



*Educational Webinar Series for Adults with
Spina Bifida*

Becoming a Parent with Spina Bifida

March 2020

This resource provided
in partnership



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Becoming pregnant and being a parent with Spina Bifida is possible!

Today's session:

- Facts about conception and parenting when you have Spina Bifida
- Making the decision to get pregnant
- Health considerations during pregnancy
- Life with your baby/toddler
- Open question and answer session

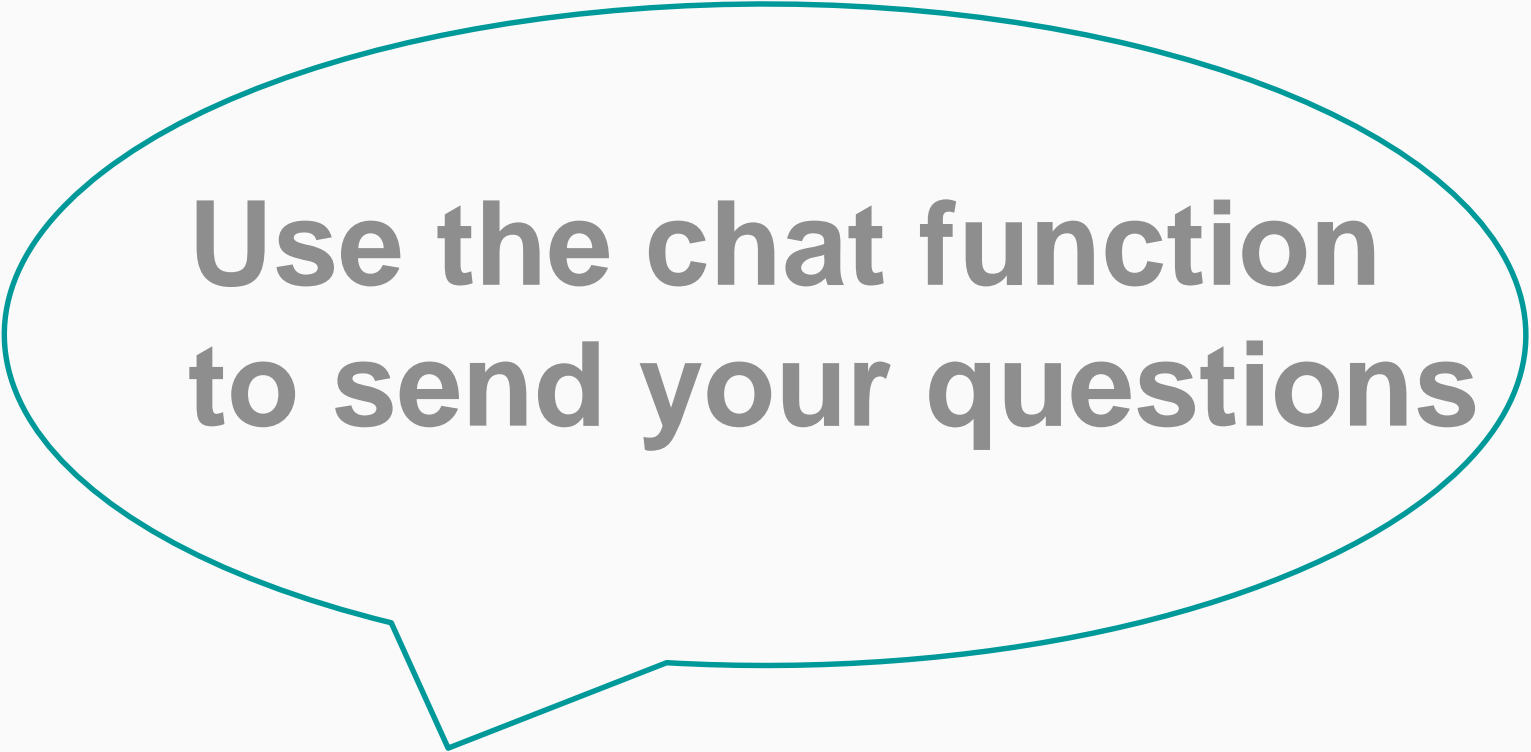
Our Speakers



Courtney Streur, MD, MS
University of Michigan

Linda Long-Bellil, PhD, JD
Commonwealth Medicine
University of Massachusetts
Medical School



A teal speech bubble with a thin outline, containing the text "Use the chat function to send your questions".

**Use the chat function
to send your questions**

Is it possible to have children when you have Spina Bifida?

- Women and men with Spina Bifida CAN conceive and become parents
- Women with Spina Bifida have normal fertility
- Little is known about fertility among men with Spina Bifida
 - Some may have low sperm count and ejaculatory dysfunction (difficulty getting the sperm out)

Plan ahead!

- Find an OB-GYN that you feel comfortable with and supports your goals (true of all your health care providers!)
 - A high risk OB-GYN is generally recommended
- Women with Spina Bifida should take 4mg or 4,000 mcg of folic acid starting 3 months before becoming pregnant
 - This is a much higher dose than for other women
 - A doctor can prescribe this for you

What other health considerations should be kept in mind?

