

# COME UP WITH A PLAN

# SPINA BIFIDA CLINICS

ON YOUR DIAGNOSIS DAY:  
Spina Bifida Families Are Here for You

WRITTEN BY MEREDITH BARNES

Now that you know your baby has spina bifida, you'll want to come up with a plan to start to get answers to all of the questions you have.

It is important to pick a specialized medical team that has experience with spina bifida. Indiana is home to one of the largest spina bifida programs in the U.S., so you're lucky to be here. You'll develop a strong relationship with your medical team. Over time, you'll consider them like family.

Many families choose their medical team based on proximity to where they live and their health insurance coverage. Find out if there are multiple medical providers in your area. Go with the one that feels like the best fit.

Spina Bifida Indiana will provide you information on services offered at various spina bifida clinics and hospitals. For example, not all clinics perform fetal surgeries. Your medical team will help you decide if prenatal surgery (often referred to as fetal surgery or FS) or postnatal surgery makes the most sense for you, your family, and your child. Please know that time is of the essence if you're considering doing prenatal surgery. It requires a significant amount of testing prior to surgery and in most cases must be done prior to 26 weeks gestation.

You'll have very many questions for both your medical team as well as for other parents who have experienced similar situations. Please reach out for support from SBIND, other spina bifida families, or Facebook groups. You're not alone. Spina bifida families of Indiana are a community amongst themselves. We'll offer you support and guidance. We're one big family and always here for one another.



## Kentucky

### Norton Children's Hospital

231 E. Chestnut Street  
Louisville, KY 40202  
502-637-7363\*  
\*SBA of Kentucky will direct you to the appropriate contact.  
Ages served: 0-18

## Ohio

### Cincinnati Children's Hospital Medical Center

3430 Burnet Ave.  
Cincinnati, OH 45229  
513-636-8059  
Ages served: 0-Transition

### Riley Hospital for Children at Indiana University Health Pediatric Spina Bifida Clinic

705 Riley Hospital Drive  
Indianapolis, IN 46202  
317-944-2353  
Ages served: 0-18

### Riley Hospital for Children at Indiana University Health Adult Spina Bifida Clinic

705 Riley Hospital Drive  
Indianapolis, IN 46202  
317-944-7458  
Ages served: Adults



## Illinois

### Ann & Robert H. Lurie Children's Hospital of Chicago Spina Bifida Clinic

2515 N. Clark St.  
Chicago, IL 60614  
Phone: 312-227-5340

### Shriners Hospitals for Children - Chicago

2211 N. Oak Park Ave.  
Chicago, IL 60707  
Phone: 773-622-5400, 800-470-0232

### University of Chicago Margaret Hackett Family Program in CNS Congenital Anomalies Duchossois Center for Advanced Medicine - Hyde Park

5758 S Maryland Ave  
Chicago, IL 60637  
Phone: 773-795-0622

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See the Spina Bifida Indiana (SBIND) website for further information: [www.sbind.org](http://www.sbind.org).



THANK YOU TO:  
American Legion  
Child Welfare Foundation



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## DID YOU JUST RECEIVE YOUR BABY'S SPINA BIFIDA DIAGNOSIS?

## A WISH LIST FOR YOU

### MOM TO MOM

"Breathe. Just Breathe. You will get through this. Lean on people close to you. Let them help you. Facebook groups are a great source of information and collaboration with other spina bifida parents both new and seasoned. We're one big community. My son with spina bifida changed my life, your child will too. For the better. Just breathe."

-LINDSAY TROHA

"When we received our son's diagnosis, I wish we would have been told that our son would bring happiness, love, and compassion to our family. I wish we were told that even though some days will be difficult there will be many more beautiful days together."

-ARISA MIDGET

"Remember that you are pregnant with a baby that was the same baby as before you found out they had spina bifida. Allow yourself to grieve, and then come up with a plan to move forward. You are now part of the spina bifida extended family! Such an amazing group of people who will support you on your best and worst days! Welcome and can't wait to see you and your baby around really soon!"

- MEREDITH BARNES

"At 19 weeks, when we found out our son had spina bifida, we felt a whirlwind of emotions. As first-time parents, we were already incredibly nervous. Receiving the diagnosis certainly threw us a curveball. That curveball, however, brought out strength and bravery in us that I didn't know we had. If only I knew that now. Our son has been the most wonderful blessing and has brought us so much happiness that there aren't words to describe it. He is strong, so resilient, and every day he continues to amaze us. Take things one day at a time, follow your gut, and know that your baby will be amazing."

