### Spina Bifida: Complex Decision Points Role of Urodynamics and CIC in Infants

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### Disclosures

Grant/research support: Centers for Disease
 Control and Prevention



- Most born with normal kidneys
- Some at higher risk for renal deterioration
- Risk for renal deterioration is modifiable



- Most born with normal kidneys
  - Historical: 90-95% have normal urinary tract when first evaluated
  - Contemporary (UMPIRE):

RBUS: 105/188 (SFU 0), 76/188 (SFU 1-2)

DMSA: 61/66 no renal defects

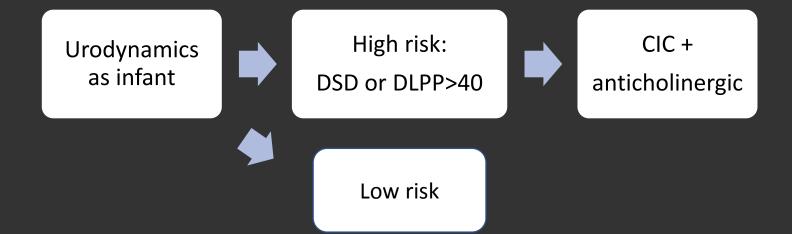


- Some at higher risk for renal deterioration
  - DSD
  - DLPP > 40 cm  $H_2O$



- Renal deterioration is modifiable
  - Historical: 695 adults since 1944
    - 56 deaths with known cause → 33% renal
  - Contemporary (2012): 1128 adults
    - Mean age 26y
    - CKD 26%
    - ESRD 1.3%

### Current proactive approach





## Urodynamics for risk stratification, but...



#### Dr. Noel Tulipan:

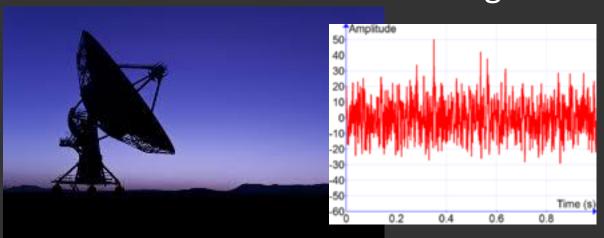
- Neurosurgeon pioneer in utero MMC repair
- "Are the urodynamics bad?"

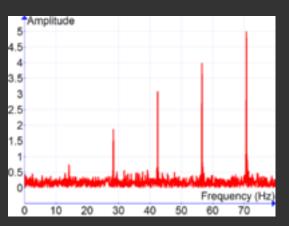


## Urodynamics for risk stratification, but...



#### Signal processing







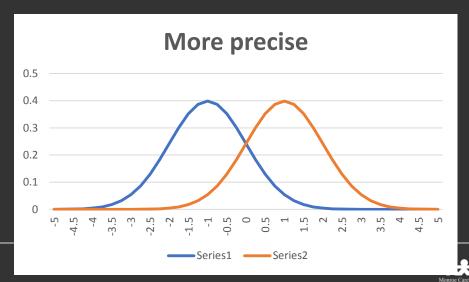
## Urodynamics for risk stratification, but...

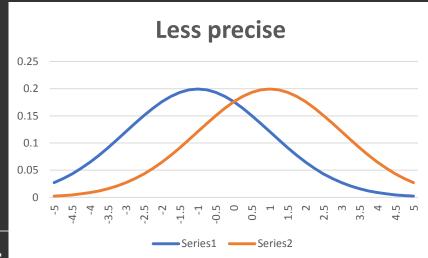
- Subjective interpretation of known risk factors: DSD, DLPP and others
- Low interrater reliability



# Consequences of imprecise measurements

Harder to detect an actual difference





# Differences in bladder function, but not urodynamics!

- Prenatal vs postnatal closure
- MOMS: Difference in voiding status
- Katowice: Better continence, fewer UTIs
- No difference in urodynamics

