

# Indiana Deafblind Services Project

## DEAFBLIND FOCUS

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## Sami's Story

by Mary Knoy

When Don and I married almost 42 years ago, I knew our marriage and the birth of our children would be among my greatest blessings. When our grandchildren came along, it was the icing on the cake. But, unbeknownst to me, God had saved a most unusual gift. It all began a few years ago when Don and I decided to begin fostering. Since that time we have cared for nine beautiful children. The last four have had special needs.

Sami was born with both a cleft lip and palate. She was transferred to Riley Hospital for Children in Indianapolis at two days old. The doctors learned Sami has CHARGE Syndrome, a genetic condition which, for Sami, included complex congenital heart disease, profound hearing loss, blindness, asthma, sleep apnea, brain atrophy, developmental delays, and dysphasia. Because food goes straight to her lungs, Sami left the hospital with an NG-tube. She was discharged to our care after seven weeks in the Newborn Intensive Care Unit.

As I write this, Sami is 27 months old. She has endured cleft lip and palate repairs, surgery on her nose, three major open heart surgeries, two pacemaker surgeries, and a cochlear implant operation. In fact,

she has had 15 different surgeries and spent a total of 98 nights in the hospital.



*Sami smiles for the camera.*

We knew Sami had "complications" as we spent two days cuddling and rocking her at the hospital prior to her release. But it was only about an hour before leaving Riley that we were given all the grave details. It did not matter. We had already fallen in love with her.

Following Sami's second open heart surgery in October, 2009, her surgeon told us Sami's heart is "unique" in that all the parts are there, but not all in the right places. I think it was that day, when we learned they almost lost her during surgery, that I realized how much I love her.

Even then we had no idea God would ask us to adopt Sami. But about 10 months after we took her home, her birth parents decided

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## What is CHARGE Syndrome?

CHARGE Syndrome is a complex genetic condition found in about 1 in 10,000 births. The cause of CHARGE Syndrome is most often a mutation in the CHD7 gene on chromosome #8. Although it is a genetic condition, it usually does not affect other family members.

"CHARGE" is an acronym in which each letter refers to an associated condition. CHARGE stands for **C**oloboma, **H**eart defects, **A**tresia of the choanae, **R**etardation of growth and development, **G**enito-urinary, and **E**ar anomalies and hearing loss.

A diagnosis of CHARGE Syndrome is made by using Major and Minor clinical features or by finding the mutation in the CHD7 gene. For more information, visit [www.CHARGESyndrome.org](http://www.CHARGESyndrome.org).

(Charge Syndrome Foundation, 2011)

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they could not meet all her medical needs and asked us if we



*Sami loves the ball pit!*

would keep her. After praying, talking it through, and waiting for God's answer, we told them we would love to adopt Sami.

Sami has colobomas that affect the optic nerve and retina in both eyes. We were told Sami would never see more than light and shadows. The ophthalmologist specifically pointed out that there were no surgeries, exercises, glasses, or treatments that would ever help her see. We were handed information on the Blind School and told to come back in a year. I bit my tongue so I wouldn't say, "What for? You have already told us you can't help her!"

We went to God for help, especially for Sami's sight. A year later we were thrilled when the ophthalmologist admitted Sami was seeing much more than was ever thought possible! Still, Outreach personnel for the Blind School believed Sami could see her hands, but probably not individual fingers. So we asked everyone to keep praying.

The colobomas were like taking a "slice out of a pie" at the back of the eyes. They are still there. And

even though the ophthalmologist told us at our last visit that Sami had virtually no sight in her left eye, Sami sees well enough with her right eye, the doctor believes, to read! That is a long way from seeing only light and shadows! Soon Sami will return to the ophthalmologist. We can hardly wait! We have noticed the left eye has begun tracking with the right!

We were told Sami has profound hearing loss in her left ear and severe to profound hearing loss in her right. Riley audiologists tried hearing aids, but even after turning them up all the way, we saw little to make us think Sami heard. Finally, it was decided to try a cochlear implant in her left ear because "there was simply no hearing to lose."

Sami's surgery was January 18, 2011. They activated the cochlear implant on February 15. We are currently in the process of gradually increasing the volume and working with pitches to see at what setting Sami may hear best.

We don't know how much hearing Sami will have in the end or if another cochlear implant will be required. Our hope is that one day Sami will be able to communicate orally. We are

working with Oral Deaf speech therapists plus Outreach from the Indiana School for the Deaf and receive consultation through the Deafblind Project. We are learning American Sign Language, and Sami already knows several words in ASL.

