



**SEXUAL AND  
REPRODUCTIVE  
HEALTH IN PEOPLE  
LIVING WITH SPINA  
BIFIDA**

*Courtney Streur  
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# Who are we?

- Courtney Streur, MD
  - Pediatric Urologist at the University of Michigan
  - Researcher on sexual and reproductive health outcomes and education for adolescents/young adults with Spina Bifida
- John Wiener, MD
  - Pediatric Urologist at Duke
  - Researcher on urologic and sexual health for people living with Spina Bifida
- Linda Long-Bellil, PhD, JD
  - Assistant Professor of Family Medicine and Community Health at University of Massachusetts Chan Medical School
  - Researcher on reproductive outcomes of women with physical disabilities
  - Mother
  - Woman living with Spina Bifida

# Disclosures

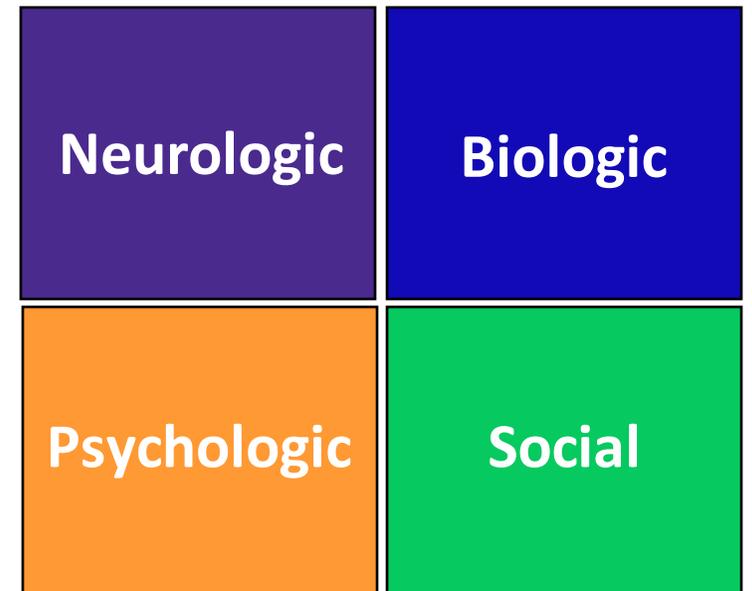
- Linda and Courtney
  - None
- John
  - Association with:
    - Centers for Disease Control and Prevention
    - Spina Bifida Association (Board of Directors)

# Break-Out Session Goal

- Equip you with the knowledge and confidence to start talking to adolescents and adults in your clinics about sexual and reproductive health.

# Overview

- How Spina Bifida impacts sexual function for men and women
  - Neurobiopsychosocial framework
  - Ways to optimize function
- How Spina Bifida impacts women's reproductive health
- "How I talk about sexual health"
- Group Discussion
- Q&A/Discussion Time with 2 adults living with SB



# Why this discussion?

- What do adolescents and adults do?
- They think about love.
- **They think about sex.**
- **Disability does not eliminate basic human needs**





Men's Health

# GUIDELINES FOR THE CARE OF PEOPLE WITH SPINA BIFIDA



## Men's Health

Workgroup Members: Hadley Wood, MD, FACS (Chair); Dominic Frimberger, MD;  
John S. Wiener, MD

### Introduction

Until recently, adult sexual function in men and women with Spina Bifida had not been widely considered, as many born with this condition did not live to adulthood. Even after the advent of modern medical breakthroughs like ventriculoperitoneal shunting, intermittent catheterization, and urinary diversion increased quality of life and longevity, many adults with Spina Bifida continue to be cared for by pediatric specialists well into adulthood. Similarly, urologic issues that affect adults are often ignored.

It is clear that sexual function is altered in a majority of men with Spina Bifida, as male sexual organs are innervated by the distal spinal cord which is often impaired by Spina Bifida. Evidence suggests that young adults with Spina Bifida generally feel under informed about sexual health, with nearly one third of respondents stating that they were not provided appropriate information related to how Spina Bifida can affect sexual function)<sup>1-3</sup> Additionally, traditional points of emphasis in men's health care, such as prostatic hypertrophy and cancer, have not been addressed in this population. The health care community now widely accepts the need for a better understanding of the specific issues that men and women with Spina Bifida face regarding sexuality, fertility, and aging reproductive organs.

This document will review the following men's health topics:

- Male sexual function
- Male fertility considerations
- Prostate cancer screening and treatment

The purpose of these guidelines is to: 1) highlight the existing evidence regarding the male sexual health in Spina Bifida, 2) make recommendations based on existing data and expert opinion, and 3) emphasize research gaps and areas for additional opportunities to improve the health of men with Spina Bifida.

### Sexual Function: Outcomes

#### Primary

1. Optimize sexual function and fertility in men with Spina Bifida.

#### Secondary

1. Evaluate and characterize penile and genital sensation.
2. Evaluate and characterize erectile function.
3. Evaluate and characterize orgasmic and ejaculatory function.
4. Maximize fertility potential of men with Spina Bifida, if desired.
5. Ensure sexual education and safe practices (Sexual Health and Education Guidelines).
6. Determine the sexual activity and interest in men with Spina Bifida.

