The Scope of Care at a Fetal Center

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Objectives

- Define the role of Maternal-Fetal Medicine specialists in patient care
- Recognize indications for referral to a fetal center
- Augment patient care with multidisciplinary approach to management of high-risk pregnancies
What is a MATERNAL-FETAL MEDICINE (MFM) subspecialist?

A physician who has advanced knowledge and training in medical, surgical, obstetrical, fetal, and genetic complications of pregnancy & their effects on both the woman and fetus.

MFM Subspecialists provide:
1. Consultations
2. Co-management
3. Transfer of care
for women with complex conditions before, during, and after pregnancy.

MFM Subspecialists provide peer and patient education:
AND
perform research on innovative approaches and treatments.

MFM subspecialists work with ALL OBSTETRIC PROVIDERS including physician assistants, nurses, NPs, CNMs/CMs, family physicians, and obstetrician-gynecologists to manage HIGH-RISK PREGNANCIES.

What is a HIGH-RISK PREGNANCY?

1. Sick women get pregnant
2. One that threatens the health or life of the woman or her fetus.
3. Pregnant women get sick

EXISTING CONDITIONS, such as high blood pressure, obesity, diabetes, or being HIV-positive.
Rates of Gestational Diabetes (GDM) and preeclampsia have DOUBLED in the last 14 years.

MULTIPLE GESTATION
3.5% of all babies born were TWINS, TRIPLET OR HIGHER ORDER MULTIPLES.
The number of MULTIPLES Born in The U.S. is at an ALL-TIME HIGH.
140,000 births in the U.S.

PROBLEMS WITH THE FETUS
Birth defects affect one in every 33 babies born in the U.S. each year.

60% of women of reproductive age are obese or overweight.

COMPLICATIONS from PREVIOUS PREGNANCIES
- e.g. preterm birth, pre eclampsia, IUGR

Birth defects are the leading cause of infant deaths, accounting for 20% of all infant deaths.
The Maternal-Fetal Medicine subspecialists’ role within a health care system

- To promote early access and sustained adequate prenatal care for all pregnant women, we encourage collaboration with obstetricians, family physicians, certified midwives, and other providers
  - Preconception, prenatal and postpartum care counseling and coordination
- The MFM subspecialist functions most effectively within a fully integrated and collaborative health care environment

TABLE 1

Scope of maternal-fetal medicine

The discipline of maternal-fetal medicine includes preconception care, specialized prenatal care and intrapartum care, obstetric and medical complications of pregnancy, diagnosis and management of fetal anomalies, fetal complications, and fetal testing. Within this scope of practice, it is recommended that, when consultation with a maternal-fetal medicine subspecialist is needed, the obstetric care provider consults with the subspecialist as soon as the condition is identified. It is recognized that the training and experience acquired by obstetric care providers may allow them to manage some complicated pregnancies. Some items listed below may not constitute high-risk conditions (e.g., breast-feeding, contraception), but are part of the continuum of care provided by maternal-fetal medicine subspecialists as well as other obstetric care providers.

Preconception care

Preconception evaluation of women to optimize maternal and perinatal outcomes. Examples include women with underlying illness, previous adverse pregnancy outcomes, or considering advanced reproductive technology.

Specialized prenatal care

1. Evaluation of pregnant women needing counseling regarding prenatal care issues and nutrition
2. Ultrasound: standard, limited, and specialized (e.g., detailed sonography, fetal echocardiogram, Doppler studies)
3. Prenatal diagnosis, aneuploidy screening, and fetal therapy (e.g., amniocentesis, fetal blood sampling and transfusion, fetal thoracentesis and thoracocentesis, fetal placement of fetal vesicocentesis and vesicocentesis, placenta, laser, fetal surgery)
4. Genetic screening for women at increased risk for genetic disorders

Labor and delivery and associated complications

Any antepartum patient admitted for "other than delivery" support for intrapartum care including before labor; first, second, and third-stage issues; intrapartum fetal monitoring; anesthesia and analgesia; operative vaginal delivery; cesarean delivery; trial of labor after cesarean.