- Anticipate changes in your bladder and bowel function
 - Some women may develop bladder incontinence
 - Some women may have difficulty catheterizing, especially if they use a bladder channel
 - Most women will have constipation and may need to alter their bowel regimen
- Increased risk of UTIs

Anticipate the possibility of physical changes during – and after – pregnancy

- Some women asked us:
 - Was it worth the permanent changes to your body?
 - Will I have lower back pain?
 - Will I experience worsening bladder and bowel leakage?
 - Will I have prolapse?



While pregnant, don't forget to...

- Visit health specialists regularly
 - OB-GYN – review all medications (i.e. seizure medications and antibiotics)
 - Urologist – UTIs, bowel and bladder management
 - Neurologist / Neurosurgeon – VP shunt
 - PM&R – monitor fit for braces and wheelchairs, consider compression hose.
PM&R doctors are “helpful in life.”
 - Pulmonologist – if you already see one
 - Anesthesiologist!

While pregnant, don't forget to...

- Take care of your mental and emotional health
 - Find time to relax and keep your stress low (if possible)
 - Make time to see friends
- Get plenty of sleep (talk to your doctor if you're having trouble sleeping)
- Eat a balanced diet and follow general nutrition guidelines for all pregnant women
 - Drink plenty of water

What should women do prior to delivering a baby?

- Schedule appointment with anesthesiologist well in advance
 - Discuss pain management during delivery, including epidurals and risk of spinal cord injury

What should women do prior to delivering a baby?

- Develop a plan for delivery *with your OB-GYN*
 - Ensure the plan is in writing and in your chart
 - Make sure all OB/Gyns in practice are familiar with you/your plan
 - Advocate for your plan
 - Enlist your partner, spouse, or coach to also advocate for you
 - Recognize that you may need to be flexible depending on circumstances

What should women expect when delivering a baby?

- Increased risk of early delivery
- Some women don't sense their labor coming
- Women with Spina Bifida are able to have healthy deliveries
 - Not all women need a C-section
 - Some may need a C-section depending on their anatomy or if had a procedure to be continent

Life with your baby/toddler - Breastfeeding

- Women with SB are just as able to breastfeed as any other woman
- Use pillows or Boppy®



Source: www.boppy.com

Getting around with your baby/toddler/child

- Be realistic about your abilities and limitations – here are some suggestions
 - Consider changing your usual method of mobility, e.g. transition from crutches to wheelchair for baby care
 - Modified cribs or co-sleeper
 - Baby bathtub in kitchen sink
 - Consider using a child harness to keep up with your toddler



Source: <https://www.walmart.com/ip/Mommy-s-Helper-Kid-Keeper-Child-Safety-Harness/19687567>

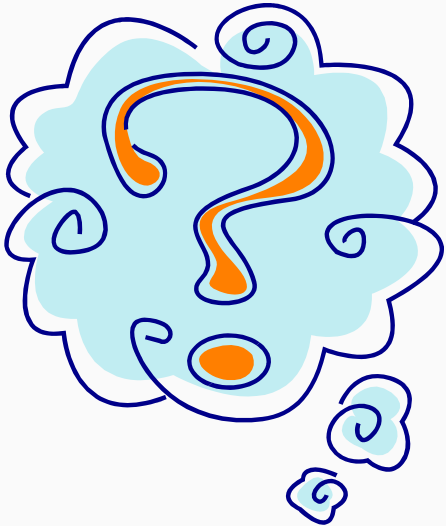
Examples



Adjusting to parenthood

- How does your relationship with your spouse or partner change?
 - Speak to your partner/spouse about your expectations for baby care and sharing duties
 - You may experience different kinds of conflict
 - Both parents may have different information and beliefs about parenting – talk about it!

Your Questions

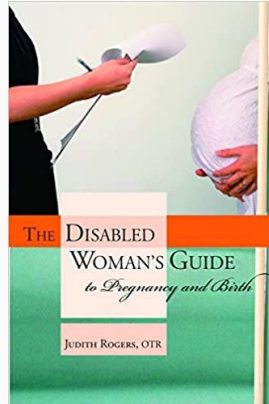
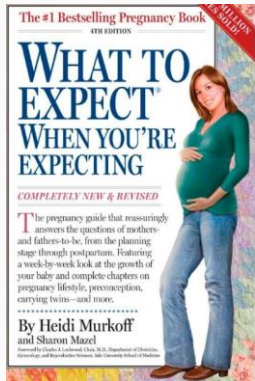


What about adoption?

Poll: Do you want a future SB-You to discuss adoption as a parenthood option?

Send your questions to jpanlener@sbaa.org

Additional Resources



- [Disabled Parenting Project](#)
- [National Research Center for Parents with Disabilities](#)
- [Association for Successful Parenting](#)
- [AbleData](#)
- [Through the Looking Glass](#)
- [Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Families](#)

Wondering about COVID-19 and Spina Bifida?

Tune in to SBA's Information and Q&A: Spina Bifida and COVID-19

Thursday, March 23, 2020:

Visit: <https://www.spinabifidaassociation.org/news/coronavirus2020/>

Thank you!

See the full list of resources* and an archived recording of this session: <https://www.spinabifidaassociation.org/education/sb-you/>

*SBA does not recommend specific products/publications.
Items portrayed are intended as examples only.

Questions?

- Judy Thibadeau, jthibadeau@sbaa.org
- Juanita Panlener, jpanlener@sbaa.org