#### Tertiary

1. Describe known therapies for decreased genital sensation, erectile/orgasmic/ejaculatory dysfunction, and infertility.
2. Assess the impact of fertility and sexual function on the quality of life in men with

## Urologic Congenitalism

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# Spina Bifida Health-care Guidelines for Men's Health



**John S. Wiener, Dominic C. Frimberger, and Hadley Wood**

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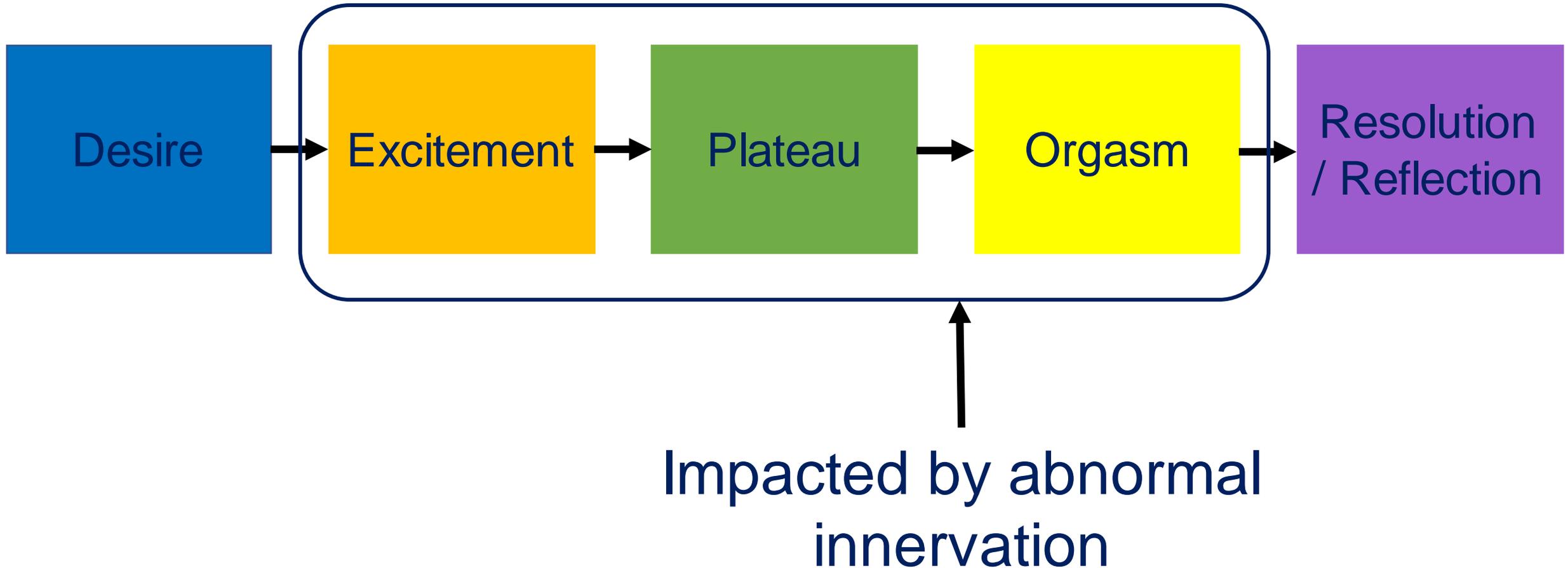
Spina bifida has traditionally been regarded as a pediatric health issue with little regard to adult consequences of the disorder. The congenital neurologic and urologic anomalies, as well as sequelae of bladder management, can have a profound impact on adult male sexual function. Abnormalities in testicular descent, development, and function; fertility; penile sensation; erectile function; ejaculatory function; and orgasmic function are common. Prostate cancer has been diagnosed in men with spina bifida, but little data are available to guide screening, diagnosis, and treatment efforts. The Spina Bifida Association has supported development of guidelines for health care providers to address male health issues in individuals with spina bifida throughout their lives. UROLOGY 116: 218–226, 2018. © 2018 Elsevier Inc.

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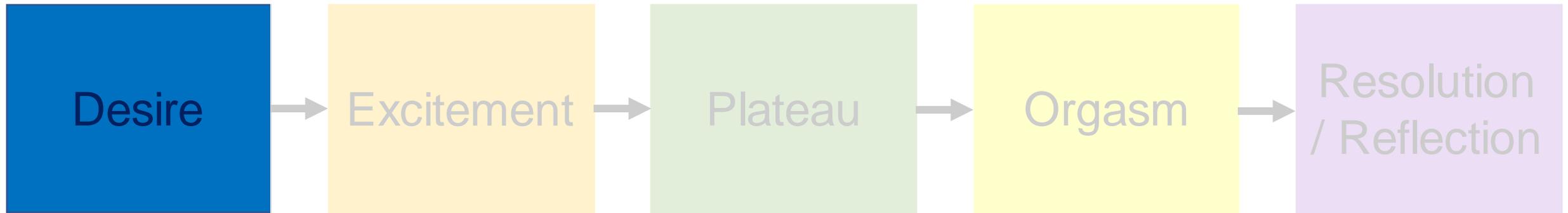
# Sexual Response Phases



# Sexual Response Phases



# Sexual Response Phases



# Men's Sexual Desire

- **Little impact by SB**
- **May be lower if sexually inactive**
- **Little impact by other factors – hydrocephalus**

