

Into Adolescence and Womanhood

A “right” of passage

Jane Lane, BSN, RN
UAB Civitan International Research Center
IRSF Family Support

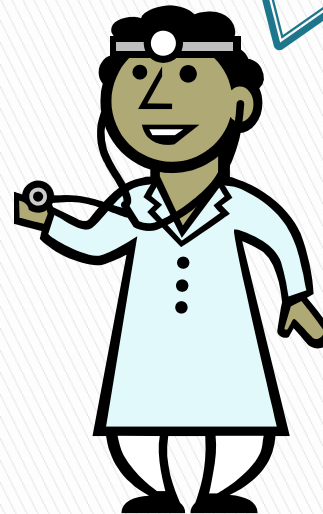
IRSF 2013 Education and Awareness
Conference
June 28, 2013

Differences in attitude



I hope it
never
happens!!

...



*I hope it
happens, but
not **too** early or
not **too** late.*

Why is her growing up hard to accept?

- ▶ Fears of the unknown and “what ifs”
 - Pain
 - Managing hygiene
 - Mothers say “Fathers no longer willing to help”
 - Fathers say “What the heck is happening”
 - Seizures
 - Loss of my “little girl”
 - Reminder of life as finite
 - Another specialist/another exam
 - Exploitation

**“Knowledge is power.
Information is liberating”...**

Kofi Annan

Liberating us from our fears



Puberty and Menarche

Puberty hormone driven



makes gonadotropin releasing hormone



makes luteinizing and follicle-stimulating hormone



make estrogen (and testicles make testosterone)




And.....

Voila!



Puberty

- ▶ **Changes in body composition, growth, bone size and mineralization occur**
 - ▶ **Physical changes categorized by Tanner stages (I–V)**
 - ▶ **Timeline from start of Tanner II to menarche → approximately 4 years**
- 

Factors affecting onset

- **Biologic**
 - Race
 - Nutrition/% body fat/activity level
 - Genetics
 - Medications
 - Anatomic/physiologic abnormalities
 - Chemical exposure
 - Preexisting conditions
- **Psychologic/Social**
 - Stress

Puberty in Rett Syndrome

Natural History Study Data 2013

- ◆ US girls with RTT achieve Tanner II averages
Breast 9.3 years \pm 1.81 years¹
Pubic hair 8.79 years \pm 1.69 years¹

compared to general US population average age 9.96 \pm 1.8 years

- ◆ Pubertal growth spurt absent in RTT²

1 Unpublished data based on 248 females in NHS

2 Tarquinio et al. Neurology October 16, 2012 vol. 79 no. 16 1653–1661

Precocious puberty

- ▶ **Changes too early**
 - Know norms for RTT
- ▶ **Breast growth, menstruation, pubic or underarm hair, rapid growth, acne, body odor**
- ▶ **Causes depend on type – central or peripheral**
- ▶ **Risk factors**
 - Female
 - African American
 - Obese
 - Exposure to sex hormones – supplements, creams
 - Other medical conditions

Precocious Puberty Definitions

Non-Rett females

- African American → Breast *or* pubic hair <6 yrs
- Caucasian → Breast *or* pubic hair <7 yrs
- All → Breast *and* pubic hair <8 yrs