-AMY VAKHARIA DAPSIS

"While you're thinking life will be tough, it will never be too hard to love your precious baby. Your child will amaze you in so many ways and all the work will be worth it in the end."

-CARLA RAFFERTY

"It is okay to feel every emotion, including guilt, but none of this is your fault, and I promise there is a silver lining. Your child is going to surpass all your expectations in ways that you have never imagined."

-KATIE ROGULICH

"At the end of the day, our kids are just kids and NOT their diagnosis. They may have spina bifida, but IT WILL NEVER HAVE THEM!"

- DANA STANKO

WRITTEN BY: REBECCA RUPNICK

I was you. I am you. I'll forever be you. I wish with all my might I could take you by the hand and guide you into your future and show you the beauty of life that is about to begin.

On the four-year anniversary of my daughter's d-day (diagnosis day) of spina bifida, I'm able to reflect on the experience in a positive manner. But I'll forever remember her d-day. I was sitting in the doctor's office crying, flooded with anxieties and drenched in fears and mourning the loss of a healthy child. Today, with a new mindset and a beautiful four-year-old I see our d-day as the day my life was given a purpose — not only to raise an astounding daughter, but also advocate for spina bifida awareness and form support groups for parents of children with spina bifida.

As you listen to your doctor tell you statistics about your child's condition, understand these are only numbers. Your child isn't a statistic. With you by your son or daughter's side, the world is filled with endless possibilities. No one, not even a doctor, can predict the future. Your child will inherit your strength, your love, your dedication, and your advocacy and will grow to be to a powerful miracle of life.

As you grapple with your emotions and try to come up with questions to ask the doctor — but can barely think as you overcome with grief and sadness — know that your answers lie in the hands of people you have never met. Find your people; find families who have experienced your d-day. They are the experts, they know your questions before you can even ask them. Network with them, meet them and their child. Here is where you will find your strength and desire to go forth.

As you think of how your life will be different as a parent of a child with special needs, don't frown on the prospects. Instead, beam a smile. You're about to embark on the most extraordinary journey imaginable. You'll learn to take nothing for granted and the tiniest of milestones will bring you to your knees in tears of pride and joy. You'll share a bond with your family that will unite you in unprecedented ways. You'll feel the love and exuberance of your child who will give you the resilience you need to overcome the challenges that lie ahead.

You are me and I am you. Be the best mom you can be. Love is all around you. And, know that the Spina Bifida Indiana community is here to support you throughout your journey.

WRITTEN BY: NICOLE FONTANETTA

Here are 10 things I wish someone would have told me when my baby was diagnosed with spina bifida:

1. Be mama first. ENJOY your baby.
2. Trust your doctors, but it's okay to ask questions. LOTS of questions. No question is unwarranted or not important. From birth to toddlers, to school age, to teens, to adults . . .
3. Find community: other families that have gone through the same things. Support is key. You're not alone.
4. Take care of yourself. Eat well, stay super-hydrated, and get your rest. Do things that nourish your mind, body, and soul. You'll be a better mama for it; I promise.
5. Say YES to help! You don't have to be Wonder-Woman (even though YOU ARE). Does someone want to make you dinner? Say yes. Fold your laundry? Say yes, even if they don't do it like you. Feed/hold/change your baby? Yes. Do something nice for you? Say YES! You deserve to be taken care of too.
6. Have fun! It's okay to skip a therapy session for your little one once in a while to go to the zoo, to a party or to just go out. Or to just take a nap.
7. Simplify. You need less than you think you do.
8. Be aware, but don't compare. Be aware of milestones and goals, but don't compare your child to other kids. Every child, spina bifida or not, is different and develops in their own time. Trust the process.
9. Make memories. Pack a picnic. Go to the park, museum or carnival. Go to the beach. Take trips. Belly laugh. Explore and take tons of videos and pictures. I promise you'll love looking back, because time goes by very quickly. Savor your child!
10. Your child will amaze you beyond your wildest dreams; children with spina bifida are the most resilient, determined, brave, and loving kiddos around!