Sawyer SM and Roberts KF, Dev Med Child Neurol 1999

Choi EK et al, Urology 2017

Lassmann J et al, JUrol 2007

Rosen RC et al, Urology 1997

Gamé X et al, Urology 2006

Lee NG et al, J Pediatr Urol 2015

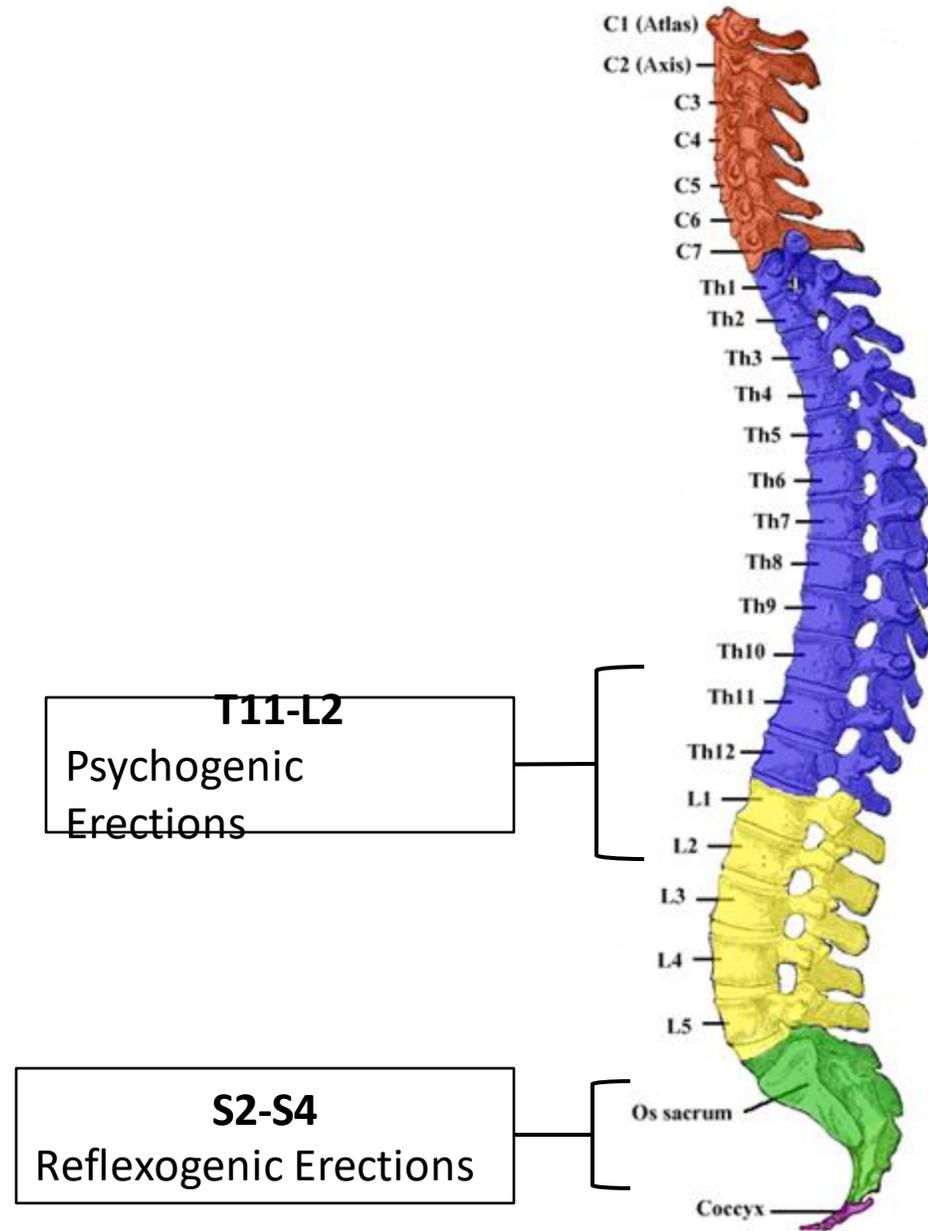
Verhoef M et al, Arch Phys Med Rehabil 2005

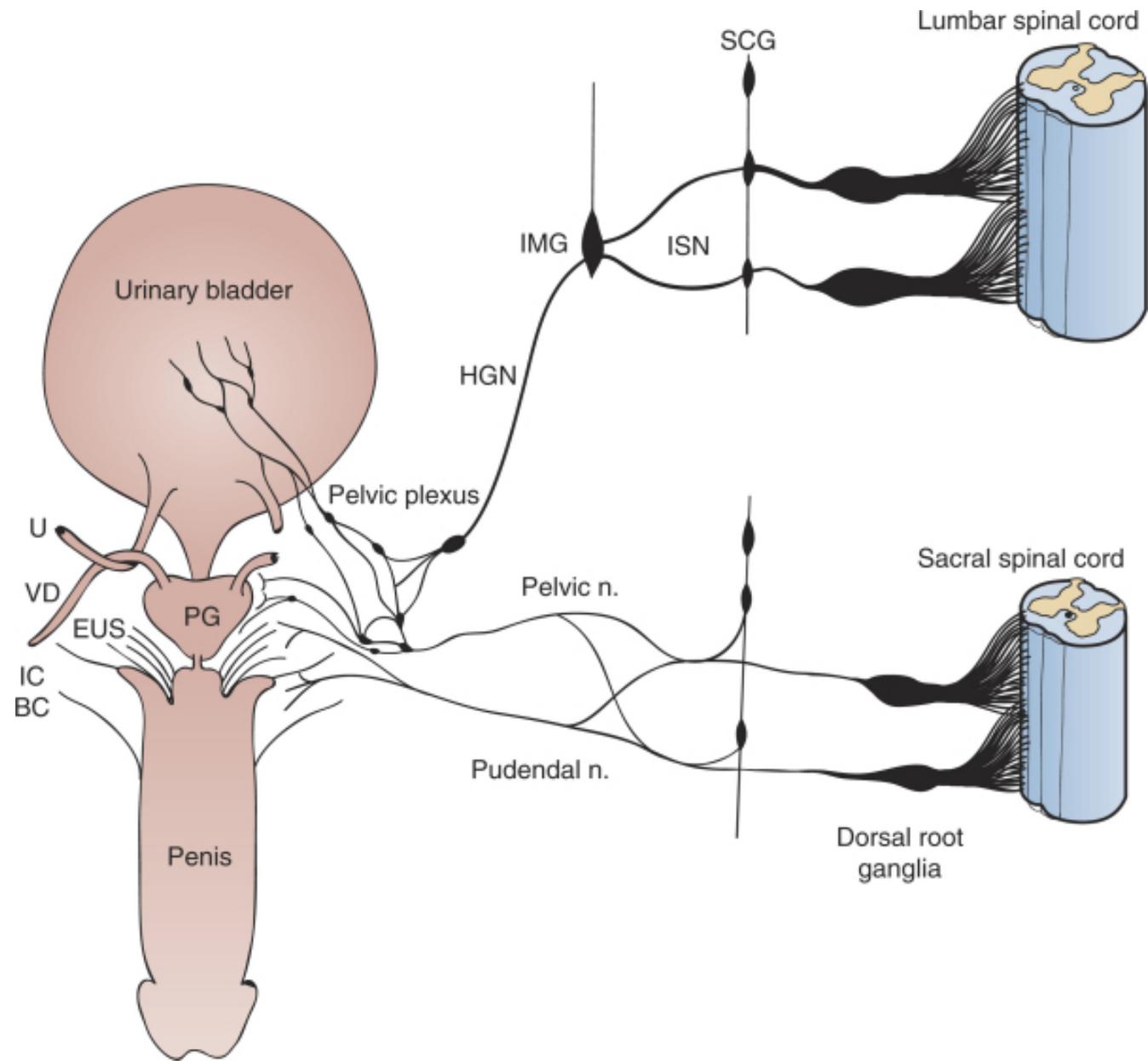
Gamé X et al, J Pediatr Urol 2014

# Sexual Response Phases



# Males





# Erections with Spinal Cord Lesions

- Reflexogenic Erection
  - Induced by physical stimulation
  - Requires intact sacral reflex arc (S2-S4)
- Psychogenic Erection
  - Induced by psychic stimulation
  - Lesions below L2
- “Mixed Erection”
  - Lesions below L2 and above S2

