

BIOETHICS NETWORK OF OHIO
P.O. BOX 181356
Cleveland Heights, Ohio 44118-1356

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BIO Quarterly BENO

A Publication of The Bioethics Network of Ohio

Volume 17

WINTER 2006

Number 4

PRESIDENT'S COLUMN

*Allyson Robichard, PhD
Cleveland State University*

There has been much discussion about the child whose parents decided the best life-plan for their daughter involved interventions to keep her from developing into a physical adult. I use 'physical adult' quite deliberately since Ashley will never develop even a child's mind, let alone an adult mind. Her parents are faced with making decisions for a being that they would like to take care of, themselves, for as long as is possible. Ashley's permanent cognitive impairment leaves us unable to consider what she herself would want since she will never be able to express such a thing. Indeed, one can rightly wonder to what extent she has wishes at all. In which case, all that is available with respect to her, is consideration of what's in her best interests. But of course, this is interwoven with the interests of her parents too, so we should not be surprised when some of the accommodations appear to favor them.

A very informative article by Nancy Gibbs appeared online at the Time/CNN site <http://www.time.com/time/nation/article/0,8599,1574851,00.html>. In it we are told about the factors considered and the arguments formulated by the Ethics Committee of Seattle Children's Hospital in determining whether or not the interventions proposed were ethically permissible. They used a benefit/burden analysis of the situation to arrive at their conclusion. It strikes me that their analysis is clear, refreshing and correct and leaves detractors [many of whom I think might be mired in the 'yuk factor'] scrambling to make a case showing the interventions ethically impermissible.

Ashley's parents say their goal was "to improve our daughter's quality of life and not to convenience her caregivers." "Keeping Ashley smaller and more portable, [the ethics committee] argue[s], has medical as well as emotional benefits: more movement means better circulation, digestion and muscle condition, and fewer sores and infections." I had not considered how crucially important the ease of manipulating Ashley would be to benefiting her circulation and digestion, not to mention skin integrity and warding off pneumonia. Since Ashley's permanent and extreme cognitive impairment blocks progressing beyond the mentality of an infant, sources of discontent will remain physical. Thus, factors affecting her physical well being are central to thinking about what would give her the best possible existence.

In discussions with some bioethics colleagues, the case has come up. While what I have outlined above

has struck most of us as the best course given the sad situation, we too wondered, as does Gibb in her article, how far would be too far? Could a case be made for the ethical permissibility of limb amputation, to achieve a smaller stature? If the legs were removed prophylactically, presumably it would be a fairly straightforward and uncomplicated medical procedure, like her hysterectomy would have been. It also seems likely she would suffer more, in the short run, since recovery from such a surgery would surely be painful. But, multiple complex and invasive cardiac surgeries for some infants and small children are justified on the ground that an extended and less distressful life benefits them and effective analgesics can be utilized to reduce physical suffering, thereby reducing the burden of such procedures.

Yet somehow, going this far can seem more unsettling than removing her uterus and breast bud tissue. If we think about removing all the things Ashley has no use for, given her cognitive impairment, we might wonder about starting down this road at all. However, there is no perfect alternative, given the state of affairs. Choosing to do nothing is choosing to do something and this too requires analysis. If Ashley were left to grow as she would, the quality of her existence would surely be diminished, when compared with the kind of existence she will now have. Perhaps this is where the balance lies. Considering the burdens and benefits of keeping Ashley a physical child against the burdens and benefits of allowing the infant's mind to exist in an adult woman's body seems to engage us at a particular level. It's difficult to articulate why limb amputation hovers on or steps over the line into a new level. Perhaps it's because although she lacks what would allow us to consider her a person, her physical body appeals to us as the vestiges of such personhood. To deliberately remove legs is to take away a crucial part of this visual cue; thus, altering her in this way strikes us as unacceptable in a way the alterations implemented do not. ∞

FEATURED ARTICLE

GENETIC COUNSELING AND TESTING IN OHIO: CAVEAT EMPTOR?