A developmental pediatrician told us Sami would never be able to learn more than 33% of what others learn due to her brain atrophy. Between that and the diagnosis from the ophthalmologist we were fighting depression. But we chose to believe Sami would do better than that. We continue praying. We ask others to pray. We take advantage of every means to help her. And we take it one day at a time.

Though behind other children her age, we know Sami is learning. She is just beginning to walk with assistance. But she recently learned to crawl! She can almost stand alone! She scoots on her back, sits up well on her own, rolls over either direction, and responds to people. Not long ago we learned that Sami's head circumference, which was previously too small to even be rated on the medical charts, has, for the first time, reached the fifth percentile. Her developmental pediatrician explained to us this means her brain activity is increasing.

Our answer to those who are negative is simply, "If you were

*"... we chose to believe Sami would do better than that . . . We take advantage of every means to help her. And we take it one day at a time."*

thrown into a place where you didn't know anyone, didn't know the language, couldn't hear, couldn't see, and had to spend an average of one out every nine days hospitalized, would you be able to adapt to that new place as quickly as someone else with all their faculties?



*It's time to play!*

Beyond these things Sami's other problem is not being able to swallow without experiencing silent aspiration. We pray that one day she will be able to eat by mouth, at least in part, but, for now, we are grateful a G-tube sustains her.

We believe God is letting the doctors take care of those things He has given them the abilities to handle. And we believe He is dealing with the rest, specifically, her sight and brain atrophy. We do not know how far God will take Sami. But we know we can trust Him to use her life for good and to take care of her. No matter what, we love her!

If we could give other parents facing similar issues one piece of advice it would have to be:

Remember that only God knows what your child will be able to accomplish. Never give up. Stay positive. Celebrate every victory. Enjoy your child. Pray. And give God the glory. Your child will be able to affect people in a very special one-of-a-kind way.

Sami continues to amaze her doctors and therapists. Some did not expect her to live this long. Some thought she would never see. Some believed she would be unable to learn. Some cannot imagine that she is so personable and interactive.

As for her daddy and me? We look at her and realize God has given us a wonderful giggling gift. She is a blessing . . . our own little miracle. Sami is our daughter.



The *Indiana Families of Children and Young Adults with CHARGE Syndrome* Facebook Page recently launched. It is located at: <http://www.facebook.com/pages/Indiana-Families-of-Children-and-Young-Adults-with-Charge-Syndrome/150844731679382>. The page is intended as a place for Indiana families to discuss concerns, share resources and find ways to support each other and their children who have CHARGE. We hope that new families will join the group and the page will become a frequently used site for ongoing discussions!

## Indiana Families Learn about CHARGE Syndrome

In September, the Indiana Deafblind Services Project sponsored a statewide workshop for families of children and young adults who have CHARGE Syndrome. Dr. David Brown (California Deaf-Blind Services), a noted expert who has worked for many years with children and young adults with CHARGE, was the speaker.

During the weekend, Dr. Brown focused on issues faced by individuals with CHARGE Syndrome and their families. Topics included: Sensory Issues, Behavior and Self-Regulation. In addition, Dr. Brown spent time talking with families individually, to better address their concerns and questions.

While the conference was intended primarily for Indiana families, the Indiana project was able to open the conference to families in neighboring states. Conference participants included seven families from Indiana, two families from Ohio, and one family from Michigan.

In addition, the Indiana families met to share information, their concerns, and to discuss how they might support each other in the future. Plans were made to develop a family group for Indiana CHARGE families. Members of the group would keep in touch with each other, provide support, discuss problems/concerns and periodically help sponsor family events. For more information, please contact: Lisa Poff at [Lisa.Poff@indstate.edu](mailto:Lisa.Poff@indstate.edu) or call 1-800-622-3035.

# Upcoming Events

**April 20-22, 2012**  
**Indiana Deafblind Services Project Family Leadership Training Program - Weekend 2 Indianapolis, IN**

For questions, contact Lisa Poff at Lisa.Poff@indstate.edu or 1-800-622-3035.

**July 20-22, 2012**  
**NFADB Deafblind Symposium on Family Leadership**

For more information, contact Lisa Poff at Lisa.Poff@indstate.edu or 1-800-622-3035.

**May 28, 2012**  
**CHARGE'd-Up for Golf on Memorial Day**  
For more information, contact info@chargesyndrome.org or call 1-800-442-7604.

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