# Men's Health

- **Erectile Function**
  - **Most can achieve erection – 56-95%**
  - **Quality of erections diminished in 13-71%**
  - **Correlated with level of lesion**
    - **Ambulation?**
    - **Hydrocephalus?**
    - **Penile sensation?**

# Predictors of Erectile Function

- Lower level of lesion increases likelihood of achieving erection
  - 33-50% thoracic level
  - 71-84% lumbar level
  - 83-100% sacral level

Diamond DA et al, Br J Urol 1986; Gamé X et al, Urology 2006; Decter RM et al. J Urol 1997; Choi EK et al, Urology 2017; Shiomi T et al, Int J Urol 2006; Verhoef M, Dev Med Child Neurol 2004

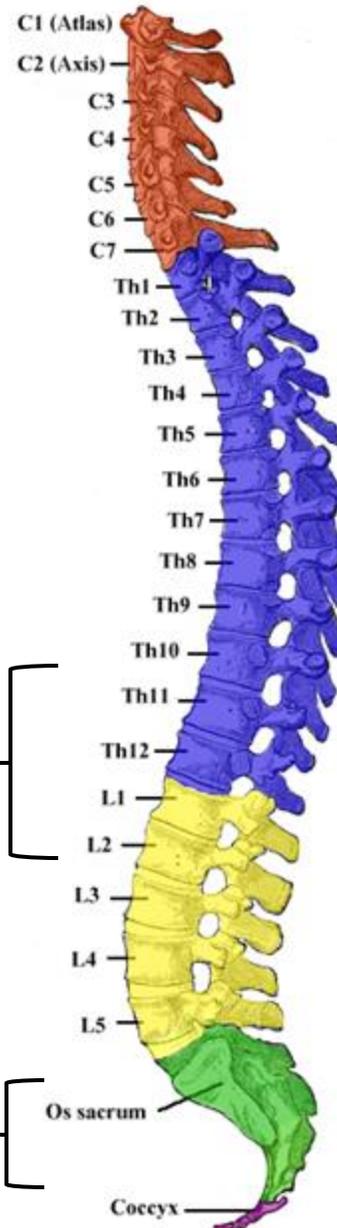
# Treatment of Erectile Dysfunction

- Palmer (Chicago) 1999-2000 – Sildenafil
  - Study of 15 men - 80% improvement in IIEF
- Szymanski 2017 – online survey
  - 25/69 used PDE-5 inhibitors
    - 76% reported improved erections
    - 56% reported improved intercourse

Palmer JS, Kaplan WE, Firlit, *J Urol*, 2000

Szymanski KM et al. *J Pediatr Rehabil Med*, 2017

# Ejaculation



## T11-L2

**Ejaculation:** First phase (sympathetic)–  
peristalsis of vas, SVs, prostatic smooth  
muscle and closure of bladder neck

## S2-S4

**Ejaculation:** Seminal fluid creation  
(parasympathetic), pelvic floor contraction for  
projectile ejaculation/semen release (somatic)

# Ejaculatory Function

- **Ability to ejaculate – 50-88%**
- **Nocturnal emissions – 52%**
- **Ejaculate without erections - 5-13%**
- **Quality of ejaculation diminished in many**
  - **“weak”, “dribbling”, retrograde**
- **Correlated with level of lesion**

Sawyer SM and Roberts KV, Dev Med Child Neurol 1999

Choi EK et al, Urology 2017

Decter RM et al. J Urol 1997

Game X et al, Urology 2006

Shiomi T et al, Int J Urol 2006

Verhoef M, Dev Med Child Neurol 2004

# Predictors of Male Ejaculatory Function

- Improved with lower levels of lesion

# Treatment of SB Ejaculatory Dysfunction

- No known research-based treatment
- Reflections of several men:
  - “Last longer”
  - “Better at satisfying a partner”