#### Possible conclusions

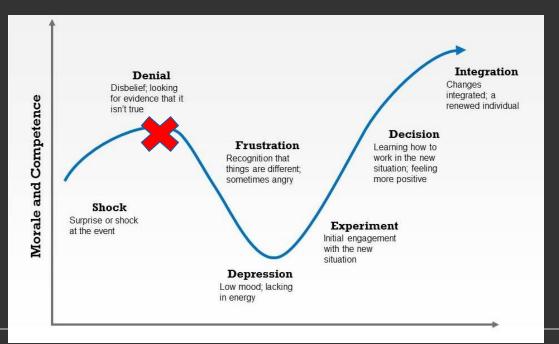
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- Urodynamics could be better



- UMPIRE: Urologic Management to Preserve Initial Renal Function for Young Children with Spina Bifida
- Baseline urodynamics < 4mo
- Initial studies: 5/2015– 9/2017











#### 9 clinical sites

- Interpret
- Refine definitions
- Re-interpret

Outside review
Chris Austin
Duong Tu
John Wiener
Elizabeth Yerkes





Re-refine definitions



# How to (try to) improve urodynamics





# How to (try to) improve urodynamics





# UMPIRE process to improve urodynamics

 All 3 reviewers agreed on overall bladder classification for only 58%





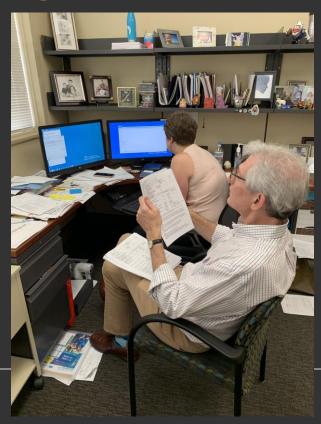
Dr. Earl Cheng:

- "This is bad."
- Convinced 6 other pediatric urologists to sit in a room for 2 days to review urodynamics



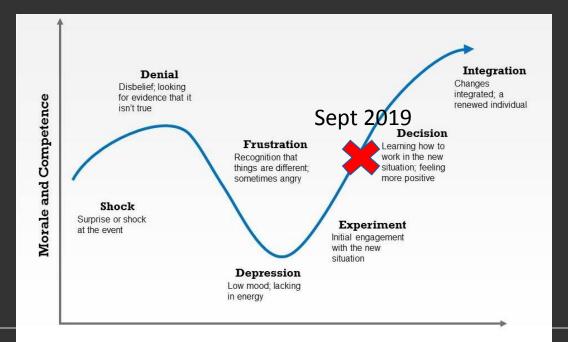
### September 5-6, Chicago







# How to (try to) improve urodynamics





### Lessons learned

- Value of face-to-face communication
- September 5: Agreed on 80/135 (58%)
- September 6: Agreed on 108/158 (68%)



# Lessons learned: problems of technique

- Fill rate
- Volume: To leak? To capacity? To pressure?
- •# Cycles best or worst cycle?
- Catheter in through void?
- Annotation

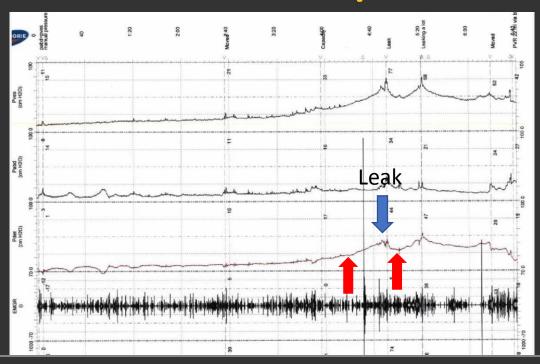


# Lessons learned problems of interpretation

- Definitions not good enough for real world tracings
  - Leak point pressure?
  - DSD?
  - DO?