Obstetric complications

1. Recurrent pregnancy loss
2. PTB prevention
   a. Asymptomatic (e.g., prior second-trimester loss, possible cervical insufficiency), prior PTB, molar pregnancy complications; short cervical length, issues related to coagulopathy, previous, or other interventions for prevention of PTB
   b. Symptomatic (PPROM, PROM, <34 wk gestation)
3. Meconium complications
4. Malpresentation and malposition
5. Shoulder dystocia
6. Abnormal third stage of labor
7. Placenta accreta, increta, percreta
8. Second- or third-trimester vaginal bleeding
9. Preeclampsia with severe elements (eclampsia with HELLP syndrome or end-organ damage
10. Severe postpartum hemorrhage
11. Cesarean hysterectomy
12. Acute fatty liver of pregnancy
13. Amniotic fluid embolism

Maternal complications

1. Hypertensive disorders
2. Cardiac disease
   a. Congenital heart disease
   b. Arrhythmias
   c. Valve disease
   d. Cardiomyopathy
   e. Pulmonary hypertension
   f. Coronary artery disease
   g. Heart transplant
### CONDITIONS APPROPRIATE FOR MANAGEMENT AT A FETAL CENTER

**Fetal anomalies**

1. Structural abnormalities  
2. Family history of abnormality  
3. Aneuploidy or increased risk for aneuploidy  
4. Teratogen exposure  

**Fetal complications**

1. Threatened miscarriage (including medical and surgical management)  
2. Multifetal pregnancies (including, but not limited to, mono/di twins, mono/mono twins, higher-order multiples; fetal growth restriction of 1 fetus; twin-twin transfusion syndrome; fetal reduction)  
3. Growth disorders  
   a. Growth restriction  
   b. Macrosomia  
4. Infections (eg, cytomegalovirus, toxoplasmosis, parvovirus, Herpes, varicella)  
5. Fetal death  
6. Hemolytic disease (red cell alloimmunization)  
7. Neonatal alloimmune thrombocytopenia  
8. Nonimmune hydrops  

**Fetal testing**

1. Antepartum fetal monitoring  
2. Sonographic assessment of amniotic fluid abnormalities  
   a. Oligohydramnios  
   b. Hydramnios  
3. Fetal blood sampling/intrauterine transfusion  
4. Screening for fetal anemia  
5. Fetal muscle/organ biopsy  
6. Fetal skin sampling  
7. Fetal surgery; fetoscopy/embryoscopy
The specialty of MFM has evolved significantly over the last few decades including advances in prenatal diagnosis and fetal intervention.

- Ultrasound
  - MRI
- Improvements in minimally invasive techniques
  - Instrumentation
- Treatments for otherwise lethal fetal disease
- Treatments to improve long-term outcome for non-lethal fetal disease
- Expertise
Diagnosis of a fetal anomaly

- Fetal anomalies affect 3% of all babies born in the United States each year
  - Leading cause of infant deaths (20%)
- Majority are diagnosed at time of anatomy survey between 18-20 weeks
- Impact on family at the time of diagnosis ranges from surprise to life-altering distress

https://www.cdc.gov/ncbddd/birthdefects/data.html
Meningomyelocele
What does this mean?

What can we do?

Who do we talk to?

Where do we go?

Fetal Center
Rationale for in utero repair of myelomeningocele

- “Two hit hypothesis” of resulting damage
  - Failure of closure of the spine
  - During course of pregnancy with trauma from fetal movement and chemical damage from fluid

- Sonographic evidence that central and peripheral nervous system insults may be progressive
  - Chiari malformation & ventriculomegaly often worsen
  - Lower extremity movement can be seen early (<17-20 weeks) then not seen later
  - Clubbing of the feet appears to be progressive

- Plasticity greatest in the young brain and nervous system
Meningomyelocele

- Patient care coordinator
- Genetic counseling and testing
- Ultrasound and MRI
- Fetal echocardiogram
- Consultation with Pediatric Neurosurgery
- Consultation with Pediatric Urology
- Options for prenatal intervention
- Recommendations for management of antenatal surveillance and delivery planning
- Expectations for neonatal treatment and ongoing care
A Randomized Trial of Prenatal versus Postnatal Repair of Myelomeningocele

N. Scott Adzick, M.D., Elizabeth A. Thom, Ph.D., Catherine Y. Spong, M.D., John W. Brock III, M.D., Pamela K. Burrows, M.S., Mark P. Johnson, M.D., Lori J. Howell, R.N., M.S., Jody A. Farrell, R.N., M.S.N., Mary E. Dabrowiak, R.N., M.S.N., Leslie N. Sutton, M.D., Nalin Gupta, M.D., Ph.D., Noel B. Tulpin, M.D., Mary E. D’Alton, M.D., and Diana L. Farmer, M.D., for the MOMS Investigators*

Option for prenatal intervention

- Prenatal repair group had significantly fewer patients who needed shunt placement by 12 months
  - 68% vs. 98% (RR 0.70, 97.7% CI 0.58-0.84)
- Prenatal surgery group had less
  - Moderate or severe hindbrain herniation
  - Brainstem kinking
  - Abnormal 4th ventricle location
- Prenatal surgery group more likely to be able to walk independently
  - 42% vs. 21% (p=0.01)