# Treatment of Ejaculatory Dysfunction in Men with SCI

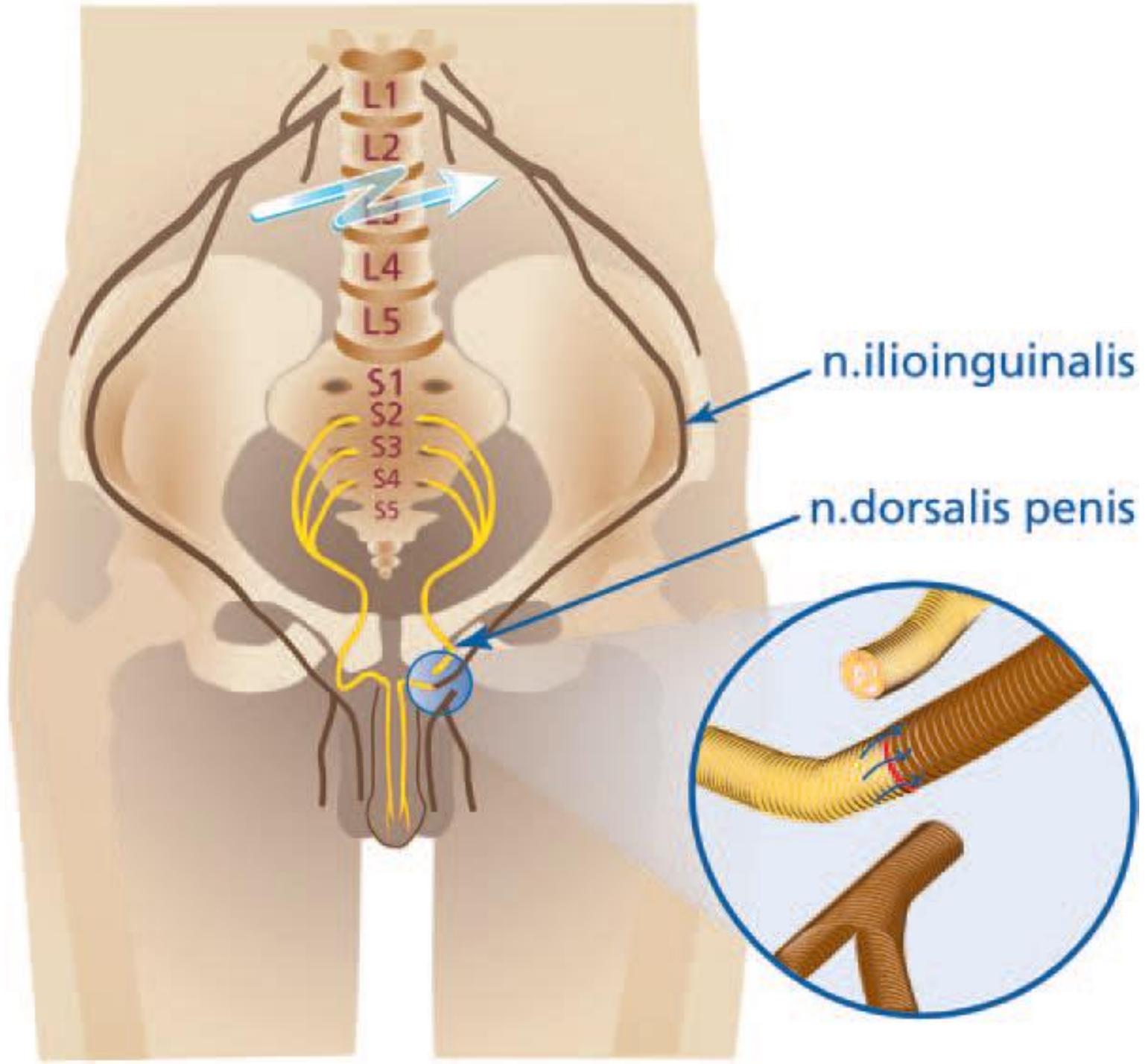
- Often for fertility purposes (obtaining semen)
  - Electroejaculation
  - Penile vibratory stimulation
    - Sometimes used at home
- PDE5i may improve ejaculation

# Other Male Arousal Treatment- Learning from SCI

- “Body Mapping”
  - Genitalia, head/neck, torso/arm/shoulder most stimulating
  - New areas of arousal at or above the level of lesion

# Men's Health: Treatment

- What can one do for abnormal penile sensation?
- TOMAX procedure – 1<sup>st</sup> described 2013
  - Tomas DeJong & Max Overgoor
  - Nerve re-routing – ilioinguinal (L1) to pudendal



# Men's Health: Treatment

- TOMAX procedure
  - Unilateral procedure
    - Penile sensation gained in 24/27 men
    - 5 gained ability to get erection by tactile stimulation
    - Improved stiffness and sex satisfaction scores
  - Bilateral procedure performed
- Performed at one center in US

Overgoor et al, *J Urol*, 2013

Overgoor et al, *Plast Reconstr Surg*, 2014

Jacobs et al, *J Sex Med*, 2013

# Sexual Response Phases



# Men's Health

- **Orgasmic Function**
  - **Ability to achieve orgasm – 20-67%**
  - **Correlated with penile tactile sensation**

# Treatment of Male Orgasmic Dysfunction

- Non-medical treatment
  - Longer foreplay
  - Addressing fatigue, depression as well as pain, spasticity
  - Body mapping sensitive areas
  - Mindfulness

# Sexual Response Phases



# Men's Health: Paternity

- Cardenas (Seattle) 2008
  - 15% without hydrocephalus; 1/25 with HC
- Decter (Hershey) 1997
  - 7/10 with L5/sacral SB – all amb w/o HC
  - 1/39 w/ higher lesion attempted – success
- Laurence (Wales) 1975
  - 9/11 married men – 23 offspring
    - None with MMC

# Men's Health: Fertility

- What can we learn from SCI world?
- Celigoj FA, Ibrahim E,... Brackett NL. Semen quality in men who sustained a SCI during prepubertal period. J. Urol. 188:521, 2012
  - Miami Project to Cure Paralysis – Male Fertility
  - 533 men – 7 injured prior to age 12y
    - All (3) injured before age 10y – azoospermia
    - Two injured at 10 and 11.6y – oligospermia
    - Two injured at 11.9 y – normospermia
  - **NORMAL NEURAL INPUT AT EARLY AGE MAY BE REQUIRED FOR NORMAL SPERMATOGENESIS**