Commentary on the New Wrongful Birth Statute

*Corey D Perry, MDiv
Grant Medical Center
Student, Capital
University Law School*

As reported in *BIO* Vol. 17, No. 2, Summer 2006, the Ohio Revised Code Section 2305.116 became effective in August 2006, barring civil actions for so-called "wrong-

ful birth” actions in the state of Ohio unless plaintiffs can show that the medical practitioner intentionally or willfully withheld information related to the medical diagnosis. This change altered the manner in which the Ohio Supreme Court had decided such cases, though the change was not as dramatic as it would have been in other jurisdictions where such actions allow for a broader recovery of damages.

Section 2305.116 had been proposed as H.B. 287. H.B. 287 was legislation that was proposed in reaction to the decision rendered by the Ohio Supreme Court in *Schirmer v. Mt. Auburn Obstetric and Gynecologic Associates, Inc.*, 844 N.E. 2d 1160 (2006). For those who are not familiar with this case, it involved the birth of a child with a condition called Trisomy 22, meaning that there is a third 22nd chromosome, resulting in severe and permanent developmental disabilities. This child was born after his parents had received genetic counseling revealing the mother’s chromosomal condition known as a balanced translocation of chromosomes 11 and 22. The effect of this condition was the potential for any children the couple would conceive having severe chromosomal abnormalities that could result in the spontaneous termination of the pregnancy or, if the pregnancy proceeded to term, the birth of a child with severe developmental disabilities.

Once the couple discovered the pregnancy, chorionic villus sampling (CVS) was performed. The results of this test indicated that the child was a female who would be a carrier of the chromosomal condition of her mother but would otherwise have normal development. Subsequent ultrasounds during the pregnancy also reported normal development. Upon delivery, however, it was discovered that the child was not a female carrier of the condi-

tion but, rather, a male child suffering from the chromosomal anomaly.

The parents sought damages for the expenses related to the birth of the child and the pregnancy, the additional cost of raising a disabled child (consequential economic damages), and the emotional and psychological effects of raising a disabled child (consequential non-economic damages). The parents sought these damages on the rationale that, had the genetic testing performed during the pregnancy accurately identified the child as having the chromosomal condition with which he was born, the parents would have elected to have terminated the pregnancy and avoided the birth.

In the course of the litigation, the parents dropped their claim related to the damages for the cost of the pregnancy and birth of their child, narrowing their claims to the consequential economic and non-economic damages. The trial court found that the state of Ohio has not recognized consequential economic and non-economic losses in wrongful birth actions and has only awarded damages for the costs of the pregnancy and delivery. The trial court then dismissed the rest of the case since the parents had dismissed their claim for that loss.

On appeal, the appellate court found that the parents had established a valid claim for the consequential economic losses. However, upon appeal to the Supreme Court of Ohio, the Court found—as had been held at the trial court—the only damages that were actionable in wrongful birth suits in the state of Ohio were those losses suffered in the pregnancy and delivery of the child and not the consequential economic and non-economic losses.

Post-Schirmer

The effect of *Schirmer* was, in and of itself,

Allyson Robichaud, PhD, Editor

a.robichaud@csuohio.edu

Jim Barlow, ThM, Associate Editor

jimbarlow@alltel.net

BIO Quarterly is published four times a year by the Bioethics Network of Ohio, PO Box 181356, Cleveland Heights, OH 44118. Phone: 216.397.4445. www.beno-ethics.org

Submissions to BIO Quarterly are encouraged. Manuscripts may be original material or reprint with permission. Appropriate subject/topics include: issue analysis, cases, report of institutional activity or programs, legislative and policy commentary, and book reviews. Please submit your article electronically to either editor for consideration. Quarterly deadlines are the 15th of February, May, August, and November.

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To determine the damages to the child in a wrongful life action, it would be necessary to compare the value of being to the value of not being.

not particularly significant at one level. The decision added very little to the actual jurisprudence of wrongful birth suits in Ohio. The establishment of negligence in the performance of the CVS or ultrasound tests was not refined. The Court declined to assign liability for the child's birth with a severe developmental disability to the physician's failure to accurately diagnosis and inform the parents of the condition. Rather, it was held that the causation of the child's disability had been caused by the inher-

ent genetic condition of the child's mother. The only element of prenatal torts *Schirmer* affected was the limitation of damages in wrongful birth actions in the state of Ohio to the costs of the pregnancy and delivery.