Gastroschisis
Gastroschisis

- Paraumbilical abdominal wall defect associated with evisceration of fetal intestine
- Incidence 5.3/10,000 births in 2012 in California
- Additional gastrointestinal issues present in 15-25%
  - Malrotation, atresia, stenosis
  - May be due to vascular disruption caused by herniated bowel
- Most favorable prognosis for abdominal wall defects because most cases are not complicated by concomitant anomalies or aneuploidy
- Survival has been reported as high as 97.8%

Vanishing gastroschisis

- Ultrasound
  - Small amount of external bowel
  - Intraabdominal bowel dilation
Vanishing gastroschisis

- 4-6% gastroschisis cases
- Defect can contract or close in utero, leading to strangulation of eviscerated bowel
- Leads to short gut syndrome
  - Extreme short gut <25 cm
  - Long term TPN → liver failure → liver and small bowel transplants
- Mortality rate reported up to 27-70%
- Standard "uncomplicated" gastroschisis mortality rate <10%
Vanishing gastroschisis

- Patient care coordinator
- Genetic counseling and testing
- Consultation with Pediatric Surgery
- Repeat consultation with Pediatric Surgery
- Recommendations for management of antenatal surveillance
- Multidisciplinary delivery planning
- Expectations for neonatal treatment and ongoing care
Sacrococcygeal teratoma
Sacrococcygeal teratoma

- Tumor volume to fetal weight ratio >0.12 before 24 weeks: poor prognosis
- Risks to fetal and maternal health
  - Continued growth of mass → vascular steal → high output cardiac failure, hydrops
  - Solid lesions >10 cm carry high perinatal mortality rate
  - Maternal mirror syndrome
  - Polyhydramnios → preterm labor
- Prenatal surgery option
- Postnatal surgical removal/repair
  - Could be disfiguring
  - Urinary/ fecal incontinence
  - Malignancy
Sacroccocygeal teratoma

- Patient care coordinator
- Genetic counseling and testing
- Ultrasound and MRI
- Fetal echocardiogram
- Recommendations for management of antenatal surveillance and delivery planning
- Consultation with Pediatric Surgery
- Consultation with Pediatric Urology
- Options for prenatal intervention
- Expectations for neonatal treatment and ongoing care
Fig. 1. Management algorithm for fetal sacrococcygeal teratoma (SCT).
Sacrococcygeal Teratoma (SCT) Treatment

Exposure of 26-week fetus through hysterotomy revealing Sacrococcygeal Teratoma (SCT)

https://www.chop.edu/treatments/fetal-surgery-sacroccocygeal-teratoma-sct/about

Closure of skin flaps after resection
Other fetal conditions requiring in utero treatment

- 32 yo G3P2 establishes prenatal care at 8 weeks gestation
- She reports history of her prior infant requiring phototherapy for elevated bilirubin levels
Rh isoimmunization

- Managed with serial MCA Doppler evaluation
Modern scope of interventions

- Fetal blood sampling and intrauterine transfusion
- Vesico- or thoracoamniotic shunt placement
- Cardiac balloon valvuloplasty and stent placement
- Vascular occlusion procedures including laser ablation and RFA for complicated monochorionic twins
- Prenatal stem cell transplantation
- Fetoscopy for laser treatment of twin-twin transfusion syndrome
- Tracheal balloon occlusion for diaphragmatic hernia
- Open fetal surgery for meningomyelocele, CPAM, sacrococcygeal teratoma
- Ex-utero intrapartum treatment (EXIT) for airway obstruction

What is a Fetal Center?

- Multidisciplinary clinic where pregnant women can receive diagnostic services, pregnancy management, prenatal consultation with subspecialists and coordinated planning for delivery
- Single site
  - Many maternal–fetal medicine divisions already provide coordinated fetal care
  - Patients may travel to multiple subspecialist visits
- Provide advanced imaging services
- Provide variety of established fetal therapies
- Innovative approaches to fetal disease
- Support services including social work, palliative care and perinatal hospice services, ethics
  - Complex emotional stressors for families considering options for pregnancy management
- Conduct, facilitate or participate in research if appropriate

