



*Educational Webinar Series for Adults with
Spina Bifida*

Women's Health and Self-Advocacy

July 2021

Our panelists

- **Tara Harris, MD, FACOG - Assistant Professor, Obstetrics and Gynecology, Baylor College of Medicine**
- **Samantha (Sami) Perez, SBA Adult Advisory Council**
- **Karen Cushnyr, SBA Adult Advisory Council**
- **Amy Saffell, SBA Adult Advisory Council**
- **Kristin Lovering-Marquis, SBA Adult Advisory Council**
- **Libby Powers, SBA Adult Advisory Council**

Let's chat!

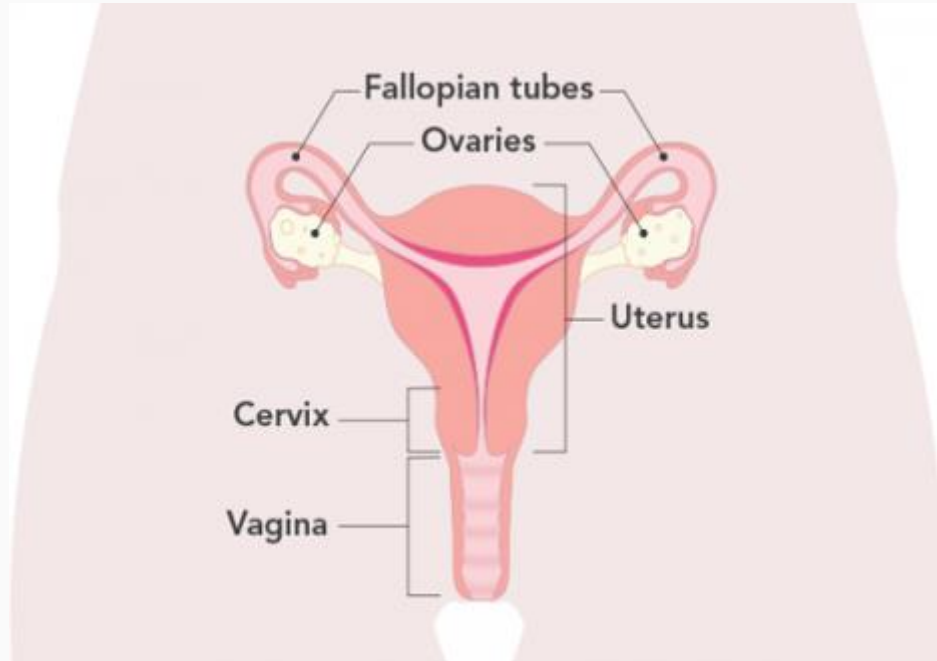


- **Click on the chat box in the Zoom system**
- **Type and send your question**

Why is it important that women with Spina Bifida discuss gynecologic and obstetric care?

- Studies have shown that women with Spina Bifida and other physical differences are more likely than the general population to have experienced difficulties with routine reproductive health maintenance and screening
- They are less likely to receive pelvic exams, pap smears, and information regarding sexual and reproductive health

Female Reproductive System



Well Woman Visit

- Comprehensive history
- Age appropriate screening
- Screening for high risk behaviors
- Counseling on maintaining a healthy lifestyle
- Diet/exercise counseling
- Minimizing high risk behaviors
- Immunizations (HPV)

Well Woman Visit

- Review anatomy
- Discuss menstrual cycles
- Pelvic health/prolapse screening
- Sexual practices and concerns
- STI testing
- Contraception

Well Woman Visit does not necessarily mean an internal pelvic examination

- Age 13-20: as medically indicated
- Age 21-39: “periodic”
- Age 40-64: annually
- Age 65+: pending medical assessment

Pelvic Exams and Pap Smears



Before your appointment, tell them...