# Women's Health



GUIDELINES FOR THE  
CARE OF PEOPLE WITH  
**SPINA BIFIDA**



**Women's Health**

**Workgroup Members: Anne Berndt, MD, MSc, (Chair); Margaret Nosek, PhD; Ashley Waddington, MD, MSc**

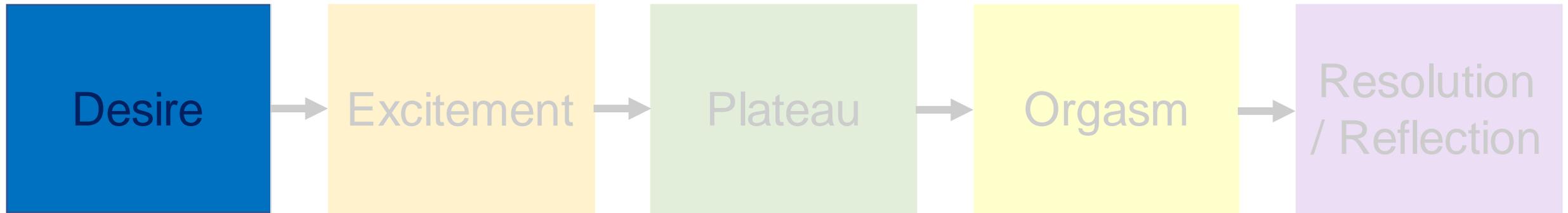


**Sexual Health and Education**

**Workgroup Members: Amy Houtrow, MD, PhD, MPH (Chair); Michele Roland, MD**

<https://www.spinabifidaassociation.org/guidelines/>

# Sexual Response Phases



# SB Sexual Desire

- Normal or near-normal

Sawyer SM and Roberts KF, Dev  
Med Child Neurol 1999

Choi EK et al, Urology 2017

Lassmann J et al, JUrol 2007

Rosen RC et al, Urology 1997

Gamé X et al, Urology 2006

Lee NG et al, J Pediatr Urol 2015

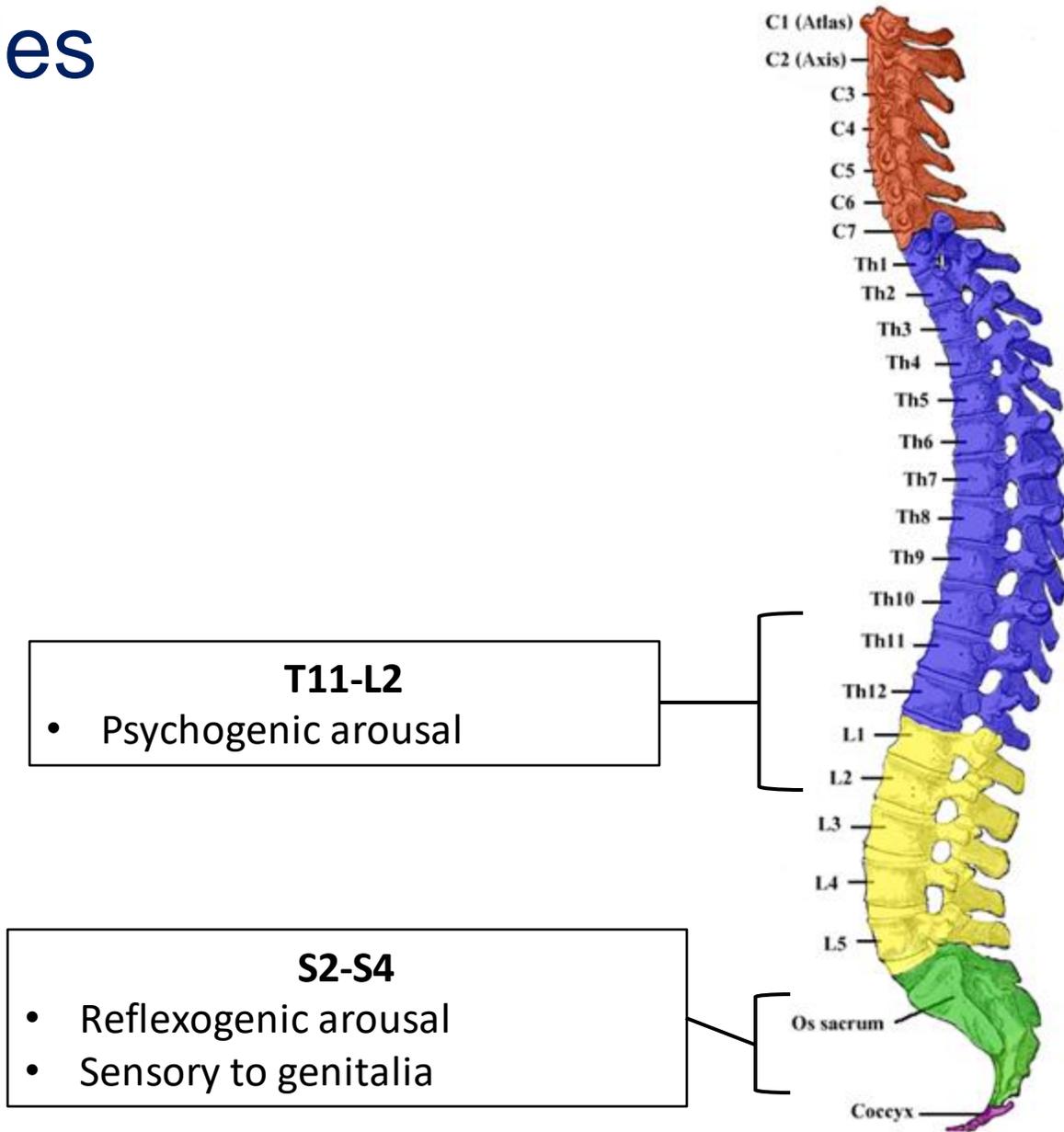
Verhoef M et al, Arch Phys Med  
Rehabil 2005

Gamé X et al, J Pediatr Urol 2014

# Sexual Response Phases



# Females



# SB Female Arousal and Lubrication

- Arousal
  - No to mild impairment
- Lubrication
  - 0-14% experience problems
  - Many women unsure

Verhoef M et al, Arch Phys Med Rehabil  
2005

Lassmann J et al, Jurology 2007

Choi EK et al. Neurourol Urodyn 2018

# Female Arousal Treatment

- “Body Mapping”
  - Identify areas of increased sensitivity
  - Often at or just above level of lesion
  - Other common areas:
    - Head/neck and torso
    - Some areas sensitive to vibratory sensation
- Longer foreplay
- Use of water-based lubrication



Hubscher CH et al. Arch Phys Med Rehabil 2021.

Anderson KD e tal. Spinal Cord 2007.

Kreuter M et al. Spinal Cord 2011.

# Sexual Response Phases



# Female Orgasm/Sensation

- 0-47% experience “problems with orgasm”
  - Many unsure if they orgasm

Sawyer SM and Roberts KV, Dev Med Child Neurol 1999

Verhoef M et al, Dev Med Child Neurol 2004

Verhoef M et al, Arch Phys Med Rehabil 2005

If I'm walking lot or sitting for a long period of time, then I'll have more numbness than usual.

