Agenda

- Critical look at MOMS and post-MOMS series
- Unpublished data
- Where we have areas to improve
- What we need
MOMS

- NIH funded
- 2003 to 2017

Pros:
- Randomized
- Adequately powered for primary outcomes
- Multi-center (3)
MOMS

Cons

- No pre-established urologic outcomes
- Secondarily funded sub-study 2005—2010
- Timing of testing standardized
  - US and UDS at 12 and 30 months
  - **UDS technique not standardized**

- **Clinical management (CIC, meds) determined by treating urologist**
Bladder Function After Fetal Surgery for Myelomeningocele

John W. Brock, III, MD, Michael C. Carr, MD, N. Scott Adzick, MD, Pamela K. Burrows, MS, John C. Thomas, MD, Elizabeth A. Thom, PhD, Lori J. Howell, RN, MS, Jody A. Farrell, RN, MS, Mary E. Dabrowiak, MSN, WHNP, Diana L. Farmer, MD, Earl Y. Cheng, MD, Bradley P. Kropp, MD, Anthony A. Caldamone, MD, Dorothy I. Bulas, MD, Susan Tolivaisa, BS, Laurence S. Baskin, MD, for the MOMS Investigators

- Death or need for CIC at 30 months

- 3 independent reviewers: “CIC” if criteria met
  52% in prenatal, 66% postnatal
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- Actually on CIC by 30 mo: 38% prenatal, 50% postnatal
- Of those who met criteria for CIC only 50% in prenatal group and 62% in postnatal group had CIC
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- Urodynamics: no evident difference
- Less trabeculation, less open bladder neck
MOMS School-age Outcomes


✔ No difference in bladder augmentation vs postnatal (6%)

✔ Mean 7.4 y: CIC 62% prenatal vs 87% postnatal (p<0.001) **

✔ More parents report volitional voiding in prenatal cohort (24% vs 4%)
  • Confirmed by uroflow in some
MOMS School-age Outcomes


- Still impacted by variations
  - Threshold for initiation of CIC
  - Parent reported voiding
  - Parents acceptance of “neurogenic bladder” or “not normal”
If it isn’t published, it didn’t happen

- Who is doing what and how?
If it isn’t published, it didn’t happen

• Who is doing what and how?

• Different fetal techniques
• Different UDS
• Different interpretation / threshold for medical management
If it isn’t published, it didn’t happen

• Who is doing what and how?

• Different fetal techniques
• Different UDS
• Different interpretation/ threshold for medical management

• We may not be speaking the same language!
Categorization of Bladder Dynamics and Treatment after Fetal Myelomeningocele Repair: First 50 Cases Prospectively Assessed

Marcela Leal da Cruz,* Riberto Liguori, Gilmar Garrone, Bruno Leslie, Sérgio Leite Ottoni, Sérgio Carvalheiro, Antonio Fernandes Moron, Valdemar Ortiz and Antonio Macedo, Jr.

From the Departments of Urology (MLdC, RL, GG, BL, SLO, VO, AM), Neurosurgery (SC) and Department of Obstetrics-Fetal Medicine (AFM), Federal University of São Paulo and Santa Joana Maternity and Hospital (AFM), São Paulo, Brazil

J Urol 2015
2011, post MOMS

First 50 patients

- 6% VPS rate
**Categorization of Bladder Dynamics and Treatment after Fetal Myelomeningocele Repair: First 50 Cases Prospectively Assessed**

ICCS technique, 1 urodynamicist

**Normal**: stable pressure, no leakage

**High Risk**: overactive with detrusor leak point pressure $>40$ (?CLPP) and filling pressure $>40$

**Incontinent**: overactive with leak $<40$ or leak point pressure $<40$

**Underactive**: underactive with $+PVR$
Categorization of Bladder Dynamics and Treatment after Fetal Myelomeningocele Repair: First 50 Cases Prospectively Assessed

ICCS technique, 1 urodynamicist

**Normal**: stable pressure, no leakage 4%

**High Risk**: overactive with detrusor leak point pressure >40 (?CLPP) and filling pressure >40

→ CIC and Antichol =56%

**Incontinent**: overactive with leak <40 or leak point pressure <40 38%

**Underactive**: underactive with +PVR  CIC 2%
Urological Evaluation of Patients that Had Undergone in Utero Myelomeningocele Closure: A Prospective Assessment at First Presentation and Early Follow-Up. Do their Bladder Benefit from it?