Ohio had recognized the three primary prenatal tort actions—wrongful pregnancy, wrongful birth, and wrongful life—for several years. The distinctions be-

tween these three actions are these. In a wrongful pregnancy, the parents of a child conceived after a negligently performed sterilization procedure may recover for the costs of the pregnancy and delivery of the unplanned child. Most jurisdictions in the United States recognize such an action.

Wrongful life actions are brought in the event of the birth of an unhealthy child following a negligently performed sterilization or negligent genetic counseling or testing. These actions have been rejected in nearly all jurisdictions, including Ohio. One of the principle reasons for the rejection of such actions is because the assessment of damages is a calculus that courts are unwilling to undertake. To determine the damages to the child in a wrongful life action, it would be necessary to compare the value of being to the value of not being. This is a valuation that the courts have repeatedly refused to undertake, going so far as to say in *Hester v. Dwivedi* "that such weighing falls within the ambit of moral, philosophical, and religious considerations rather than judicial."¹

Wrongful birth actions—like *Schirmer*—are actions brought by the parents of an unhealthy child born after the negligent performance of a test to detect a fetal defect or after negligent genetic counseling. The thrust of this action is that the parents of the child were denied the ability to make an informed decision regarding whether or not to maintain the pregnancy, resulting in the birth of the unhealthy child. In these actions, there is no claim that the performance of the test or negligent counseling caused the defect in the fetus itself. Rather, the claim is, but for the negligent counseling or test, the parents would have

aborted the pregnancy and an unhealthy child would not have been born.

Wrongful birth actions are recognized in many jurisdictions. The first wrongful birth action in America was brought in 1967 in New Jersey in *Gleitman v. Cosgrove*.² However, in spite of a forty-year history, there is a great disparity among the state jurisdictions regarding what damages are recoverable in these actions and varying rationales as to why certain damages are actionable and others are not.

As plead in *Schirmer*, damages may be sought for the expenses of the pregnancy and delivery and the consequential economic and non-economic losses. Jurisdictions such as New Jersey, South Carolina, and Virginia typify the arguments for the recovery of consequential economic damages in these actions from a public policy perspective.³ The holdings in these jurisdictions express the rationale that tort recovery is intended to allow for the loss that the plaintiff has suffered and that, to disallow such a recovery in these instances, would be counter to the purpose and philosophy of tort actions. Further, as noted in *Naccash*, such actions should allow for the recovery of consequential non-economic damages as well, since the burden of raising a child with a severe genetic disability can be just as damaging emotionally and psychologically as it is physically or financially.

Other jurisdictions have also allowed for the recovery of consequential economic and non-economic damages, though along different rationales. Illinois, in *Siemieniec v. Lutheran General Hospital*, implicitly allowed for the recovery of consequential non-economic damages on the ground that such a recovery could be founded on the principle that the parents were within the "zone of danger" provision, which is actionable in Illinois for those who can show that they have suffered emotional and mental effects from witnessing the injury to a related third person.⁴

However, for as many jurisdictions as are willing to recognize wrongful birth causes of action, there are as many that do not recognize the action—such as Georgia and Wisconsin⁵—or limit the damages recoverable to only those damages associated with the pregnancy and delivery of the child. In that respect, the decision in *Schirmer* to likewise limit the recovery of such damages to only those associated with the pregnancy and delivery is not novel. The rationale that is employed in these cases, as was employed in *Schirmer*, is that the valuing of being versus non-being is a calculus that is best left to the arena of public policy and, therefore, to the legislative process.

Post-§2305.116

It is into this area, then, that Ohio has now entered. With the introduction of H.B. 287 and its enactment, Ohio has joined the ranks of those ju-

risdictions that have statutorily restricted actions for wrongful birth. While jurisdictions such as Georgia and Wisconsin have not recognized these torts as a matter of jurisprudence, states such as Minnesota and Idaho have enacted statutes that deny the action altogether.⁶

As in Ohio, these statutes preclude any person pleading a cause for an action in which a fetus would have been aborted but for the act or omission of another person. However, Ohio's statute creates a provision within which such an action may be plead if it can be shown that the actor withheld information from the parent(s) of the child intentionally or willfully. This section of §2305.116 reads: (C) Nothing in this section shall preclude a person from bringing a civil action or from receiving an award of damages in a medical claim based upon an intentional or willful misrepresentation or omission of information related