Precocious puberty

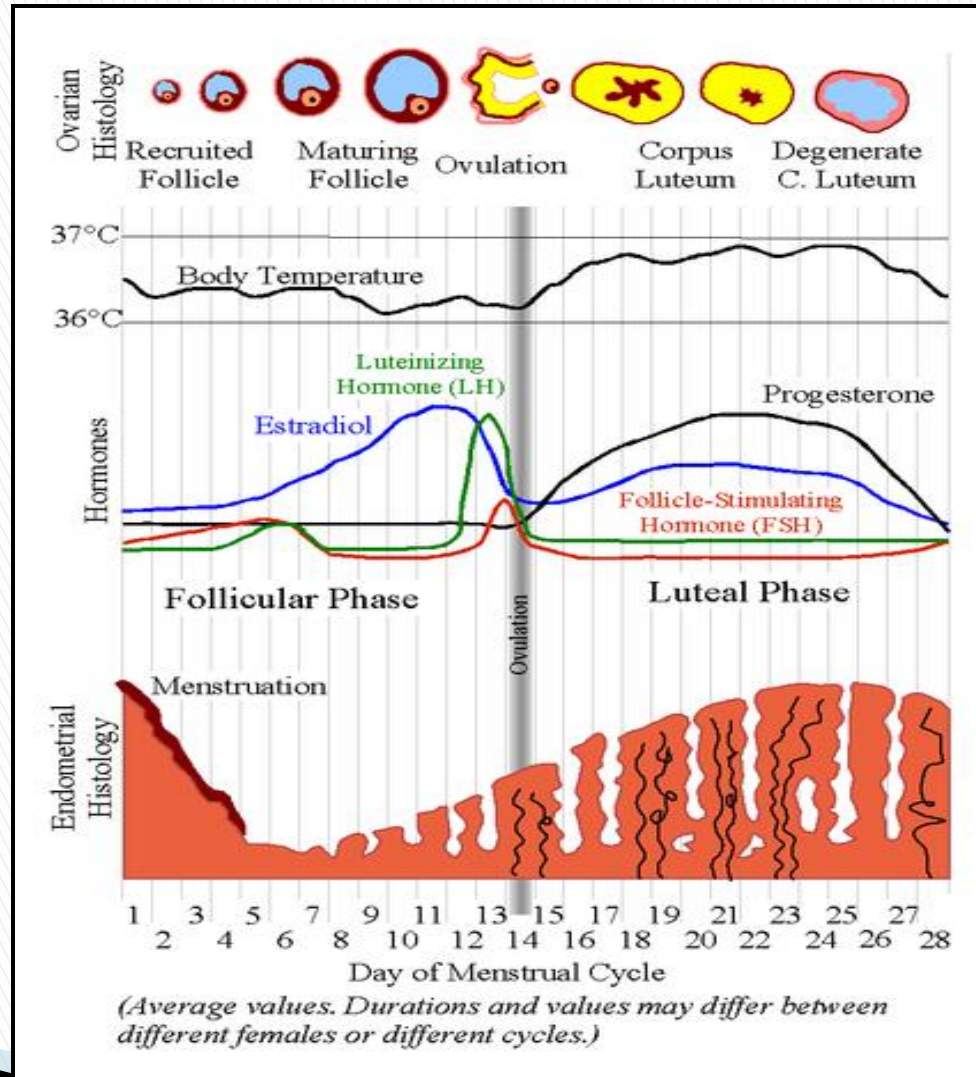
- ▶ May result in short height
- ▶ Endocrinologist visit
 - Review history and exam
 - Blood test
 - Gn-RH
 - thyroid
 - Xray of wrist and hand
 - MRI
- ▶ Treatment
 - Central type – Lupron monthly injections until reaches normal age for puberty

Menarche

- **Marked by start of menstrual cycle usually in Tanner IV**
- **Influenced by body fat**
 - **17% BF required to begin menstruation and 22% BF to maintain¹**
- **Variable experiences**

¹ American Academy of Pediatrics and Committee on Sports Medicine and Fitness. Pediatrics. 2000;106:610

Menstrual Cycle



Menarche and Rett Syndrome (RTT) Natural History Study Data – 2013¹

- Mean (average) age of menarche
 - RTT = 12.14 years¹
 - Non RTT – US = 12.5 years²
 - Non RTT – Canada = 12.72 years³

1 Unpublished data


2 Anderson SE et al. Pediatrics 111(4 Pt 1): 844–50

3 <http://www.ncbi.nlm.nih.gov/pubmed/21110899>

Related Issues of Menstruation

- **Discomfort– PMS/Cramps even prior to menarche**
 - Behavior clues
 - Violence/aggression/self-abuse
 - Crying/Tantrums
 - Restlessness
 - Irritability
 - Change in socialization
 - Meds, warm packs, baths and massage
- **Hygiene**
 - Pads and tampons
 - Menstrual flow is odorless until it comes in contact with air and bacteria
 - Bathing and meticulous personal care essential
- **Seizures**

Fathers only

- ▶ Share responsibility just like always
 - ▶ Biologic function
 - ▶ No accusations just because of Tanner stage
 - ▶ Same child as the day before
 - ▶ Everyone needs you as much as ever
 - ▶ Don't use as an excuse
 - ▶ Single dads
- 

Fathers only

▶ Breast development

- Bra types

▶ Periods

- Last anywhere from 2–7 days, average 5 days.
- Repeat on average every 28 days (“the menstrual cycle”) but can repeat anywhere from 21 to 35 days.
- Can be sporadic and unpredictable
- Usually irregular for 1st couple of years

Fathers only

- ▶ **Sanitary products – Keep array on hand**
 - Pantyliners for light flow
 - Regular sanitary napkins for heavier days/nights
 - What are wings??
 - Night pads, for bedtime or really heavy periods
 - Wrap in paper to discard in garbage
 - Tampons
 - Read insert for placement
 - Swimming
 - Toxic Shock Syndrome

Fathers only

► Hygiene

- Change pads min of every 4 hours during the day
- Can add to diaper
- Send products to school
- Baths are good!
- Deodorant on your “sweet” girl

► Don't be embarrassed to ask for help

- Fathers on RettNet
- Web-based Father's only sites
- Female buddies
- School nurses

Variants in development

- ▶ **Thelarche – breast development**
 - Premature – < 1 year, but may be benign
 - Delayed – no development by age 13 years
- ▶ **Pubarche – pubic hair growth**
 - Premature – < 7 yrs in Caucasian/ < 6 yrs in African American
 - Delayed – > 13.5 yrs
- ▶ **Menarche – menstruation**
 - Premature – < 9 yrs cause for discussion/evaluation
 - Delayed – if > 3 yrs beyond thelarche or ≥ 15 yrs → primary amenorrhea

Where can things go wrong?

