

# The making of fetal surgery: revisited

## Establishment of an interdisciplinary center for open fetal surgery for spina bifida

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### Abstract

Respecting the criteria set out by the MOMS Trial<sup>1</sup>, the Maternal-Fetal Management Task Force in the Position Statement on Fetal MMC repair<sup>2</sup>, the ACOG Committee Opinion<sup>3</sup> and the DGGG Committee Opinion<sup>4</sup> the establishment of the first interdisciplinary fetal surgical center for the open treatment of the Spina bifida in Germany, at the Heidelberg University Hospital was possible.

However, highly selected cases<sup>5</sup>, a multidisciplinary coordination of care, continuous review of the procedure (uterine exposure, closure, PNCH technique), reevaluation of goals and preparedness for the unimaginable are paramount.

“Prenatal surgery for MMC reduced the need for shunting and improved motor outcomes at 30 months but was associated with maternal fetal risks. ... The trial was stopped for efficacy of prenatal surgery ...”, *MOMS Trial, NJEM, 2011*<sup>1</sup>

“...it is a highly technical procedure with potential for significant morbidity and possible mortality, even in the most experienced hands; *should only be offered at facilities with expertise, in multidisciplinary teams* and facilities able to provide intensive care.” *ACOG Committee Opinion 550, 2013*<sup>3</sup>

“... due to the increased risk, high complexity, required infrastructure and adequate training of specialists ... should be limited to specialized centers and be performed in as an interdisciplinary approach *in close cooperation with competent, well established international programs.*” *DGGG Committee Opinion on fetal surgery 193, 2013*<sup>4</sup>

“It is essential to *establish minimum criteria for centers offering open MMC repair* to ensure optimal maternal and fetal outcomes and patient safety” *Position Statement of fetal MMC repair, AJOG, 2014*<sup>2</sup>

### Methods

*...should only be offered at facilities with expertise, in multidisciplinary teams ...*

#### Infrastructure

- One of the largest medical centers in Germany
- 15 hospitals, over 50 clinical departments
- 1930 beds, over 1 million patients each year
- Most active biomedical research center in Germany

#### Multidisciplinary approach

- Fetal Care Team (4 Physicians)
- Pediatric Neurosurgery (2 Physicians)
- Neonatal Intensive Care (3 Physicians)
- Anesthesiology (3 Physicians)
- Maternal Fetal Advocate (1 Midwife)
- Genetic Counseling (1 Physician)

#### Expertise and Services

- Individual members have extensive expertise
- Experienced in MFM, Hysterotomy, EXIT, Critical Care Obstetrics, Early Preterms
- Extensive expertise in Postnatal Closure of MMC
- Experience in working as a group (EXIT procedures, High Risk Pregnancies) with adequate annual volume of procedures

*... in close cooperation with competent, well established international programs ...*

#### Guidance and Training

- Cooperation with the St. Louis Fetal Care Institute - Teaching, Mentoring, Evaluation, Perioperative care, On Spot experience in St. Louis as a Team, exported training

*... is essential to establish minimum criteria for centers offering open MMC ...*

#### Evaluation, Pre- / OP / Postop management

- Strict adherence to the MOMS Protocol
- Operation in adherence to the St. Louis Protocol
- STL Colleagues present in the OR for the first cases
- 24h MFM/OB/Neo and Anae availability

#### Counseling: full disclosure and non directive

- Multidisciplinary, multiple days, nondirective
- Discussion about:
  - other available therapies and centers (postnatal, fetoscopic, abortion)
  - limitations and possible complications and long term outcomes
  - Institutional experience and cooperation
  - fertility and subsequent deliveries
  - Prior decision, a 24h reflective period is respected

#### Long Term Care

- Multidisciplinary Spina Bifida Center with longstanding experience available in Heidelberg and referral centers
- Long Term Evaluation Protocol in place

#### Outcomes, data registries and reporting

- Collaborative and interdisciplinary review and standardized evaluation of the maternal and fetal data
- For quality assurance adherence to available registries to track outcomes and data and maintain transparency
- Long Term outcomes reporting and participation in long-term data collection and evaluation in cooperation with other German and international centers

### Discussion

As a major collaborative effort, under the umbrella of the University Hospital Heidelberg, the first interdisciplinary German center for the prenatal treatment of the spina bifida has been established.

Using one of two the primary models of training, the exported training, in which following an initial interdisciplinary visit of the German team to St. Louis, an experienced group from the Saint Louis Fetal Care Institute traveled to our center to train our staff in our own environment establishing the capacity for the open fetal surgery for the MMC.

Coordinated by the Department for Maternal Fetal Medicine, in adherence to international recommendations, a fetal board was established. Candidate cases are discussed by a multidisciplinary panel and evaluated against existing standards, offering a maximum security and the highest standard by combining the knowledge and expertise of a team.

#### References

1. A randomized trial of prenatal versus postnatal repair of meningomyelocele, Adzick et al., *NEJM* 364, 2011.
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ACOG – American College of Obstetrics and Gynecology  
DGGG – German Society of Obstetrics and Gynecology  
MOMS – Management of MMC Trial<sup>1</sup>  
MFM – Maternal Fetal Medicine  
PNCH – Pediatric Neurosurgery  
ANAE – Anesthesiology  
NEO – Neonatology  
MMC - Meningomyelocele