Ohio has still allowed for recovery where the actions of the practitioner have been so flagrant and egregious as to shock one's conscience

to medical diagnosis, care, or treatment.⁷

What is the legal effect of such a provision? If it can be shown by a plaintiff that a practitioner had knowledge of a fetal defect but withheld that information from the patient or intentionally misrepresented such information to the patient, an action could still be maintained for wrongful birth in Ohio. Is it realistic, however, to be able to establish such a claim? How likely would it be that a practitioner was asked to perform genetic counseling who then, upon discovering a fetal defect, intentionally withheld such informa-

tion from the patient for the purpose of depriving the patient of an informed choice as to whether or not to proceed with a pregnancy? It could be argued that, while unlikely, it is not impossible for such an event to occur.

It could be further argued that where some states, such as Idaho—which adopted its statute in a similar reaction to the verdict in a wrongful birth case, *Blake v. Cruz*⁸—have barred all recoveries for such actions, Ohio has still allowed for recovery where the actions of the practitioner have been so flagrant and egregious as to shock one's conscience and violate the most basic tenets of the practitioner-patient relationship. However, having removed the tort of wrongful birth from the field of medical malpractice and negligence into the realm of an intentional tort, not unlike an assault or battery, has altered the complexion not just of wrongful birth actions themselves but of medical malpractice and the concept of standard of care itself.

The basic premise of medical malpractice is that a duty is owed by the medical practitioner, typically a physician, to the patient. That duty is defined as the standard of care. When the practitioner departs from that standard of care in such a way as to cause an injury to the patient and the patient suffers resultant damages, the practitioner is found to be liable to the patient for those damages. While much debate has raged about the appropriateness of when and how such actions are brought and the resultant damage awards, it would be challenging to find a large constituency in the country that would hold that such a rationale is flawed.

Some may claim, quite accurately, that it is the court that holds the practitioner accountable to the standard

Disagreements over how the system of determining these cases works may exist, but most would agree that some mechanism that operated on these basic premises is sound.

Within medical malpractice, the standard of care is established by the medical practitioners themselves. It is impossible for a court or jury to establish what constitutes the standard of care for the treatment of a particular injury or illness. Courts rely upon the testimony of expert witnesses to establish the standard of care that practitioners within a specialty or area of practice employ and to determine whether or not the practitioner in question deviated from the standard sufficiently to cause the injury to the plaintiff, such that the practitioner is liable for those damages. Some may claim, quite accurately, that it is the court that holds the practitioner accountable to the standard, since no other mechanism exists in our society to recompense the injured party for the practitioner's departure from that standard. In that sense, therefore, the courts enforce the standard established by the practitioners and create the ground upon which those who have been injured by the practitioner's departure may find redress for their injury.

However, if, as in these cases, no grounds exist for recovery apart from a showing of willful or intentional misrepresentation, where do the boundaries of the standard of care for genetic counseling and testing in these jurisdictions lie? Practitioners may claim that the boundaries lie in exactly the same place as they did before—within the community of those practitioners. However, if a patient seeks genetic counseling or testing from a physician in these jurisdictions and that physician departs from that standard of care sufficiently—albeit with no lack of intentionally misleading the patient—as to deprive the patient of the constitutionally protected right to abort the pregnancy through a lack of information

and the patient then gives birth to a child with severe disabilities, where does the patient go to find justice? What redress is available to that patient for the lost privilege of making an informed, protected decision? If there can be no redress, can there be a meaningful standard of care?

Further, while it is currently possible to limit such a liability in such a narrow fashion as with §2305.116, how far can such protection be extended? With the rampant debates regarding tort reform and its necessity, where could such limits be imposed with justifying public policy arguments of preserving medical resources and containing escalating costs?

It alters the landscape not just of wrongful birth actions, but also where, how and why our society chooses to enforce the damages suffered by its citizens.