Brain – pituitary or hypothalamus



Thyroid



Adrenals

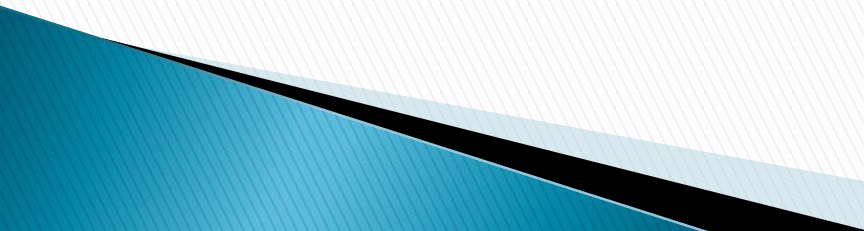


Ovaries




Reproductive tract – uterus or vagina

“THAT” behavior that causes parental angst

- ▶ Wanting to duplicate “good feeling” is normal
 - ▶ Medications (SSRIs) may be helpful option
 - ▶ As receptive language ability matures, begin basic message
 - Private behavior to be done in a private area
 - Will provide private time and space when possible
 - When not possible, acknowledge, remind and redirect CALMLY
 - May require consistent repetition and reinforcement
 - Avoid negative remarks/actions
- 

Factors to consider

- ▶ **Physical causes**
 - Poor hygiene
 - Irritating or tight clothing
 - Rashes, UTI, vaginal irritant or STD
 - ▶ **Evaluate medications**
 - Some have these side effects
 - ▶ **Assess lifestyle**
 - Boredom
 - No private time
 - ▶ **Analyze private space and opportunity**
- 

**Don't
FORGET!**




As she matures....

- ▶ **Become comfortable yourself**
- ▶ **Talk to your daughter about what is happening to her body**
- ▶ **Find a physician/NP who is comfortable**
- ▶ **Keep a diary to note patterns**

Medications and Procedures for Menstrual Management and Birth Control



Menstrual Management and Birth Control– *a very personal decision*

- ▶ Let nature take *her* course
 - ▶ Hormonal methods
 - ▶ Oral Contraceptives/Birth Control Pills
 - ▶ Depo–Provera injection
 - ▶ Topical skin patch
 - ▶ Vaginal rings
 - ▶ Intrauterine device (IUD)
 - ▶ Surgical methods
 - ▶ Endometrial ablation
 - ▶ Hysterectomy
- 

Why consider menstrual management?

- ▶ Hygiene
 - ▶ Comfort
 - ▶ Safety
 - ▶ Health conditions that are exacerbated by hormonal cycle, such as seizures
- 

Hormonal methods

Hormonal Method	What it is and why it is used	Other considerations
<p>Oral contraceptives</p> <p>Types:</p> <p>Combination:</p> <p>21–28 day – long list</p> <p>90 day – Seasonale®</p> <p>Seasonique®</p> <p>326 day – Lybrel®</p> <p>Progestin only</p> <p>“Mini pill”</p>	<ul style="list-style-type: none"> • Pills containing varying levels of synthetic estrogen and/or progesterone • 21, 28, 90, or 365 days administration • Given daily by caregiver • Used to regulate periods, reduce cramping or heavy menstrual flow, protect against pregnancy, or stop hormone fluctuations that cause seizures 	<p>Pros:</p> <ul style="list-style-type: none"> • Well-understood • Improves bone density • Decreases cancer risk <p>Cons:</p> <ul style="list-style-type: none"> • Increased risk of deep vein thrombosis (blood clot) in non-ambulatory • Nausea, vomiting, headaches, weight gain, irregular bleeding, hypertension