Antonio Macedo Jr., Marcela Leal, Atila Rondon, Valdemar Ortiz, Antonio Fernandes Moron, and Sérgio Cavalheiro

1Department of Urology, Federal University of São Paulo, São Paulo, Brazil
In utero myelomeningocele repair and urological outcomes: the first 100 cases of a prospective analysis. Is there an improvement in bladder function?

Antonio Macedo Jr, Sergio Leite Ottoni, Gilmar Garrone, Riberto Liguori, Sergio Cavalheiro, Antonio Moron, Marcela Leal Da Cruz
A comparative analysis of bladder pattern of patients that underwent *in utero* versus postnatal myelomeningocele repair. *Macedo J Urol in press 2019*

**Initial CMG**
- Group 1 (prenatal): n= 88  DO 76.8%; high risk 56%
- Group 2 (postnatal 1\textsuperscript{st} seen after one year): n= 86  high risk 50 %
- Group 3 (postnatal 1\textsuperscript{st} seen before one year) n=38  high risk 50%
• 14 patients > 5 years
• 71 % F
• 86% use CIC 79% in diaper
• 14 patients > 5 years
• 71% F
• 86% use CIC          79% in diaper

PRENATAL CLOSURE DOES NOT IMPROVE BLADDER OUTCOMES
Prenatal myelomeningocele repair: Do bladders better?

Maya Horst, Luca Mazzone, Thomas Schraner, Christine Bodmer, Ueli Möhrlein, Martin Meuli, Rita Gobet

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30 prenatal closures 2010-2015

8 pt with 2 years followup vs. 8 consecutive postnatal closures

- 50% “normal” bladders in prenatal
- CIC 50% vs 100% of postnatal **
30 prenatal closures 2010-2015

8 pt with 2 y followup vs. 8 consecutive postnatal closures

- 50% "normal" bladders in prenatal
- CIC 50% vs 100% of postnatal **

DOES IMPROVE BLADDER OUTCOMES?
Evaluating Bladder Function and Safety in Prenatal Fetoscopic Versus Prenatal Open Myelomeningocele Repair

Jonathan Gerber, MD, Paul F. Austin, MD, Alexandra N. Borden, PA-C, William E. Whitehead, MD, Jonathan Castillo, MD, Heidi Castillo, MD, Michael A. Belfort, MD, Duong D. Tu, MD. Texas Children's Hospital, Houston, TX, USA.

• POMR (n=15) vs FMR (n=13)
• Inclusion: baseline CMG within 9 months and followup within 18 months.
• Initial UDS, 73% of POMR patients were high risk
  • 36% improve without intervention
• 54% of FMR patients were high risk
  • 43% improve without intervention
• At follow up, 40% of POMR high-risk vs 7.7% of FMR
Nearly 100 fetal closures

Significant revisions in technique over time

Observed increase clinical tethered cord compared to open cohort

Other outcomes?
18 patients, fetal closure elsewhere
50% developed clinical tethered cord

This is not good for the bladder—are some closures more at risk?
Single-center vs Multi-center?

• Urodyamics → management

• Consistent subjectivity vs compounded subjectivity?

• It will be difficult to understand what we are doing
Three Phase Counseling

- **Phase 1:** 2-3 hours about spina bifida
  - Group consultation: MFM, NICU, Ped Surg, NS, Fetal nursing, SW, Genetics
  - Includes expectation for long term followup and participation in MDC

- **Phase 2:** 1-2 hours, same team
  - Why to consider fetal repair, maternal risks, implications prematurity

- **Phase 3:** Same team + anesthesia
  - Anesthesia for mother and baby
  - What happens if intraoperative distress
  - Sign surgical consent
Phase 4? Transition of Care

- Who is going to be providing the urologic care?
- Have we prepared the family adequately?
- Have we made the connection?
Our good friend urodynamics...it does matter but there are issues
HAPPY BIRTHDAY !!