Where such limitations are imposed, what mechanisms remain available to the society to enforce the standard of care established by the practitioners? Decreased insurance reimbursements? Decreased referrals or business? Strengthened peer review procedures? And even if these mechanisms would serve to provide effective enforcement of those standards, what resources would be available for those injured by those breaches that would inevitably occur?

It is uncertain where or when the issues related to wrongful birth suits and the other prenatal torts will be resolved. Debate has swirled around whether or not wrongful birth actions and the lack of recognition or barring of their pursuit suffer from bad nomenclature. Needless to say, the ongoing division regarding the acceptability of abortion itself fuels the debate. Regardless, the actual effects of these decisions exist in the midst of our society in families such as the Schirmers. While Ohio's enactment of §2305.116 may appear to offer some redress for the most egregious cases, it alters the landscape not just of wrongful birth actions, but also where, how and why our society chooses to enforce the damages suffered by its citizens. Perhaps such concerns will not plague these citizens in the future because of universal coverage—though that will still not necessarily redress the psychological and emotional effects—but for now, those seeking genetic counseling in Ohio do so in an environment that is unique in almost every way from the rest of medical practice in the state and would be well considered to follow the adage, *caveat emptor*, buyer beware. ∞

¹Hester v. Dwivedi 733 N.E. 2d 1161 (2000), at 1166.

²Gleitman v. Cosgrove 49 N.J. 22 (1967).

³New Jersey, see *Berman v. Allan* 80 NJ 421 (1979); South Carolina, see *Phillips v. United States* 575 F. Supp. 1309 (1983); Virginia, see *Naccash v. Burger* 223 Va 406 (1982).

⁴*Siemieniec v. Lutheran General Hospital* 117 Ill. 2d 230 (1987).

⁵Georgia, see *Etkind v. Suarez* 271 Ga. 352 (1999); Wisconsin, see *Slawek v. Stroh* 62 Wis. 2d 295 (1974).

⁶M.S.A. §145.424, subd. 2; I.C. §5-334.

⁷O.R.C. §2305.116(C).

⁸See *Blake v. Cruz* 108 Idaho 253 (1984).

BIOETHICS CASE ANALYSIS COMPETITION 2007

Presented by
The Bioethics Network of Ohio (BENO)

Judged by the Ethics Committee,
St. John West Shore Hospital
Westlake, Ohio

All graduate and undergraduate professional students of any discipline are eligible, including individuals in fellowship or training programs. This case analysis essay competition is sponsored by BENO to stimulate the interest and education of students from multiple disciplines in applying principles of bioethics in healthcare.

Essays must be written in response to the case study below and are **limited to 1000 words**. Participants are encouraged to address various ethical principles and concepts relevant to the case. Entries will be judged on the following criteria:

- ✓Comprehensive discussion
- ✓Consideration of relevant moral principles
- ✓Discussion of compelling ethical arguments
- ✓Persuasive conclusion to the ethical dilemma

Prizes totaling \$1000 will be awarded at the BENO 17th Annual Conference [May 10-11] banquet, Thursday May 10, 2007: first place, \$350; second, \$300; third, \$200, and fourth, \$150.

Essays must be **postmarked by Monday March 26** and mailed to Sister Judy Weirick, Vice President Mission and Ministry, St John West Shore Hospital, 29000 Center Ridge Rd, Westlake, OH, 44145, or received via email by **Monday March 26** to: Judy.Weirick@csauh.com. Please include postal, phone and email contact information.

All entries become the property of BENO. Prizes will be awarded on the basis of the number of entries submitted and the merit of their analysis. Therefore, we reserve the right not to award all prizes. Winning essays may be published in an upcoming

ing issue of *BIO-Quarterly*.

THE CASE

Ms. B is a 77-year-old female residing in a nursing home. She has a history of diabetes and several major strokes, which resulted in aphasia and serious cognitive deficits. She is alert, but oriented only to name. She can speak a few words, but does not follow commands consistently. Ms. B was admitted to the hospital because of new mental status changes and a fever. At the hospital she was diagnosed with pneumonia and a urinary tract infection and treated with antibiotics. A swallow evaluation, done early in the patient's hospitalization, noted poor nutrition, as well as the risk of aspiration. Therefore a permanent feeding tube was recommended by the attending physician. However, it was noted that Ms. B could not give consent for the surgery required to place the percutaneous endoscopic gastrostomy (PEG) tube. As noted, given her cognitive status she was not a competent decision maker. Efforts were made by a social worker to find family or friends who could serve as proxy decision-makers for Ms. B. However, she had no immediate relatives and there were no other relatives or friends known by the nursing home; she seemed to have outlived everyone she knew.