List of Combination Oral Contraceptives

- Alesse® (containing Ethinyl Estradiol, Levonorgestrel)
- Apri® (containing Desogestrel, Ethinyl Estradiol)
- Aranelle® (containing Ethinyl Estradiol, Norethindrone)
- Aviane® (containing Ethinyl Estradiol, Levonorgestrel)
- Azurette® (containing Desogestrel, Ethinyl Estradiol)
- Balziva® (containing Ethinyl Estradiol, Norethindrone)
- Beyaz® (containing Drospirenone, Ethinyl Estradiol, Levomefolate)
- Brevicon® (containing Ethinyl Estradiol, Norethindrone)
- Cesia® (containing Desogestrel, Ethinyl Estradiol)
- Cryselle® (containing Ethinyl Estradiol, Norgestrel)
- Cyclessa® (containing Desogestrel, Ethinyl Estradiol)
- Demulen® (containing Ethynodiol, Ethinyl Estradiol)
- Desogen® (containing Desogestrel, Ethinyl Estradiol)
- Enpresse® (containing Ethinyl Estradiol, Levonorgestrel)
- Estrostep® Fe (containing Ethinyl Estradiol, Norethindrone)
- Femcon® Fe (containing Ethinyl Estradiol, Norethindrone)
- Gianvi® (containing Drospirenone, Ethinyl Estradiol)
- Jolessa® (containing Ethinyl Estradiol, Levonorgestrel)
- Junel® (containing Ethinyl Estradiol, Norethindrone)
- Kariva® (containing Desogestrel, Ethinyl Estradiol)
- Kelnor® (containing Ethynodiol, Ethinyl Estradiol)
- Leena® (containing Ethinyl Estradiol, Norethindrone)
- Lessina® (containing Ethinyl Estradiol, Levonorgestrel)
- Levlen® (containing Ethinyl Estradiol, Levonorgestrel)
- Levlite® (containing Ethinyl Estradiol, Levonorgestrel)
- Levora® (containing Ethinyl Estradiol, Levonorgestrel)
- Lo/Ovral® (containing Ethinyl Estradiol, Norgestrel)
- Loestrin® (containing Ethinyl Estradiol, Norethindrone)
- Loestrin® Fe (containing Ethinyl Estradiol, Norethindrone)
- LoSeasonique® (containing Ethinyl Estradiol, Levonorgestrel)
- Low-Ogestrel® (containing Ethinyl Estradiol, Norgestrel)
- Lutera® (containing Ethinyl Estradiol, Levonorgestrel)
- Lybrel® (containing Ethinyl Estradiol, Levonorgestrel)
- Microgestin® (containing Ethinyl Estradiol, Norethindrone)
- Microgestin® Fe (containing Ethinyl Estradiol, Norethindrone)
- Mircette® (containing Desogestrel, Ethinyl Estradiol)
- Modicon® (containing Ethinyl Estradiol, Norethindrone)
- MonoNessa® (containing Ethinyl Estradiol, Norgestimate)
- Necon® 0.5/35 (containing Ethinyl Estradiol, Norethindrone)
- Necon® 1/50 (containing Mestranol, Norethindrone)
- Nordette® (containing Ethinyl Estradiol, Levonorgestrel)
- Norinyl® 1+35 (containing Ethinyl Estradiol, Norethindrone)
- Norinyl® 1+50 (containing Mestranol, Norethindrone)
- Nortrel® (containing Ethinyl Estradiol, Norethindrone)
- Ocella® (containing Drospirenone, Ethinyl Estradiol)
- Ogestrel® (containing Ethinyl Estradiol, Norgestrel)
- Ortho Tri-Cyclen® (containing Ethinyl Estradiol, Norgestimate)
- Ortho Tri-Cyclen® Lo (containing Ethinyl Estradiol, Norgestimate)
- Ortho-Cept® (containing Desogestrel, Ethinyl Estradiol)
- Ortho-Cyclen® (containing Ethinyl Estradiol, Norgestimate)
- Ortho-Novum® 1/35 (containing Ethinyl Estradiol, Norethindrone)
- Ortho-Novum® 1/50 [DSC] (containing Mestranol, Norethindrone)
- Ovcon® (containing Ethinyl Estradiol, Norethindrone)
- Portia® (containing Ethinyl Estradiol, Levonorgestrel)
- Previfem® [DSC] (containing Ethinyl Estradiol, Norgestimate)
- Quasense® (containing Ethinyl Estradiol, Levonorgestrel)
- Reclipsen® (containing Desogestrel, Ethinyl Estradiol)
- Safyral® (containing Drospirenone, Ethinyl Estradiol, Levomefolate)
- Seasonale® (containing Ethinyl Estradiol, Levonorgestrel)
- Seasonique® (containing Ethinyl Estradiol, Levonorgestrel)
- Solia® (containing Desogestrel, Ethinyl Estradiol)
- Sprintec® (containing Ethinyl Estradiol, Norgestimate)
- Sronyx® (containing Ethinyl Estradiol, Levonorgestrel)
- Tilia® Fe (containing Ethinyl Estradiol, Norethindrone)
- Tri-Legest® Fe (containing Ethinyl Estradiol, Norethindrone)
- TriNessa® (containing Ethinyl Estradiol, Norgestimate)
- Tri-Norinyl® (containing Ethinyl Estradiol, Norethindrone)
- Triphasil® (containing Ethinyl Estradiol, Levonorgestrel)
- Tri-Previfem® [DSC] (containing Ethinyl Estradiol, Norgestimate)
- Tri-Sprintec® (containing Ethinyl Estradiol, Norgestimate)
- Trivora® (containing Ethinyl Estradiol, Levonorgestrel)
- Velivet® (containing Desogestrel, Ethinyl Estradiol)
- Yasmin® (containing Drospirenone, Ethinyl Estradiol)
- Yaz® (containing Drospirenone, Ethinyl Estradiol)
- Zenchent® (containing Ethinyl Estradiol, Norethindrone)
- Zovia® (containing Ethynodiol, Ethinyl Estradiol)

