP, said Thursday a lot of physicians didn’t even know about it when she learned firsthand. And among those who did, there was a misconception it didn’t need to be treated.

The liver condition unique to pregnancy affects approximately one in 1,000 pregnancies in the U.S., but more where there are high Latino and Scandinavian populations, such as this region for the latter, she said. Her experience with the condition led to her becoming active in ICP Care, a national organization whose leader from Miami lost a baby to it.

“As a three-time ICP sufferer, I am committed to raising awareness for this deadly disease,” the Spring Valley native said.

Boyer encourages expectant moms to go to their doctors and ask to get a fractionated bile acid test, though these are still processed at only a relatively few labs in the country. The test will signal the presence of ICP, but she cautioned outcomes can be normal initially, so the testing should be repeated if there are symptoms.

The ICP Care group was previously called “Itchy Moms,” and that’s one of those symptoms, she said, noting there’s no accompanying rash. In her own case, the itching with her daughter Sydney, her firstborn, was so extensive she shared about it with a pregnant friend. Teaching biology at Spring Valley Schools at the time, she told a fellow teacher when both were attending a conference.

“She said she’d been itchy, too, so I didn’t think a lot more about it,” she said.

Then came the serious pain in her liver, Boyer said. Originally, the thought was it could be the baby, pushing on that organ.

She now recognizes it was ICP. The liver filters out a lot of toxins in the blood, she explained. Bile is produced in the liver’s cells, which is transported out to the digestive tract. Unfortunately, ICP interferes with that process.

“The toxins get backed up,” she said, adding not only is that the situation with the mother, but the baby, too. Yet, the baby can’t do this processing and is relying on mom for it.

Unaware of ICP when her daughter was born, Boyer coped until 41 weeks of her pregnancy, when distress set in and she had to be induced, she said. Fortunately, the girl was born otherwise healthy.

Pregnant with her first son, she was so sick she couldn’t gain weight (another symptom), she said. Meantime, at approximately 33 weeks, she was itching so bad, she couldn’t sleep.

“I finally scratched my skin right off,” she said, frustrated with the itching’s relation to her pregnancy hadn’t been confirmed.

Boyer said her sister, Dr. Amaris Moore of Spring Valley, was the first to diagnose her condition after doing some significant research (she also has a brother, Cyrus, of Madison). At the outset, her sister advised bringing it up

— SEE BOYER 5A —
Hilary Boyer held two-year-old son Lucas at the family’s home in Spring Valley last week. Boyer suffered from Intrahepatic Cholestasis of Pregnancy (ICP) during her pregnancy with him, with son Alec, now age five, and daughter Sydney, now eight. However, her condition wasn’t diagnosed until she was expecting the second of those children. (Herald photo by Bill Kirk)
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during the next doctor’s visit, but after consulting with a specialist, insisted she go to the doctor immediately. She managed to get the bile acid test done and it was found her liver function was elevated.

ICP makes the uterus more sensitive to contractions, she and her sister learned. Soon thereafter, she entered pre-term labor. Attempts to stop it failed and she was transported by ambulance to a Twin Cities hospital, going into labor three times before finally getting it stopped.

A medication—Ursodeoxycholic Acid—was given to her to lower the bile acids, protect the baby’s heart, reduce aging in the placenta and help with transporting the bile from the liver to the digestive tract—all affected by ICP, she said. She was back home on bed rest, then it was arranged to deliver at 36 weeks Alec, who arrived healthy, weighing six pounds, 14 ounces.

ICP is a temporarily reversible condition, confined to the boundaries of pregnancy, Boyer said. Although older women are slightly more likely to develop it, it can happen to any. The likelihood increases as estrogen and hormones interfere, so its occurrence rises if progesterone injections are administered for multiples, for example.

“In 60-to-90 percent of cases, it will happen in future pregnancies,” she said.

Boyer said her husband, Tom, a 9-1-1 dispatcher for St. Croix County, paramedic for the Ellsworth Ambulance Service and Spring Valley firefighter, hesitated about the couple having a third child, based on her history with ICP. She persisted, only to lose 20 pounds, ultimately almost unable to move, hardly sleep and ending up in the hospital.

“It was 10 times worse than before,” she said, remembering by 34 weeks of her third pregnancy, it felt like every one of her joints was going to explode.

While there was no preterm labor this time, it was determined she’d deliver at 35 weeks, she said. However, a test showed the baby’s lungs weren’t mature, so two more days were spent before the delivery. On top of that, her son had a breached birth.

To Boyer’s dismay, he was born non-responsive despite aggressive management of her condition and was airlifted to Children’s Hospital.

“I am lucky that my worst ICP story had a happy ending, and he is now a happy, healthy two-year-old, but not everyone is so lucky,” she said.

“My position with ICP Care has allowed me to bring help and support to thousands of women around the country and around the world, to receive the proper care and medicine they need to bring their babies safely into the world,” said the member who joined after the birth of Lucas, started as a moderator and has since advanced to support group manager.

“Our number one goal at ICP Care is to raise awareness to help recognize the symptoms and understand proper management,” she said. “The good news is that, with proper management, the risk of stillbirth associated with ICP is similar to that of an uncomplicated pregnancy.”

In addition to stillbirth, pregnant women run the risk of complications including preterm delivery, respiratory distress syndrome, fetal distress and arrhythmia if left untreated for ICP, she said. ICP Care has approximately 1,300 members, is largely an electronic entity (“a Yahoo! Group”) and she personally answers at least 25 posts on an average day. There are also private and Spanish-speaking groups, and she’s aware of several women in this vicinity who’ve had ICP besides herself, most recently someone in New Richmond who gave birth earlier this month.

The ICP activist has stopped teaching in public schools, but operates a kennel with her spouse, she said. They met when both were in high school and he transferred from Cottage Grove, Minn., to Spring Valley. They were married in 2002 and live on acreage from the Century Farm of her parents, Kevin and Valerie Anderson.

Boyer recommended people interested in more information visit icpcare.org.