At this point, strong disagreement among members of the medical team developed over the appropriateness of placing a PEG tube, which some argued was "life support," without which the patient would "slowly starve to death." Others noted eating was one of Ms. B's few pleasures in life. There was also disagreement over who had the authority to make this decision. The medical team differed in what they viewed as in the patient's "best interest." Seeking a guardian was not a realistic option, as it would take at least 6 to 8 weeks for the court to even consider the case. Therefore the medical team called for an ethics consult. What sorts of issues, ideas, ethical considerations would be central in any discussion concerning what ought to happen to Ms. B? Given these, what ought to happen to Ms. B?∞

IN THE LITERATURE

Jim Barlow, *ThM*

Seeking the Cure

John Gibeaut

ABA Journal, October 2006: 44-53

It is rare in bioethics literature to find discussion of healthcare fraud, its impact on patient care, or its cost. This article presents a legal view of the issue and is full of interesting and important information.

Gibeaut notes some history of government cheats going back to the Civil War. Fraud (selling

diluted gun powder, rotten rations, selling and reselling diseased/weak horses to the cavalry, etc.) was so bad that Lincoln led Congress to pass the False Claims Act (FCA) of 1863. The FCA, called Lincoln's Law, empowered both the government and private citizens to sue cheaters in court. Today the law is one of the most significant tools used to fight fraud. It is especially effective because private litigants may sue in the government's name. These whistleblowers (called relators in the law) may file claims in secret (called *qui tam*) and may receive a portion of any money recovered.

Originally the FCA and the *qui tam* provision were used regarding general government procurement. However, Congress has taken action beginning in 2007 to use the FCA in aggressively targeting fraud in federally funded healthcare!

In practice, states are now being encouraged to pass their own fraud laws to go after Medicaid theft. And the federal government is making it a worthwhile endeavor for States Attorneys to put resources into investigation and prosecution by doubling and tripling the percentage of recovered funds they may keep.

In reality, **healthcare fraud is the greatest single drain on federal and state treasuries**—not the "\$500 toilet seat." It is a "monster problem." Last year the Medicaid expenditure (roughly 60% federal funds and 40% state funds) was expected to be \$334 billion, and the Medicare expenditure (all federal funds) was expected to be \$343 billion, for a total of \$677 billion. (Contrast these annual costs to Social Security at \$550 billion.) The estimates of healthcare fraud run as high as 10%. This percentage may seem tolerable, but calculate the dollar amount. The new federal encouragement for states to initiate *qui tam* prosecutions is only directed at Medicaid. The Federal Department of Justice is understaffed and does not have the resources to investigate Medicare fraud.

Gibeaut admits there are criticisms of the new program: (1) financial incentives for relator/whistleblower can be millions of dollars, (2) it may attract politically ambitious headline seeking attorneys general, and (3) it may be one more incentive for physicians not to accept Medicaid patients.

The Troubled Transformation of Britain's National Health Service, Rudolf Klein. *NEJM*, July 27, 2006: 409-15.

Envious and sometimes rosy American references to the British National Health Service (NHS) are occasionally punctuated by an interesting peek behind the curtain. These reports/articles are not usually written as an expose' but often do expose realities of "crisis" in the British system that are not

routinely understood by US observers. In reporting on political and systemic changes currently being attempted in the NHS, much is revealed about the shortcomings of their system. Klein writes about (1) the major undertaking to transform the NHS—a “new model” for British healthcare, and (2) how and why the system reached its point of current crisis (his term).

Klein argues first that the crisis is not fiscal. The government promised and delivered sizeable budgetary increases to bring the NHS spending up to that of other European countries. During the period of 1999 to 2007, spending increased from \$75 billion US to \$160 billion, or a rate of 7.3% above inflation. This unprecedented increase is more than double the average increases of previous decades. So the crisis is not due to “fiscal stringency.”