Hormonal methods

Hormonal Method	What it is and why it is used	Other considerations
Contraceptive Patch (Ortho-Evra®)	<ul style="list-style-type: none">• Patch of synthetic estrogen and progesterone• Placed on lower abdomen, upper arm, buttocks or torso• Replaced weekly• Periods every month• Used to regulate periods, reduce cramping or heavy menstrual flow, protect against pregnancy, or stop hormone fluctuations that cause seizures	<p>Cons:</p> <ul style="list-style-type: none">• Long-term health affects not studied in developmental disorders (DD)• Increased risk of deep vein thrombosis (blood clot) in non-ambulatory• 60% more estrogen exposure• Reduced effectiveness in >198 pounds• Reports of those with DD removing prematurely• Skin reactions

Hormonal methods

Hormonal Method	What it is and why it is used	Other considerations
Levonorgestrel IUD (Mirena®)	<ul style="list-style-type: none">• Progestin released by device placed in uterus• Effective for 5 years• Can be used to reduce blood loss and pain associated with menstruation, in addition to preventing pregnancy.	<p>Cons:</p> <ul style="list-style-type: none">• Must be inserted by physician• May need sedation for GYN exam and insertion• Risk of uterine perforation• Insertion may be difficult and painful in those who have not had children• Risk of infection if sexually active• Regular string checking for placement

Hormonal methods

Hormonal Method	What it is and why it is used	Other considerations
Depo-Provera®	<ul style="list-style-type: none">• Injection of Progestin• Given every 3 months in buttocks or arm• Used to regulate periods, protect against pregnancy	<p>Cons:</p> <ul style="list-style-type: none">• Must be given by RN or MD• Reduces bone density – not recommended for RTT• Can cause heavy, irregular bleeding• Can cause significant behavior changes• Can cause significant weight gain• Long-term effects in DD not known

Hormonal methods

Hormonal Method	What it is and why it is used	Other considerations
Vaginal Rings (NuvaRing®)	<ul style="list-style-type: none">• “Self” – inserted vaginal ring changed once a month• Combination estrogen and progesterone• Birth control but monthly menstruation and uncertain reduction of menstrual flow	<p>Pros:</p> <ul style="list-style-type: none">• Not a daily pill <p>Cons:</p> <ul style="list-style-type: none">• Dependent on others for insertion• Same risks as combination BCP• Vaginal infections, increased discharge, and irritations

Deep Vein Thrombosis Risks and Contraceptive Considerations

*WHO US Medical Eligibility Criteria for Contraceptive Use – 2010

TYPE	RECOMMENDATION Surgery with prolonged immobilization (ie in a wheelchair)	RECOMMENDATION Surgery without prolonged immobilization (ie “ambulatory”)
Combined OC, patch, ring	Unacceptable health risk	Advantages generally outweigh risks
Progestin only pills, depo provera, implants	Advantages generally outweigh risks	No restriction
IUD (levonorgestrel-releasing/LNG and copper)	LNG - Advantages generally outweigh risks Copper – No restriction	No restriction for both

Surgical methods

Hormonal Method	What it is and why it is used	Other considerations
Endometrial Ablation	<ul style="list-style-type: none">• Outpatient procedure• Endometrial lining is purposely removed or destroyed• Methods include laser, heat, electricity freezing, or radio waves• Local, spinal or general anesthesia• Used to decrease menstrual flow	<p>Pros:</p> <ul style="list-style-type: none">• Short recovery• May result in permanent stop of menstruation <p>Cons:</p> <ul style="list-style-type: none">• May result in permanent changes in uterine anatomy• Risk of lacerations and burns• Usual surgical risks