- If this is your first pelvic exam and pap smear
- If you need assistance to transfer to the exam table
- If you'd like to bring someone with you to help you transfer
- Ask them if the table moves up and down

What to Expect During a Pelvic Exam

1

Lie on back with feet in stirrups



2

Doctor examines outside of vaginal area



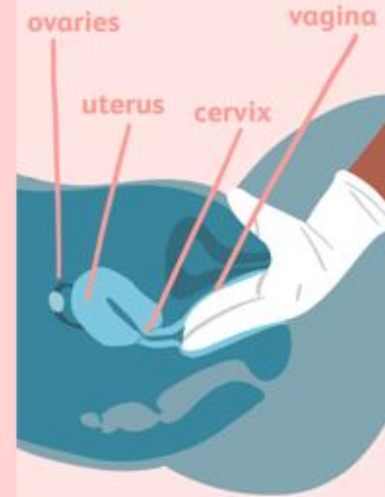
3

Speculum separates vagina walls; doctor examines cervix



4

Doctor inserts 2 fingers to check uterus and ovaries



What to Expect During a Pap Smear

1

Speculum separates
vagina walls



2

Swab inserted into vagina,
collects cells from cervix



3

Cell samples sent to
pathology lab



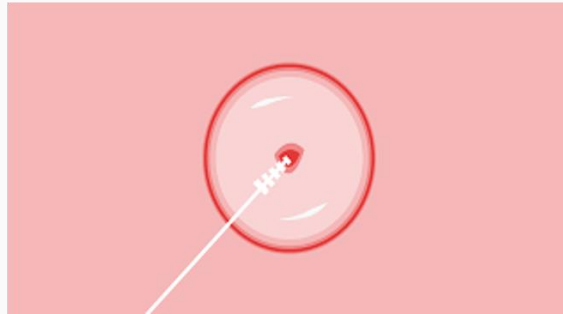
verywell

Illustration by Emily Roberts,
VeryWell

What about consent?

- Ask your doctor what they are doing during each step
- It's okay to say "my body can't get into this position"
- Ask what type of sensation is usual
- **ALWAYS** say something if it hurts
- At some point, it may not be possible to stop some procedures

Tools of the trade



Mammograms

Call ahead:

- What options are available if I can't stand or don't have enough balance?
- Tell the tech if your body doesn't turn or bend in ways they expect. You may have to tell them a few times and explain that you have a curvature or scoliosis.

Hysterectomy

Find out before the surgery:

- Will it be an abdominal surgery? What is recovery time? Will the scar tissue lead to problems down the road?
- Will it trigger menopause? What medications help make the transition to menopause (hot flashes, night sweats, etc)?
- What pelvic floor changes are to be expected? Will there be changes to intercourse?

Sexual Concerns (We All Have Them)

- Bladder and bowel incontinence
- Positioning/mobility
- Risks of fractures
- Sexual response
- Lubricants

Pre-Conception Planning and Counseling

- If you want to get pregnant, alert your doc to be sent to appropriate consultation
- Folic acid supplements of 4 mg daily, ideally at least three months prior and continued until at least 12 weeks gestation

Pregnancy and Delivery Considerations

- What type of sensations should you feel or not feel?
- Anesthesia
- Your body's position



What to Know about Contraception and Spina Bifida

- There are many hormonal and non-hormonal options
- Women with Spina Bifida should discuss the risk of blood clots with their clinician

Hormonal Contraception Uses

- Menstrual suppression
- Painful or heavy cycles
- Menstrual migraines
- PMS symptoms
- Catamenial (menstrual) seizures

Hormonal Contraception

- Either contain both estrogen and progesterone or are progesterone only
- Multiple medical contraindications to estrogen
 - Hypertension
 - Migraines with aura
 - History of DVT/PE
 - Caution in seizure disorders

Hormonal Contraception

- May have side effects
 - Small increase in DVT/PE, heart attack, stroke with estrogen containing methods
- Increased association of breast cancer, decreased risks of ovarian and uterine cancer

