

Bense Family

From: Constant, Patti (MDH) [Patti.Constant@state.mn.us]
Sent: Monday, February 25, 2013 12:51 PM
To: Undisclosed recipients:
Subject: FW: Celebrate 50 years of Newborn Screening/National Kick-Off
Attachments: Invitation.pdf; Share a Story.pdf

Dear Friends of the Minnesota Newborn Screening Program –

Please join the Minnesota Department of Health's Newborn Screening Program for a celebration of 50 years of Newborn Screening. A traveling display from the Association of Public Health Laboratories (APHL) will make Minnesota its first stop on a thirteen state tour in 2013 celebrating the life-saving role of newborn screening. We invite you to join us in the Great Hall of the State Capitol on Friday, March 8 from 11:00am -12:30pm. There will be a short program starting at 11:30am with special guests to include MDH Deputy Commissioner Jim Koppel, Korissa Olson (mother of Everett, 4), and Evan Hromada (a Marquette University Freshman). Both Everett and Evan were born with Galactosemia and thanks to Minnesota's Newborn Screening Program and its partners, were identified early and treated so that they avoided disability.

The APHL display will also will be on exhibit:

- At the Minnesota Department of Health March 4-6 along with a historical presentation of Newborn Screening.
- At the 2013 Early Hearing Screening Detection and Intervention / Birth Defects Conference for Local Public Health Professionals on Thursday March 7.
- In the lobby of the Science Museum of Minnesota from March 9 – March 14. Bring your families to see it and spend some time at the Museum!

We hope to have as many parents, families, partners, and stakeholders at this celebration as possible. Help Minnesotans understand the importance of Newborn Screening and the difference it can make. Attached you will find an official invitation – please share it with others that may be interested as all are welcome.

We encourage families to bring their children. Because there will be a press release and media involvement, if you know families and/or providers that would be willing to share their story of how newborn screening impacted their lives, please share the attached information "Share a Story" as appropriate. We are hoping to be in contact with a few families that would be willing to share their story.

On behalf of the Minnesota Department of Health's Newborn Screening Team we look forward to celebrating 50 Years of Newborn Screening with YOU at the Capitol.

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Join us in celebrating ^{11:30 am} ^{12:30 pm}

50 years of saving babies' lives through Newborn Screening

Please join us on March 8, 2013 at the State Capitol to share in the celebration of Newborn Screening's 50th anniversary. View a touring display and listen to personal stories of how Newborn Screening has affected the lives of individuals here in Minnesota.

Date: March 8, 2013

Time: 11 am—12:30 pm (Speakers will begin at 11:30 am)

Location: Great Hall in the State Capitol

The APHL 50th anniversary display will also be available for viewing at the Science Museum of Minnesota from March 9 to March 14.





WHEN 1 IS THE BIGGEST NUMBER

Everett's Story

Korissa Olson is a model mom. She feeds her family organic food, exercises every day and performs in a professional gospel singing group.

Her son, Everett, was born April 14, 2008, in Minneapolis' North Memorial Hospital. It was, said Korissa, "a great pregnancy" and "a perfect textbook delivery," with no drugs, no complications.

"I felt great, and Everett was beautiful," she said.

But when a nurse asked Korissa about newborn screening, she said, no.

Someone had handed her a flier after church one day, discouraging the practice. "I'm an educated person," said Korissa. "I was reading up on vaccines, on food for newborns, on caring for a newborn. But you

don't think about newborn screening when you're pregnant. I just filed [the information] in the back of my head. I really didn't have time to research it, and there are no known genetic disorders in my family."

But the nurse came back a second time. And then a third. "She gave me a brochure," said Korissa, "and I read it, and I realized that this is not an invasive test. They're not putting anything into my baby's body, they're just taking out a few drops of blood." She said, "I have a strong belief in God, and I just knew right then and there that I was gonna have this test."

Soon afterward, Korissa and her husband took Everett home, a seemingly healthy baby boy. But at his first health check-up four days

later, Korissa said, "My pediatrician sat me down right away and showed me this paper from the Minnesota Department of Health with the word *galactosemia* on it. She told me Everett had tested positive for this disorder."

The pediatrician advised further testing to confirm the result. In the meantime, she said, Korissa should stop breastfeeding, since babies with galactosemia lack the enzymes needed to digest the milk sugar galactose.

"I felt very strongly about breastfeeding," said Korissa, "so it was really, really hard. Then I read *cataracts, brain damage, liver failure, learning disabilities*. I was overwhelmed. I thought surely it was a false positive; he looked so healthy."



Korissa went home and did her own research. “I realized how serious it was,” she said, “so I did stop breastfeeding.” The very same day, Everett got sick.

“He became instantly lethargic, his eyes rolled to the back of his head. I called the pediatrician and said, ‘I just can’t wake him up.’”

Everett was admitted to the neonatal intensive care unit with severe jaundice, a problem routinely treated by giving babies fluids, including breast milk. But because Everett was suspected of having galactosemia, doctors knew breast milk could be fatal.

The newborn screening result,

said Korissa, “saved our little Everett’s life.”

Everett was discharged three days later; and two weeks later, Korissa and her husband received confirmation that their son had the most severe form of galactosemia.

“It was hard at first,” said Korissa, “but I think we were very, very blessed. Untreated galactosemia has a 75% mortality rate, but we had an early diagnosis. I’ve actually called the nurses back and thanked them over and over again [for encouraging newborn screening].”

Everett, for his part, is now a “sparkly” four-year-old who loves people and loves to play. He has,

said his mom, become a “spokes-tot” for newborn screening, appearing in *Parents* magazine, on the cover of *Minnesota Medicine* and with Korissa at legislative hearings. Other than minor speech problems and a galactose-restricted diet, he looks and acts “very normal.”

Said Korissa, “Galactosemia only affects about one in 60,000 babies. You think, *that’s not going to happen to me*. But when your baby is the one, one is the biggest number.”

She said, “I wake up most mornings thankful that Everett had that test. My life—and Everett’s life—would have been so very different without it.” •

In 2008, the Minnesota Public Health Laboratory Division screened 71,636 infants. Eight were diagnosed with some form of galactosemia, including Everett.