Surgical methods

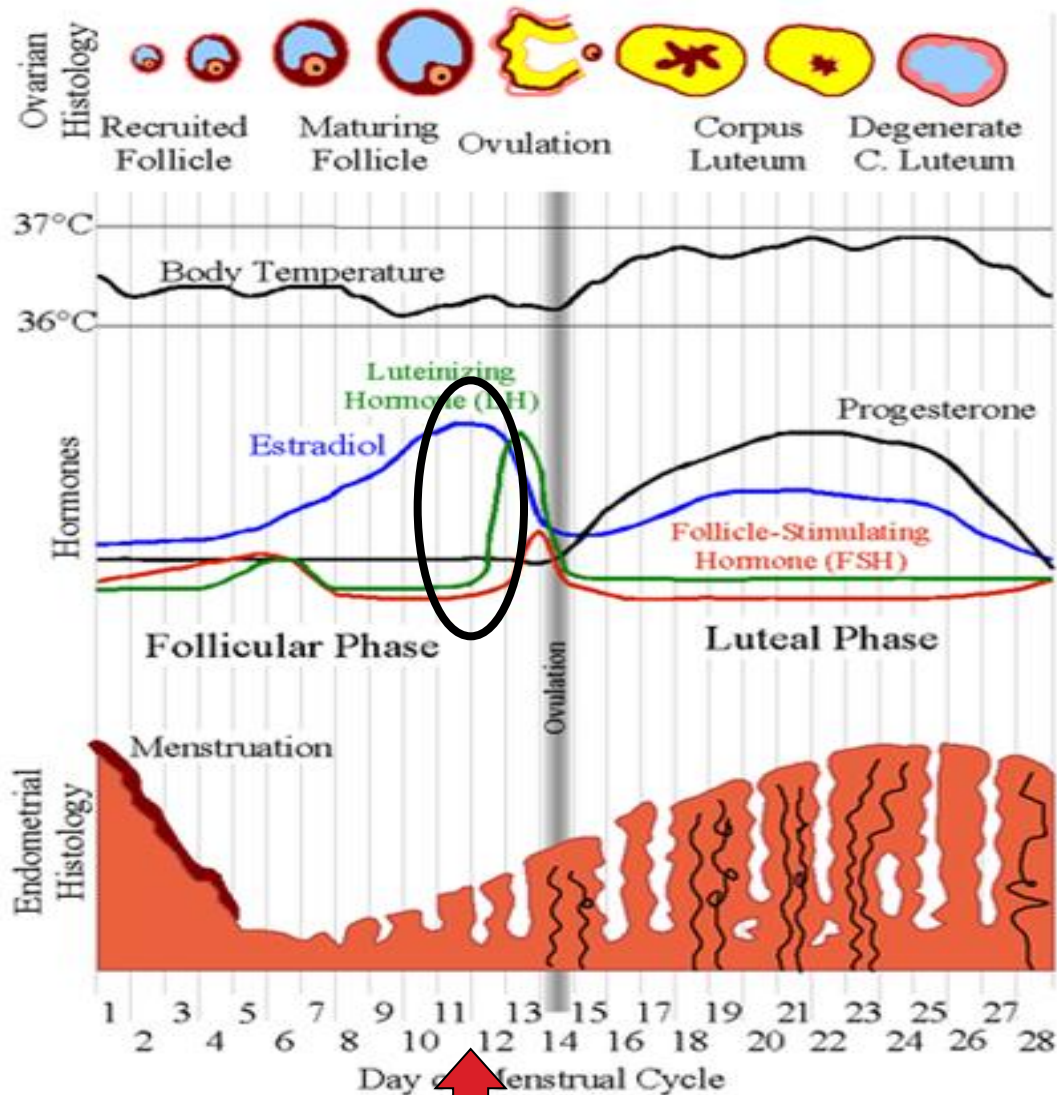
Hormonal Method	What it is and why it is used	Other considerations
<p>Hysterectomy</p> <ul style="list-style-type: none">• Total – uterus and cervix, +/- ovaries• Subtotal – uterus only• Complete – uterus, cervix, ovaries, and fallopian tubes• Radical – uterus, cervix, upper vagina, and parametrium. Often includes lymph nodes, ovaries and fallopian tubes	<ul style="list-style-type: none">• Inpatient procedure• General anesthesia• Techniques variable<ul style="list-style-type: none">AbdominalMiniLaparotomyVaginalLaparoscopy	<p>Pros:</p> <ul style="list-style-type: none">• Permanent and complete• Uncomplicated management after initial procedure• Decreases cancer risk dependent on extent of procedure <p>Cons:</p> <ul style="list-style-type: none">• Major surgery risks• Significant recovery time• DVT risk increases if immobile post op• May be difficult and costly medical/legal process

Hormones, Seizures, and Antiepileptic Medications



Relationship Between Seizures and Hormones

- ▶ Hormones influence seizure occurrence
 - *Estrogen* – excitatory affect on brain cells
 - *Progesterone* – inhibitory affect on brain cells
- ▶ Seizures associated with ovulation or menstruation are called *catamenial epilepsy* and are caused by hormone fluctuations




(Average values. Durations and values may differ between different females or different cycles.)

Seizures and Womanhood

- ▶ Seizures may increase during puberty
 - Hormone fluctuations
 - Sleep disruption
 - Antiepileptic drug blood levels may be adversely affected by
 - Fluid retention
 - Rapid weight gain
 - Oral contraceptives
- ▶ Women with epilepsy are 4–7 times more likely to have irregular cycles
- ▶ Seizure and menstrual cycle diary

Catamenial Epilepsy Treatment Options

- Adjusting existing seizure medications during cycle
 - Intermittent perimenstrual medications
 - clonazepam (0.05–0.1 mg/kg/day) or clobazam (5–10 mg/day; up to 30 mg/day)
 - Hormonal manipulation aimed at increasing progesterone
 - Progesterone (days 10–26 of cycle)
 - Combination oral contraceptive (estrogen AND progestin)
 - Diuretics
 - Sleep medications
- 

Effects of Oral Contraceptives on Antiepileptic Medications

- ▶ Decreases levels of **Lamictal™/lamotrigine**
 - May result in increased seizures
 - Higher doses of lamotrigine may be required
 - May experience large fluctuations of lamotrigine between OC active/placebo phase
- ▶ Increases levels of **Dilantin™ /phenytoin**
 - Toxicity
 - Drug levels after estrogen therapy begun
- ▶ No effect on **Depakote™ /valproate** and **Tegretol™ /carbamazepine**