Oral Contraceptives



Typical use: 9 in 100 women will get pregnant every year

Perfect use: 1 in 100 women will get pregnant every year

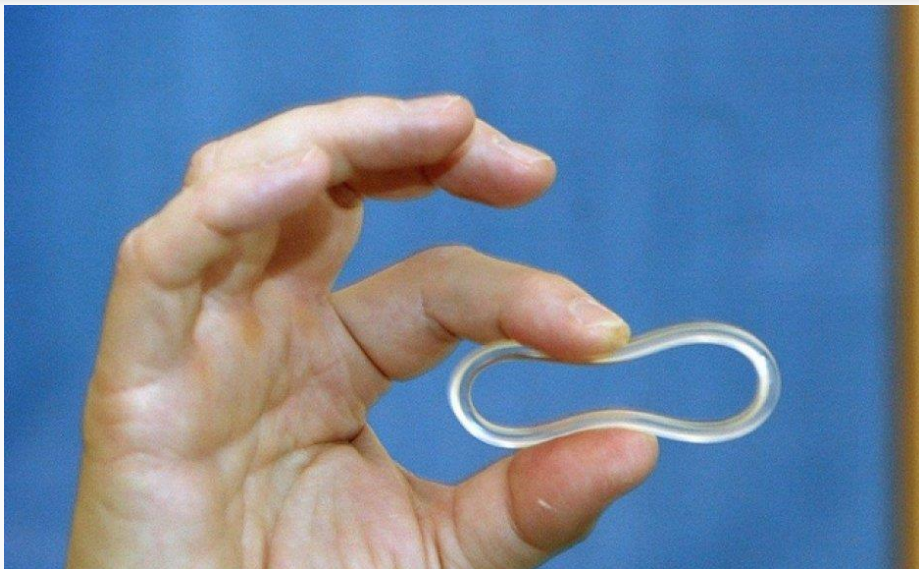
Patch



Typical use: 9 in 100 women will get pregnant every year

Perfect use: 1 in 100 women will get pregnant every year

Vaginal Ring



Typical use: 9 in 100 women will get pregnant every year

Perfect use: 1 in 100 women will get pregnant every year

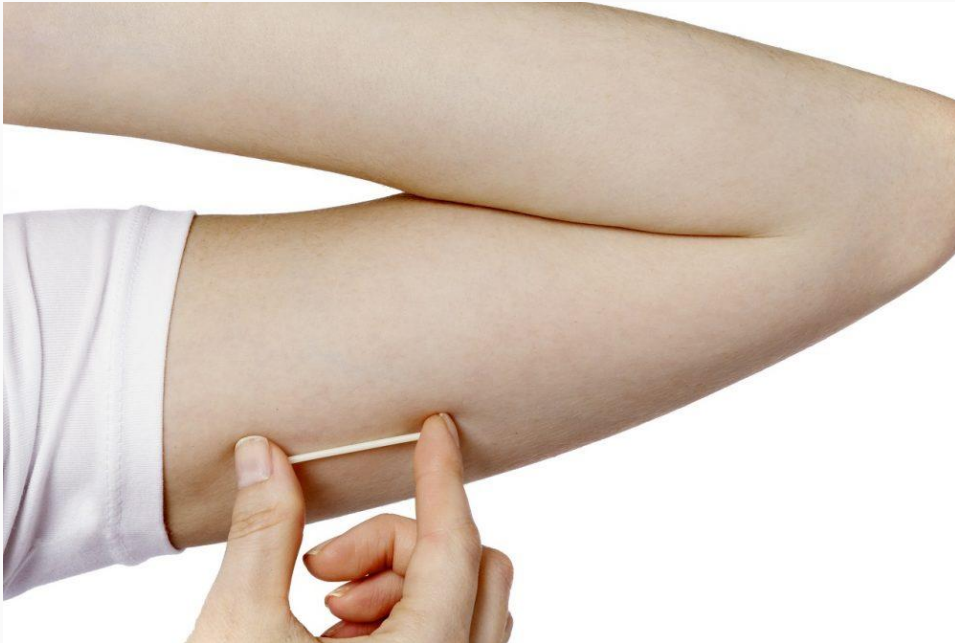
Shot



Typical use: 6 in 100 women will get pregnant every year

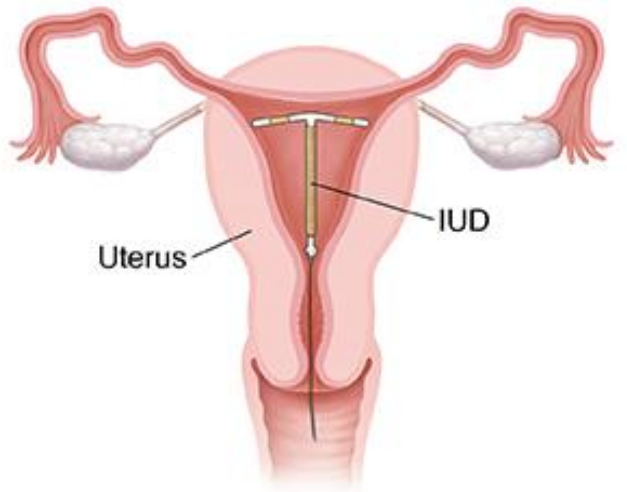
Perfect use: 1 in 100 women will get pregnant every year