# Treatment of Female Orgasmic Dysfunction

- Map out most sensitive areas of body
  - Often just above level of lesion
- Longer foreplay
- Use of sex aids
  - Vibratory stimulation
  - Gentle vacuum (Eros device)
- Try other forms of sex
  - Anal
  - Oral

Alexander M and Rosen RC, J Sex and Marital Therapy  
Kreuter M et al, Spinal Cord 2011  
Streuer CS et al, J Sex Med 2020

# Sexual Response Phases



**Neurologic**

**Biologic**

**Psychologic**

**Social**

# Psychosocial Considerations

- Confidence
- Sexual abuse and coercion
- Societal stigma of people with disabilities as asexual
- Difficulty finding sexual health care

# Sexual Confidence

- Impacted by:
  - Overall self-confidence
  - Body image
    - Often poor
    - Concern about abdomen, legs, chair, buttocks (SB)
  - Perception of “ability” compared to those without disabilities
  - Negative experiences with partners
  - Surgical scars
  - Incontinence
- May be difficult to set/enforce boundaries

When I was younger I felt very ashamed of my body and as I've grown up that hasn't changed a whole lot.

# Sexual Abuse/Coercion

- Women with physical disabilities at 4x the risk of sexual abuse
  - Also at increased risk of intimate partner violence

Casteel C et al, Inj Prev 2008

Basile KC, Breiding MG, Smith SG, American Journal of Public Health 2016

I just felt so alone and I wanted that feeling, I don't think I really wanted sex, I wanted someone to love me.

I was just trying to satisfy a person, so if it hurt me it didn't matter.

# Sexual Health Care

- Lack of providers
- Stigma

So why are you here?

But what do you mean?

But you're in a wheelchair.  
You can't stand.

For birth control.

Well, because I don't like having  
babies.

Do you stand when you have sex?



# Managing Partner Relationships

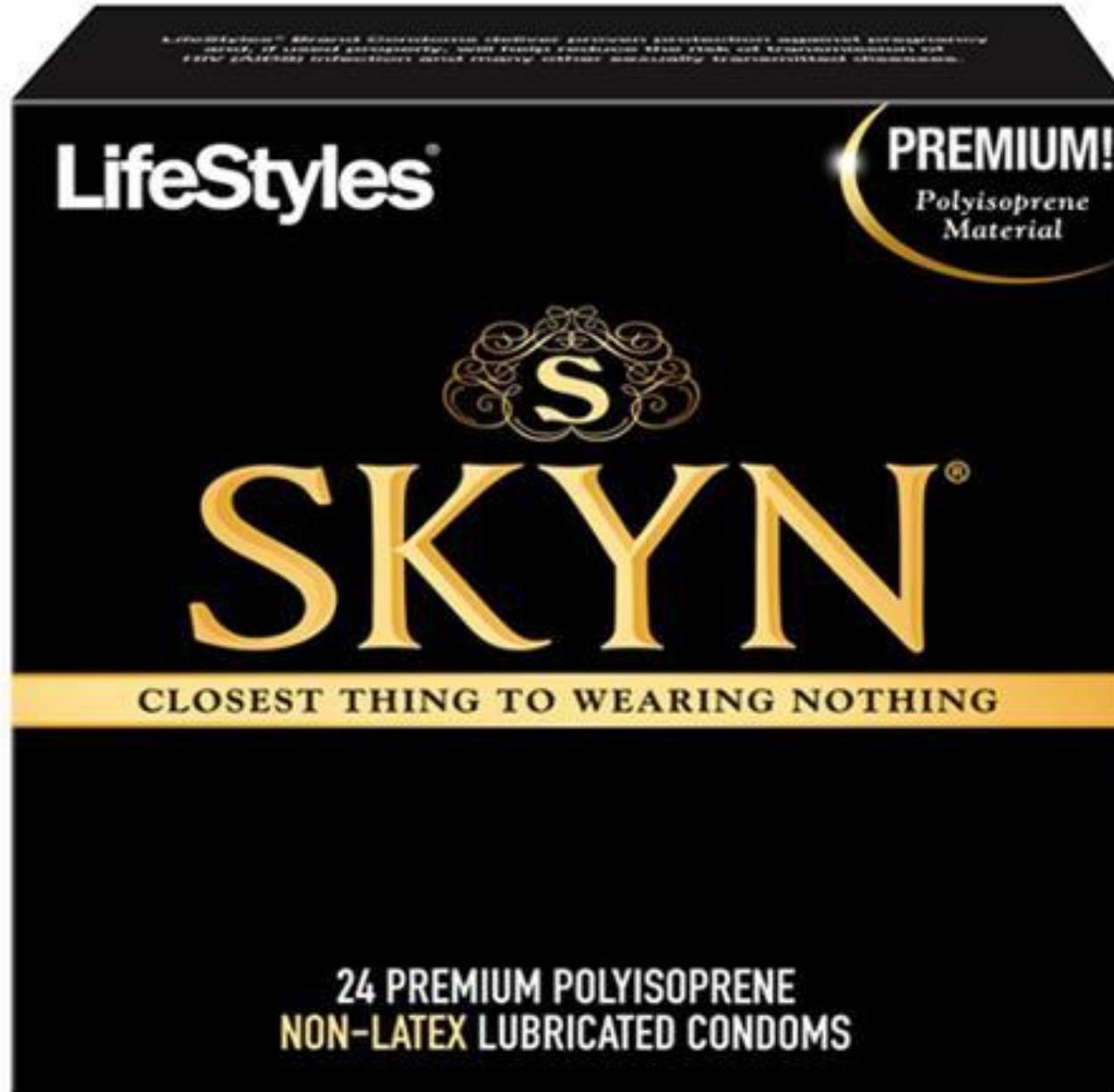
- Encourage emotional support and intimacy with partner
- Seek sexual pleasure of the partner
- Open communication– feedback, experimentation, problems
- Trial and error
  - Recognize this can be frustrating for some
- Use a variety of sexual behaviors/expressions
  - Long foreplay
  - Massage
  - Use aids, fantasy, experimentation
- Peer mentorship programs, sexual health counselors, physical/occupational may be beneficial if open/honest



I genuinely believe that I have a better sex life than most of my friends because I have to communicate what I need during sex and that has made it a lot easier for me to communicate what I want as well.

