Becoming a Parent with Spina Bifida

Educational Webinar Series for Adults with Spina Bifida

March 2020
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

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Commonwealth Medicine
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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:

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?

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