SLIDE 1

Treatment decisions for seriously ill newborns are especially difficult. New births are normally hopeful events filled with great anticipation and joy. When an infant is born with a hopeless prognosis, it is a devastating event.

Some infants are born with abnormalities that are life threatening. Even if these can be addressed, the child may face a lifetime of severe disabilities. No one wants a child to suffer. Caring for an infant with serious health problems can be a great burden on the family, emotionally, physically and financially.

Is it ever morally acceptable to let nature take its course and allow seriously ill newborns to die naturally, without medical interventions?

SLIDE 2 - Treatment decisions for seriously ill newborns

While adult patients have autonomy and can, either directly or through their agents, participate in making their own health care decisions, infants and young children do not have autonomy. Therefore, decisions about life-sustaining treatment of seriously ill children must be made by others.

In most cases, these decisions are made by the child’s parents. In these cases, the presumption is that the parents will make treatment based on the same basic standards of medical indication, best interest, benefits and burdens, and relational potential.

In rare cases, when there is doubt whether the parents are looking after their own best interest rather than the child’s, the courts may choose to get involved. When this happens a surrogate decision maker is appointed to represent the interest of the child.

SLIDE 3 – Standards of Treatment and Decision Making

As we discussed in Module 3, there are four basic standards that are commonly considered when making decisions to forgo or withdraw life-sustaining treatment of a patient that does not have decision making capacity. These considerations apply to small children and newborn infants as well as adults who no longer have decision making capacity.

Considerations include: medical indications, benefits and burdens, best interest, and relational potential. Medical indications focus on the physical condition of the patient. Does the treatment address the underlying pathology? Is the patient healthy enough to undergo treatment?

Benefits and burdens compares the pain and suffering that treatment imposes on the patient and compares it to the benefits that the patient will receive from the treatment. Benefits and burdens also
considers the riskiness of the treatment and the likelihood that it will be successful. Does treatment provide more benefits than the burdens that it imposes on the patient?

Best interest focuses on the quality of life after treatment. This standard takes into consideration the values of the patient. Will the patient’s future life be made better by the treatment or will that life become unbearable by the patient’s standards. If the patient’s standards are not known will the resulting quality of life be acceptable to most reasonable people?

Relational potential focuses on the patient’s ability to have continued “meaningful relationships” during or after treatment, even if those relationships are minimal. Without such relationships, life loses its appeal.

SLIDE 4  **BABY K – Anencephalitic birth**

One of the most important cases involves the birth of Baby K, a child born with a functioning brain stem but no brain. Having a functioning brain stem allowed her heart to beat and her lungs to function. The lack of a functioning brain meant that she would remain irreversibly comatose throughout her life and treatment would normally be considered futile.

Contrary to the medical staffs’ recommendation, Baby K’s mother requested that she receive life sustaining treatment. The hospital continued treatment but sought to overturn the mother’s decision through the courts.

Meanwhile the mother sought a ruling from the courts asking it to require the hospital to treat her daughter under the Americans with Disabilities Act (ADA) and the Emergency Medical Treatment and Active Labor Act (EMTALA). The courts eventually ruled for the mother, stating that Baby K could not be denied treatment based on EMTALA.

The court did not rule on whether the hospital was discriminating based on disability. This was a narrow decision based on the law that made it illegal for hospital emergency rooms to refuse patients until they were stable.

SLIDE 5  **BABY K**

The courts did not taken into consideration the principles that medical ethicists commonly use to make decisions regarding life-sustaining treatments. In the Baby K case, the decision was decided solely on the bases of a law that requires hospital emergency rooms to treat patients regardless of their status or ability to pay.

The principle used here was justice. A justice approach looks at events through lens of such things as fairness, equality and rights. The reasoning is that all people have the right to emergency medical care. Baby K’s mother requested emergency medical care and therefore the hospital must provide such care. It did not matter that the physicians deemed such care futile.
Baby K’s best interest was not considered, nor was her potential to have meaningful relationships. The burdens imposed on her were not compared to the benefits she received and the medical indications were not considered. Baby K lived for two years before dying.

