From Newborn Loss
Come the Gift of Hope

National Association of Catholic Chaplains
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Presenters

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Who We Are

- Director of Spiritual Care

- Education Coordinator-Critical Care and Organ Donation Liaison

- Priest Chaplain
About Binghamton

- Binghamton lies in the state's Southern Tier region near the Pennsylvania border, in a bowl-shaped valley at the confluence of the Susquehanna and Chenango Rivers. About 4 hours north of New York City. About 1.5 hours from Syracuse.

Of Binghamton Fame…

- Carousels
- Spiedies
- IBM, BAE, Lockheed Martin, Chobani Yogurt
- Binghamton University, Broome Community College, Davis College
About Lourdes

- Member of Ascension Health
- Licensed for 267 inpatient beds
- Ambulatory Surgery, Diabetes Center, Wound Care Program
- Bariatric Program
- LAH, Hospice, Palliative Care, Home Health Support
- Mission in Motion Mobile Mammogram
- Center for Oral Health Mobile Dental Clinic

About Lourdes...

- 11 Surgical Suites
  - Ophthalmology Surgery/Laser Treatment
  - GI Endoscopy Suite
  - Arthroscopy
- DaVinci Robotic Surgery Procedures
  - 2 Minimally Invasive Surgical Suites
- Outpatient Services
  - Diagnostic Imaging
  - Outpatient Laboratory
About Lourdes Hospital
Women’s & Children’s Services
• Low risk, family centered maternity program
• 1200 births per year
• 20 single rooms with private baths
• 2 operating rooms on the unit
• Patients from multiple counties in NY and PA
• No NICU, PICU, or capability of long term mechanical ventilation of an infant.

December 2012
• A Doctor has to give a patient some hard news.
• Then Mike receives THE call.
• Stress, what’s running through my mind.
• CMS/Joint Commission Requestor Regulations.
What is Anencephaly?

- Pronounced an-en-sef-uh-lee
- Neural tube defect
- Anencephaly is a terminal birth defect in which a baby is formed without parts of the brain and skull.
- Prevalence: 1 in 1000 U.S. pregnancies
- Several end in miscarriage or elective termination.

- (NIH statistic)
Cause

• As the neural tube forms and closes, it helps form the baby’s brain and skull (upper part of the neural tube), spinal cord, and back bones (lower part of the neural tube).
• If the neural tube does not close, the brain does not form beyond the brain stem.
• The baby does not see, hear, smell, taste or touch.

About Anencephaly

• Anencephaly can be diagnosed during pregnancy or after the baby is born.
• There is no cure or standard treatment for anencephaly.
• Don’t progress to brain death and live for several hours after being born.
Pathways to Donation

• Donation after Brain Death.
• Donation after Circulatory Death (DCD).

Our First Meeting

• Knew donation pathways.
• Did not want mechanical ventilation.
• My offer.
• What I learned afterward.
• Our journey from January through June.
Alison & Daniel’s Birth Plan

- Planned Caesarian Section
- Introduce Ourania to Calliope
- Birthday cake
- Baptism
- Take Ourania outside to feel the sun
- Take Ourania home

Involved Departments

- Social work
- Hospice
- Now I Lay Me Down to Sleep
- Educating the WCS unit
- Nurses were specifically prepared…
Spiritual Care

• Clergy involvement
  – Fr. Tim: the family’s pastor
    • Gowned and ready for the Sacrament soon after birth
  – Fr. Kris: Hospital Chaplain
• Carrying out the plan

Donation

• Ourania is the second time that a baby in the U.S. has donated for research.
Background

• Both parents, Alison & Daniel are devout Roman Catholics.
• Both professors in chemistry at Broome Community College.
• Early in the pregnancy they learned their baby would be anencephalic.

• Strong family bond in decision making.
• Choice of a Catholic Hospital that supports their beliefs.
• A challenging ministry for both family and the Priest.
Hospital Ministry

• Helping the family in their journey to vent their feelings (pain, sorrow, fear, anxiety, uncertainty or joy, laughter and hope).
• The need for prayer, compassion and the sacraments on a daily basis.

Hospital Ministry

• Learning experience.
• My multiple roles as Priest Chaplain.
• Unexplained bond between Ourania and me.
Alison and Daniel’s Perspective

• Hope dies last.
• To be with their baby daughter Ourania, to baptize her so she is with the Lord and that there was a purpose and destiny for her birth.

My Perspective

• My hospital and theological learning about human dignity,
• following the example of our Lord in his healing ministry – prayer, physical touch, need for God and God’s compassion,
• the Sacrament of Baptism the faith in the Promise of the Resurrection after death was realized.
Conclusion

• Spiritual Care is an integral part of Healthcare.
• The Holistic approach to Healing ministry.
• Parents expressed gratitude to all the individuals involved in their care.