Effects of Antiepileptic Medications on Oral Contraceptives

- ▶ These AED's **increase breakdown** of contraceptives, *making them **less effective***
 - Tegretol reg or XR/carbamazepine
 - Carbatrol/oxcarbazepine
 - Dilantin/phenytoin
 - Topamax/topiramate
 - Phenobarbital
 - Mysoline/primidone
- ▶ These AEDs have **no effect** on contraceptives
 - Depakote/valproate
 - Lamictal/lamotrigine
 - Keppra/levetiracetam
 - Gabatril/tiagabine
 - Felbatol/felbamate
 - Neurontin/gabapentin

Menopause and Aging



Menopause

- ▶ Average age on onset – 51 years (40–65)
- ▶ Anecdotal reports with RTT suggest early aging in appearance, but unsure of impact on age of menopause
- ▶ Changes that occur
 - Ovaries stop making estrogen
 - Change in periods 1st sign – until they stop
- ▶ Periods stop – pathology or menopause?

Menopause and Seizures

- ▶ Menopause generally occurs significantly earlier in women with high seizure frequency
- ▶ Reports of seizures during menopause vary
 - 40% report worsening seizures
 - 27% report improvement of seizures
 - 33% report no change
- ▶ Hormone replacement therapy associated with increase in seizures (more in those with catamenial epilepsy)
- ▶ In RTT, seizures diminish and EEG's tend to improve as women grow older

Health Maintenance and GYN exams

Breast Health

▶ Considerations

- Family history
- Living environment – residential or home care

▶ Signs of problem

- Lump or hard, flat area on breast
- Nipple changes and/or discharge
- Change in size, contour, texture, or temperature
- Swelling in armpit

▶ Breast exams

- Monthly “at home” exam; Annual physician exam; Mammography ? tolerability

GYN Problems

- ▶ **Infection/Vaginitis – non specific**
 - Fecal source
 - Hygiene
 - Bubblebaths
 - Pinworms
 - Masturbation
 - Abuse
- ▶ **Infection/Vaginitis – specific**
 - Intestinal bacteria
 - Yeast
 - STD' s

GYN Problems

- ▶ **Vaginal bleeding**
 - Precocious puberty
 - Trauma
 - Vulvo–vaginitis
 - Foreign body – tampon
 - Urethral prolapse
 - Bleeding disorder
 - Tumor/polyp/fibroid
- ▶ **Amenorrhea**
 - Primary r/o structural abnormality
 - Secondary r/o pregnancy
- ▶ **Carcinoma**

Human Papillomavirus (HPV)

to vaccinate or not vaccinate?

- ▶ **Why?** HPV is most common cause of cervical cancer
- ▶ **When?** HPV is transmitted during intercourse, *including non-consensual*
- ▶ **What?** Cervarix™ and Gardasil™ vaccines
- ▶ **Who?** Preteen girls 11–12 yrs; 13–26 yrs if didn't receive as a preteen
- ▶ **How?** Given as shots; 3 doses over 6 months
- ▶ **Why consider when not sexually active?**
Sexual abuse

Gynecological Exams In Special Populations: *a conundrum*

- ▶ Equal rights protection – all individuals should be treated equally
 - American College of Obstetrics and Gynecology doesn't distinguish between care of those with and without developmental delays
- ▶ Practical application – not necessary if not sexually active
 - Reluctant to subject her to the discomfort

Pelvic exam

- ▶ Pelvic exam – exam of female organs
 - Speculum exam – looks into the vagina
 - Cells can be collected from the cervix (Pap Smear).
 - Discharges from the cervix / vagina can be collected to look for infection.
 - Bimanual exam – gentler, but less effective to see
 - All of the above PLUS feels for abnormalities of uterus, ovaries, vagina, cervix and sometimes rectum
 - Alternative positions rather than stirrups
 - Can perform PAP without speculum

PAP smear

- ▶ Specific part of a gynecological “pelvic exam”
- ▶ Involves gentle scraping of the cells of the cervix.
 - cells are send it to the lab for examination under the microscope to check for abnormal changes.
- ▶ It is a screening test for cervical cancer or precancerous change of the cervix.
- ▶ Blind brush cervical smear less traumatic than scrapping and doesn't require speculum

New Guidelines for PAP

ACS and USPSTF March 2012

- **21–29 years**
 - PAP every 3 years and no HPV test unless abnormal PAP
- **30 – 65 years**
 - PAP and HPV test every 5 years OR
 - PAP alone every 3 years
- **Less than 21 years and Over 65 years**
 - No PAP or HPV test
- **After hysterectomy with no hx of cervical cancer**
 - No PAP
- **Those who have had HPV vaccine**
 - Follow above recommendations
- **High risk –DES exposure, organ transplant, HIV**
 - May require more frequent