SLIDE 6 - BABY DOE – DOWN SYNDROME

The Baby Doe case is very different from the case of Baby K. While Baby Doe was born with serious medical issues, the life threatening conditions were easily addressed. Baby Doe was born with Down syndrome. He also was born with esophageal atresia which resulted in his esophagus not connecting with his stomach. Though surgery to correct this condition was routine with a nearly 100% success rate, the parents refused to allow the surgery. Baby Doe died six days later.

Baby Doe was in good physical condition with the exception for the inability to swallow. The surgery to fix the defect was routine and was almost certain to resolve the problem. Therefore the surgery was medically indicated.

Was surgery in Baby Doe’s best interest? Without surgery baby Doe would shortly die. With surgery the child would face the same challenges that anyone with Down syndrome faces. Many people with Down syndrome live full, happy and productive lives. While there are no guarantees, the expectation was that the surgery would provide benefits to the child without imposing burdens on him. Potentially Baby Doe would have the same normal relationships that others with Down syndrome experience.

In 1984 Congress passed the Baby Doe Amendment making the refusal to provide food, water, or medically indicated treatment to a disabled child an act of child abuse.

(U.S.C.A. TITLE 42, CHAPTER 67, Sec. 5106a)

SLIDE 7 - ETHICS COMMITTEES

Cases, like Baby K and the Baby Doe, highlighted the need for some kind of formal structure to insure that ethical issues surrounding patient care were addressed in a balanced and effective manner. The establishment of hospital ethics committees (HECs) are a response to that need. Typical committees consist of physicians, nurses and other healthcare workers, social workers, chaplains, ethicists, and community members.

The underlying goals of ethics committees are to raise consciousness about the moral dimensions of healthcare decision making, to provide a forum ethical discussions within the institution and to give support and direction to healthcare providers and patients alike as they struggle to work through challenging problems. Formally, the committees address these goals through education, policy review and case consultation.

SLIDE 8 - Education
The role of education begins with educating the committee members themselves. While occasionally an ethics committee includes an ethicist, members of the ethics committee are not expected to have formal training in bio-medical ethics. Ethics committees rely on a diverse membership with individuals with special knowledge and a variety of skills. The expertise of the committee as a whole is greater than any particular part.

Education of committee members is a continuing responsibility as new members join the committee and as new issues arise in policy as practice. While individual members are encouraged to pursue their own education individually, a collective approach helps develop a shared language and a common understanding of ethical principles and analytical procedures.

HECs also take responsibility for ethics education for the hospital staff, including doctors, nurses, social workers, and other hospital personnel involved in patient care and treatment. The goal here is to create a culture where moral deliberation is a core part of the hospital culture and everyone involved with patient care is familiar with the ethical resources that the committee represents.

This can be done through forums, discussion groups, or by including select staff members on a cases by case basis. Education is the foundation for all three HEC roles: institutional education, policy development and case consultation.

SLIDE 9 – Policy Review

The need for better policies is often brought to light in the consultation process. Reviewing cases can uncover the need for new policies or show the weakness of existing policies. For example, hospitals need clear-cut policies regarding the treatment of patients who lack decision making capacity.

While the HEC is not ordinarily tasked with developing policy, the committee can and is often asked to contribute to the process of developing policies pertaining to both clinical practice and institutional governance. Often new policies are reviewed by HECs and on occasion the committee proposes changes to administrative or clinical policies.

More commonly, review of existing policies is a regular task for ethics committees. With ever changing technologies, government regulation, and a growing public awareness of new treatments and protocols, clashes between new hospital practices and existing policies are bound to occur.

SLIDE 10 - CASE CONSULTATION

The report of the American Society for Bioethics and Humanities defines healthcare ethics consultation as individuals or groups whose goal is to resolve uncertainties and conflicts “regarding value-laden concerns that emerge in health care.” While all health care professionals typically engage in ethical decision making as part of their everyday duties, healthcare ethics consultants differ in that they take on the a distinctive role of responding to specific ethical concerns that require a distinctive set of competencies.

Sometimes the conflicts that ethics consultants are called to address are between patients and physicians, but they may also be conflicts between members of the healthcare team. Much of this work
can be done informally, before an official ethics consultation is called, by providing an atmosphere where different sides can be heard and where positions can be clarified and articulated. A formal consultation usually consists of a period of fact finding and data gathering, meeting with all interested parties, and then gathering together to make recommendations and suggest paths of action.