<table>
<thead>
<tr>
<th>Level</th>
<th>Activities</th>
<th>Lead</th>
<th>Personnel</th>
<th>Facilities</th>
<th>Additional Organizational Activities</th>
<th>Reporting of Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Diagnosis and management of most congenital anomalies CVS Amniocentesis Vasa previa</td>
<td>MFM</td>
<td>Genetic counselors (certified) Palliative care team Access to pediatric subspecialists</td>
<td>Level II ACOG Obstet unit Level III NICU (AAP certified) Ultrasound unit (ALUM certified)</td>
<td>Monthly multidisciplinary case conferences</td>
<td>None</td>
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<tr>
<td>II</td>
<td>Same as level I + midlevel therapy intrauterine transfusion Laser for TTS+ Selective reductions in MC twins Shunt placements</td>
<td>MFM with additional training in fetal intervention OR pediatric surgeon with additional training in fetal intervention</td>
<td>Same as level I + Access to pediatric radiologist with additional training in fetal MRI Access to pediatric cardiologist with additional training in fetal cardiology Dedicated nurse coordinators</td>
<td>Same as level II</td>
<td>Database and IT support Weekly multidisciplinary case conferences Internal quality improvement program</td>
<td>Transparent de-identified outcomes reporting</td>
</tr>
<tr>
<td>III</td>
<td>Same as level II + Full availability of all evidenced-based maternal–fetal interventions Additional developing interventions Cardiac interventions Fetoscopic tracheal occlusion Fetoscopic MMC repair</td>
<td>Co-directionship with both above individuals</td>
<td>Same as level II + Full-time pediatric radiologist with additional training in fetal MRI Full-time pediatric cardiologist with additional training in fetal cardiology Anesthesiologist with experience in uterine relaxation techniques Ethicist Research coordinators (certified)</td>
<td>Same as level II</td>
<td>Same as level II + Medical school affiliation CME approved MFM fellowship rotations OR fellowship in fetal intervention (latter preferred) Ongoing research efforts in clinical trials or animal research Innovation approval committee</td>
<td>Transparent de-identified outcomes reporting</td>
</tr>
</tbody>
</table>

CVS, chorionic villus sampling; MFM, maternal–fetal medicine; ACOG, American College of Obstetricians and Gynecologists; NICU, neonatal intensive care unit; AAP, American Academy of Pediatrics; ALUM, American Institute of Ultrasound in Medicine; TTS, twin–twin transfusion syndrome; NIC, monochorionic; MRI, magnetic resonance imaging; IT, information technology; MMC, myelomeningocele; ACR, American College of Radiology; IAC, Intersocietal Accreditation Commission; GME, graduate medical education.

No one specialist can take sole responsibility for the treatment of a mother and fetus with a complex condition.

Box 1. Components of Experienced Fetal Care Team
- Functional team experienced in collaborative patient care with a designated leader
- Care coordinator
- Fetal echocardiographer
- Fetal surgeon—with experience performing hysterotomy and closure (this could be a pediatric surgeon or a perinatologist)
- Genetic counselor
- Magnetic resonance imaging—equipment and expertise to perform and interpret fetal cases
- Maternal fetal medicine specialist
- Neonatology
- Obstetric anesthesia
- Pediatric anesthesia
- Pediatric neurosurgeon
- Social work
- Ultrasound—equipment and expertise to perform and interpret fetal cases

Consider both maternal and fetal well-being

Ensure proper training, credentialing, infrastructure and support are in place

Mechanisms for provision of training, regulation and oversight should be developed

Collaborative registries and research

Development of training programs

Balance between development of new centers, skills, and patient access
Why chose a fetal center?

- Advanced prenatal diagnosis
  - Ultrasound and MRI
- Fetal intervention and treatment if indicated
- Preparation for continuity of care from fetal life, through delivery, neonatal stabilization and management, and even early childhood
- In most cases a fetal care center does not assume care, but rather *augments* care
Indications for referral to a fetal center

Fetal anomalies

Fetal conditions requiring treatment

Complicated monochorionic twin gestations

Conditions We Treat at the Center for Fetal Diagnosis and Treatment

Total cases: 26,831

- Complicated Multiples: 3,817
- Miscellaneous: 3,916
- Neurologic Abnormality: 3,340
- Congenital Heart Disease: 3,216
- Myelomeningocele (Spina Bifida): 2,712
- Lung Lesion: 2,547
- Genitourinary Defects: 2,556
- Gastrointestinal Anomalies: 2,099
- Congenital Diaphragmatic Hernia: 1,695
- Neck Mass: 505
- Sacrococcygeal Teratoma: 372
- Hematologic/Imune: 56

Types of birth defects, by percentage and number, referred to the Center for Fetal Diagnosis and Treatment (CFDT) at CHOP (1995 - December 2020). Congenital heart disease is evaluated by the Fetal Heart Program, in collaboration with the CFDT.

https://www.chop.edu/centers-programs/center-fetal-diagnosis-and-treatment/volumes-outcomes
Patient-centered fetal care centers

- “Our goal will be to present an opinion that encourages the advancement of thoughtful practice, ensuring that current and future patients have realistic access to centers with a range of fetal therapies with appropriate expertise, experience, subspecialty and institutional support while remaining focused on excellence in care, collaborative scientific discovery, and maternal autonomy and safety.”

CHOC Children's and UC Irvine Health have committed to developing the first comprehensive fetal diagnostic and treatment program in the region.
FUTURE SPECIAL DELIVERY
The Fetal Care Center of Southern California

UCI Health CHOC

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