Preparing for pelvic exam

- ▶ **Anticipate questions**
 - Period calendar and description of cycles
 - Medications
 - Write down questions
- ▶ **Prepare your daughter**
- ▶ **Insist you be allowed to stay**
- ▶ **Ask for alternative positioning**
- ▶ **Sedatives (for her, not you)**
- ▶ **Consider other options**
 - Ultrasound
 - Blind brush by bimanual exam


Sexual Abuse

**Exploitation and abuse occurs
twice as often in those with
developmental disabilities**



Adults with developmental disabilities are 4–10 times more likely to be abused than other adults

**Over 90% of abusers will be
people you know, trust, and
regularly encounter**



Who could do such a terrible thing?¹


- ▶ Natural family – 16.8%
- ▶ Step family – 2.2%
- ▶ Acquaintances
 - Neighbors and family friends – 15.2%
 - Informal paid services “baby sitters” – 9.8%
- ▶ Strangers – 8.2%
- ▶ Service providers – 44%
 - Direct care staff
 - Personal care attendants
 - Psychiatrists

Parental Roles and Responsibilities

You are her protector

- ▶ **NO ONE THINKS IT CAN HAPPEN TO THEM**
 - “She is ALWAYS with us”
- ▶ **Teach her what is acceptable and what is not**
- ▶ **Ask questions and encourage her to “tell”**
- ▶ **Don’t be so afraid that you ignore the signs**
 - Physical and psychological
- ▶ **Follow your instincts and take action**
 - remove, report, seek care, document everything

Healthy thinking about maturation

- ❖ Realization that physical maturation is **NORMAL**
 - ❖ Recognition of her full potential as a maturing individual
 - ❖ Recognition of normal from abnormal
 - ❖ Keeps her healthy and safe from abuse
- 

Fear list

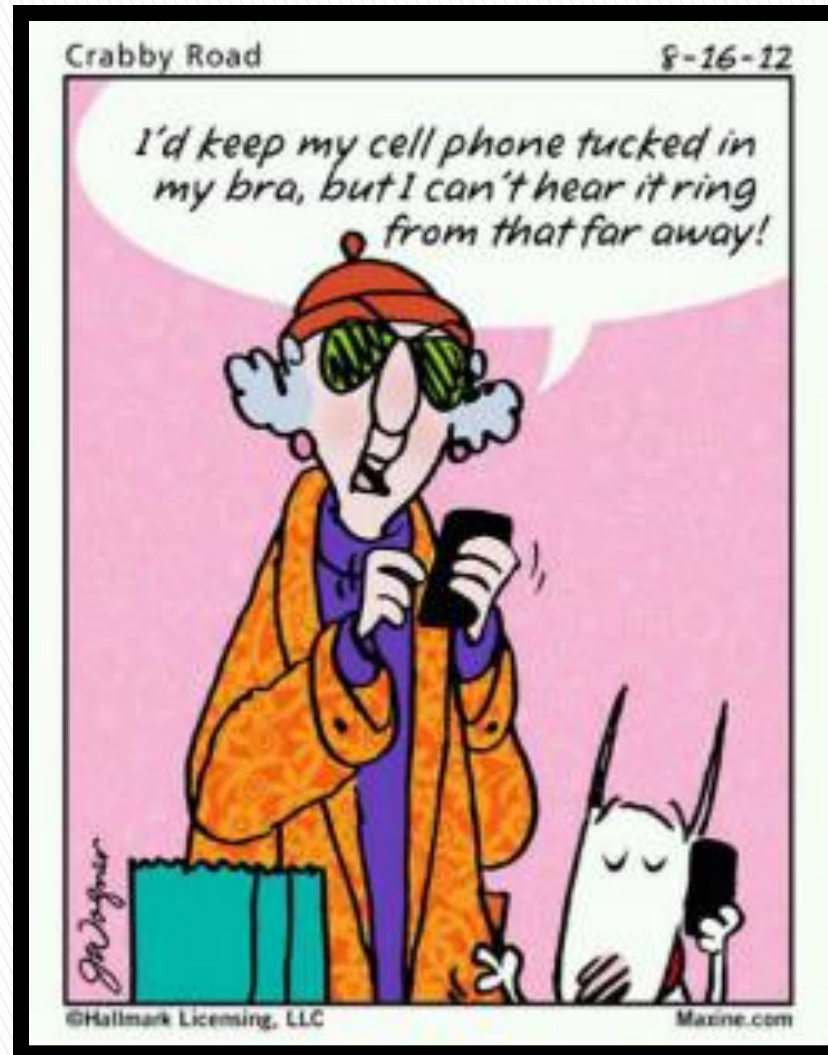
➤ Manageable

- ✓ Pain
- ✓ Hygiene
- ✓ Seizures
- ✓ Another specialist/another exam

➤ Work in progress

- ✓ Mother fears of no help/Father fears of unknown
- ✓ Reminder of life as finite
- ✓ Safety for no exploitation

Questions?



Contact information:
jlane@uab.edu

UAB Civitan Research Center
800-822-2472, ext 7