# Sexual Health

- Sexual Health
- Sexual Health  
transmission  
for adults
- History
- Discussion
- Discussion
- Discussion



3  
part of  
gular care

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## Pediatric Urology

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# How to Discuss Sexual Health With Girls and Young Women With Spina Bifida: A Practical Guide for the Urologist



**Courtney S. Streur, David E. Sandberg, Claire Z. Kalpakjian, Daniela A. Wittmann, and Elisabeth H. Quint**

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<b>OBJECTIVE</b>	To provide urologists with a practical guide for how to provide sexual health counseling to girls and women with spina bifida.
<b>METHODS</b>	The recommendations and research of several sources were synthesized to create this guidance, including clinical guidance from the Spina Bifida Association and American College of Obstetricians, the current literature on the sexual health of girls and women with spina bifida, and the multidisciplinary experience of the authors.
<b>RESULTS</b>	Sexual health education should be viewed by urologists as a continuous discussion, starting in early childhood and gradually building through adolescence. Developing a plan for when and how to bring it up, utilizing parents as educational partners, identifying who will provide the detailed one-on-one counseling if not the primary urologist, establishing a referral network for specialized care (eg, adolescent gynecologist, physical therapist, or sex therapist), becoming familiar with how spina bifida impacts sexual health, and being prepared for challenges are key to providing these girls and women with competent sexual health education. Urologists should also screen for abuse at each visit and be familiar with reporting and resources for when abuse is identified.
<b>CONCLUSION</b>	This guidance can serve to direct urologists in providing competent sexual health education to girls and women with spina bifida. This will ensure these girls and women receive the basic education they need, and that they can be referred to appropriate sexual health experts as indicated. UROLOGY 151: 72–78, 2021. © 2020 Elsevier Inc.

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**SPINA BIFIDA**

**DON'T STOP ME**

**I'M HER  
LIVING PROOF**



**Commonwealth  
Medicine**

# Women's Reproductive Outcomes



# Methods – Two Studies

- Study of Reproductive Health and Women with Early Onset Disabilities
  - Semi-structured interviews of 41 women including 7 with spina bifida
  - Have a physical disability or health condition that affected their ability to walk or to use their arms or hands at the time of their pregnancies.
  - Disability onset before puberty
- Study of Pregnancy in Women with Physical Disabilities
  - Semi-structured interviews of 25 women including 1 with spina bifida
  - Women ages 18-55 with onset at any age
  - Have a physical disability or health condition that affected their ability to walk or to use their arms or hands at the time of their pregnancies.
- In both studies, women were recruited through email lists, social media, and snowball sampling

# Increase in Births

Evidence suggests that the percentage of women with disabilities who are giving birth is increasing.

–Among with spina bifida, births increased by 56% between 2003 and 2013 (Shepard, 2018)

–In California, percentage of women who gave birth more than doubled between 2000 and 2010 (Horner-Johnson, 2017)

Shepard CL, Yan PL, Hollingsworth JM, and Kraft KH. Journal of Pediatric Urology, 2018; Horner-Johnson W, Biel FM, Darney BG, Caughey AB. Disability and Health Journal

# Research Questions

- What information do women get about sexual and reproductive health (SRH) and their right to sexual expression from family, health professionals, and other sources
- Barriers and unmet needs for reproductive health care
- Impact on women's decisions about reproductive health

# Information about Puberty

“Menstruation was kind of a surprise as this came on, you know . . . we just went and got what I needed. Nobody ever really explained like tampons to me, the changes in my body.”

“We were pretty open. . . I think growing up in the hospital and having to be so open about so many different things having to do with my body, it just didn't seem like a big deal to me.”

Women had a range of information about the onset of puberty

# Messages from Families

“My parents were always of the mentality that I could do whatever I wanted in any aspect of my life whether it be having a family or working or higher ed or whatever.”

“I just honestly think that she never thought I would get pregnant. My body, it was so different, you know?”

Families vary in messages they give disabled children about sex.

# Care Coordination

I went to see a high risk OB and they immediately got in contact with my urologist and my neurosurgeon to make sure that everybody was on board . . . during pregnancy and during delivery.

I grew up in the X city and all of the surgeries I had had done happened at the same hospital that she was born so all of my doctors that had done my other surgeries were involved in the planning of what if I needed a C-section.

Care was coordinated with other specialists during pregnancy and delivery

# Previous Surgeries

My doctors were not planning a C-section because I've had some other surgeries in my abdominal area and they were afraid of excess scar tissue and things like that. They said, "If we need to do one we can but we don't want to plan to do one."

"It looked like someone had poured a jar of rubber cement in there."

It was necessary to consider the impact of previous surgeries

# Anesthesia

I had an anesthesia consult about two months before she was born . . . They did tell me that I couldn't get an epidural because of my back . . . but I did get IV pain medication.

Q: "Did you meet with an anesthesiologist ahead of time?"

A: "No. Not ahead of time but just when I was in there. . . . I wish I had known more options for pain, for managing the whole situation.

Approaches to anesthesia were inconsistent

“My OB was great. But I also think, you know, things only happened the way they happened because we planned ahead.”

# Conclusion

- Messaging from families and the information that women had about puberty and pregnancy varied
- Although there was care coordination among the small number of women involved in this study, there was room for improvement in some aspects of care
- Planning ahead and management were key

# Funding

- 90SF0018-01-00, Switzer Fellowship, National Institute on Disability, Independent Living and Rehabilitation Research
- R01HD074581, Health Needs and Disparities in Care for Women with Mobility Disabilities. Eunice Kennedy Shriver National Institute for Child Health and Human Development

# References

Shepard, C.L., Yan, P.L., Hollingsworth, J.M. and Kraft, K.H., 2018. Pregnancy among mothers with spina bifida. *Journal of pediatric urology*, 14(1), pp.11-e1.

Horner-Johnson, W., Biel, F.M., Darney, B.G. and Caughey, A.B., 2017. Time trends in births and cesarean deliveries among women with disabilities. *Disability and health journal*, 10(3), pp.376-381.

# For more information:



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