Implant



Typical and Perfect use:
less than 1 in 100 women
will get pregnant every year

Progesterone IUD



Typical and Perfect use:

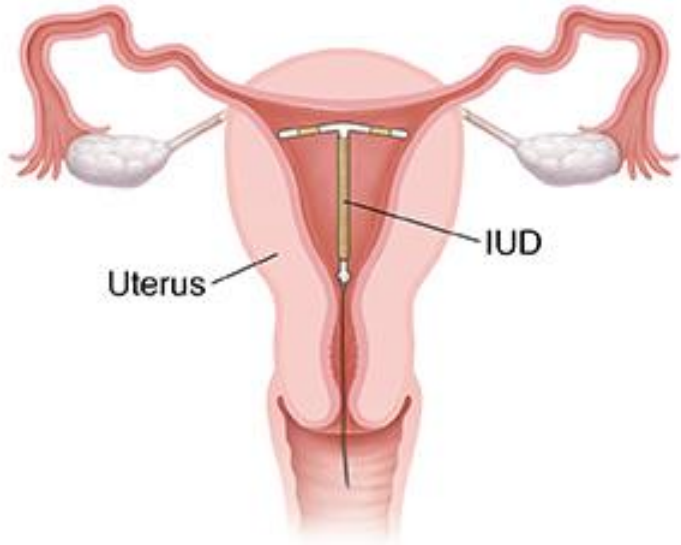
less than 1 in 100 women will get pregnant every year



Contraception: Non-Hormonal Methods



Copper IUD



Typical and Perfect use:
less than 1 in 100 women
will get pregnant every
year



Condoms: Male

Male Condoms***:

Typical use: 15 in 100 women will get pregnant every year

Perfect use: 2 in 100 women will get pregnant every year



Condoms: Female

Female Condoms:

Typical use: 21 in 100 women will get pregnant every year

Perfect use: 5 in 100 women will get pregnant every year



Sponge

Typical use: 12-24 in 100 women will get pregnant every year

Perfect use: 9-20 in 100 women will get pregnant every year



Spermicide

Typical and Perfect use:

20-30 in 100 women will get pregnant every year



Sterilization

Typical and Perfect use:
less than 1 in 100 women will get pregnant every year



Withdrawal Method

Typical use: 22 in 100 women will get pregnant every year

Perfect use: 4 in 100 women will get pregnant every year



Fertility Awareness Methods

Typical and Perfect use:

12-24 in 100 women will get pregnant every year

A calendar grid illustrating a typical menstrual cycle. The days of the week are listed at the top: Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, and Saturday. The days of the month are numbered from 1 to 31. Key events are marked with red text and lines:

- 6 First day of Period**: Marked on Wednesday, day 6.
- 13 First day of fertile window**: Marked on Wednesday, day 13.
- 24 Last day of fertile window**: Marked on Monday, day 24.
- 3 First day of Period**: Marked on Wednesday, day 31.

Red horizontal lines indicate the duration of the period (from day 6 to day 13) and the fertile window (from day 13 to day 24).

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
31	22	23	24	25	26	27
3	4	5	6 First day of Period	7	8	9
10	11	12	13 First day of fertile window	14	15	16
17	18	19	20	21	22	23
24 Last day of fertile window	25	26	27	28	29	30
31	1	2	3 First day of Period	4	5	6

Fertility Awareness Methods

Typical and Perfect use:

12-24 in 100 women will get pregnant every year

A calendar grid illustrating a typical menstrual cycle. The days are numbered 1 through 31, with columns for Sunday through Saturday. Key events are marked with red text and lines:

- 6 First day of Period**: Marked on Wednesday, day 6.
- 13 First day of fertile window**: Marked on Wednesday, day 13.
- 24 Last day of fertile window**: Marked on Sunday, day 24.
- 3 First day of Period**: Marked on Wednesday, day 3 of the following month.

Red horizontal lines indicate the duration of the period (from day 6 to day 13) and the fertile window (from day 13 to day 24).

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
31	22	23	24	25	26	27
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Your Questions



- **Click on the Q&A button in the Zoom webinar system**
- **Type and submit your question**

Resources from this presentation

Facebook event page
SpinaBifidaAssociation.org
SB-YOU playlist on YouTube

<https://www.youtube.com/user/SBAOrg/playlists>

Thank you!

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