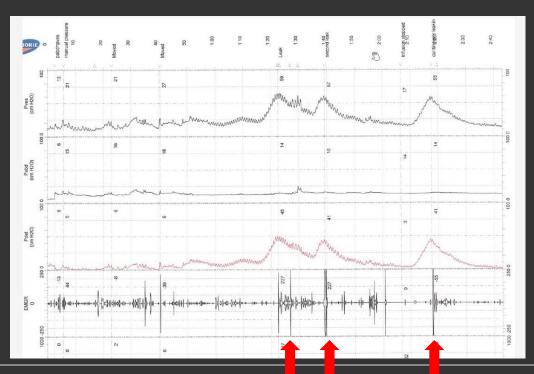


### Where to measure pressure?



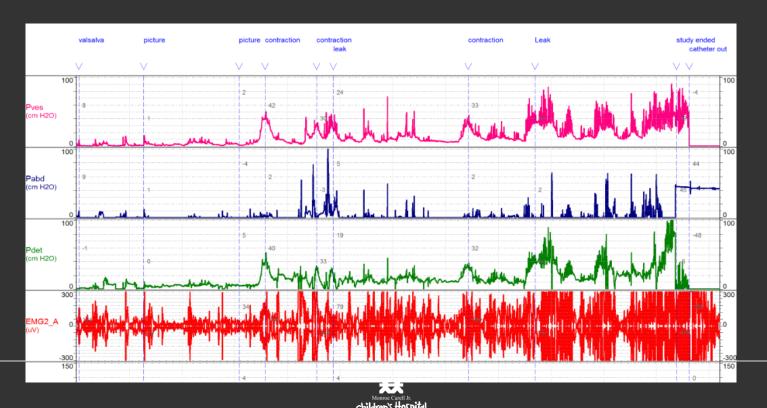


### Is it DSD?

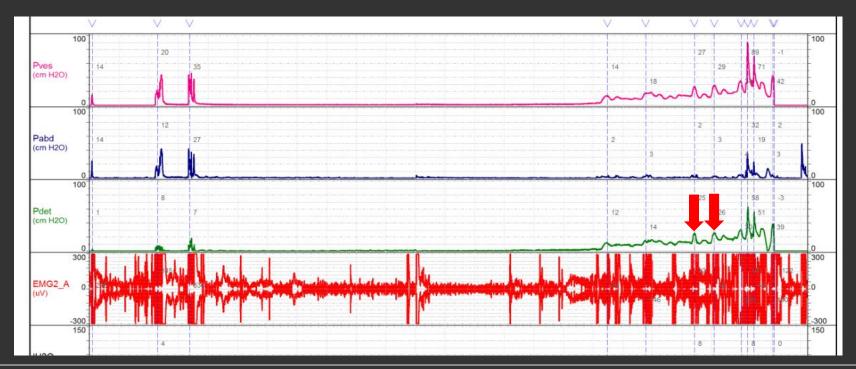




### Is it DSD? Or movement?



### Is it DO?





#### Lessons learned - action item

- Well tempered urodynamics for infants/children with spina bifida
  - Standardize technique
  - Standardize interpretation

### So why bother?

- In 20s
  - CKD rate 26%
  - Low ESRD rate
  - What about 30s, 40s?
- USRDS: average onset of ESRD in spina bifida = 41y

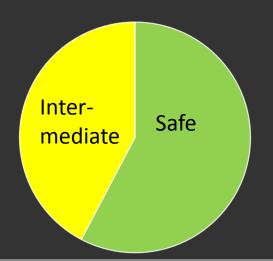
#### Who needs CIC as an infant?

- UMPIRE indications for CIC + oxybutynin, OR
  - DLPP or end fill pressure > 40 cm H2O, and/or
  - DSD
- CIC + oxybutynin for everyone, OR
- Expand urodynamic indications for early intervention



#### "Good" and "bad" intermediates

Originally characterized as safe



Originally characterized as hostile





### Take home points

- Renal deterioration risk is modifiable
- Urodynamics important part of risk stratification
- In research studies, urodynamics only useful if technique and interpretation standardized