Since its creation in 1948, the NHS has as a healthcare system, become highly centralized and swamped by “hyperactive government” political oversight so that “ministers were answerable for every dropped bed pan in the NHS....” This “command-and-control system” as Klein refers to it, became the center of the crisis characterized by persistently long waiting lists, inefficiency, and wide variations in quality of service.

The new transformative model is a move away from politician-led NHS to a patient-led NHS. “Ministerial fiat” is being replaced by *patient choice* and *competition*. The political-philosophical change over is painful, confusing, and not yet complete, but Klein says “all the elements of the new model are in place....”

In simple terms, there are five essential targets of change: (1) increased patient/treatment capacity, (2) new and additional funding mechanisms, (3) introduction of quality and clinical excellence monitoring of services instead of politicians themselves), (4) increased patient choice of both location and provider (including outside of NHS private treatment), and (5) a payment-by-results system with DRG-like and “block contract” elements similar to the US system. All this will create a “mimic market” that Klein is careful to distinguish from privatization or a US market system.

But with this transformative process under way, the NHS faced a public and political crisis in 2006 due to temporary financial shortages resulting in thousands of jobs lost and cancelled medical procedures. Implementation and re-engineering of the system—a “creative destruction”—are encountering predictable resistance: “medical morale remains brittle.” Yet, Britain’s physicians are now the best paid in Europe. Klein remains optimistic that the *elements* of the transformation model—competition, patients’ choice, and payment by results—are “tight and clear cut.” He is concerned, however, that the

process and pace of the transformation may not be crisis-exempt.

Why the Groningen Protocol Should Be Rejected, Frank A Chervenak, et al. *Hastings Center Review*, Sept-Oct 2006: 30-33.

The authors are responding to Verhagen and Sauer who wrote articles proposing a protocol for decision making concerning euthanasia for newborns, an action that is now permitted under Dutch Law. It seems that 21 of 22 cases cited in regard to the Groningen Protocol were infants with spina bifida. Although it is not clear until the end of the article, it is the use of this *diagnosis* that is the central issue for the authors. Spina bifida may on occasion qualify for euthanasia, but generally it does not meet the criteria of hopeless, unbearable suffering, and unacceptable quality of life. It is not fatal. Normal intellectual function is possible.

Meanwhile, the authors take significant issue with the failure (and difficulty) to define with any precision such concepts as “hopelessness,” “unbearable suffering,” and “quality of life” in regard to newborns. Certainly newborns can feel pain; however, the idea of suffering and quality of life cannot be experienced because newborns lack the essential required cognitive capacity and psychosocial experience that give such concepts any meaning.

But the authors’ final and central argument against spina bifida and Groningen is that there should be no need to be debating the justification of euthanasia regarding spina bifida babies. The reason? If pregnant women routinely received high quality prenatal obstetric care that included second trimester ultrasound, abortion would eliminate the issue entirely. And, forsooth, in November 2005 the Dutch endorsed just such a practice. That seems to substantially neutralize the authors’ criticisms making the article’s title somewhat odd.

The First Fourteen Days of Human Life, Patrick Lee and Robert P George. *The New Atlantis*, Summer 2006: 61-67.

A clear and factual understanding of the first two weeks of human life is ethically important for two reasons: (1) some assign no individual moral status to an embryo until implantation (up to as long as six days after fertilization), and (2) some argue that embryos are not human beings until the possibility of twinning has passed and the primitive streak appears at about fourteen days. Interestingly, the “two week” argument is used by moral conservatives and liberals alike.

Lee and George suggest the “two week argument” can no longer be sustained as a significant

developmental marker point in light of known embryology. Their argument involves somewhat complex biological processes such as maternal signaling factors, bilateral symmetry, polarity, compaction, cavitation, etc. These processes have a “unitary trajectory”—the maturation of the human embryo. All this occurs in the first week of life and prior to implantation which when it does occur, does not change or transform in any way the biological nature of the developing organism itself.

Next, the authors address the biology of monozygotic twinning, a possibility up until about the fourteenth day of gestation. It is commonly argued that since it is not certain that a zygote is going to become one or two embryos until after development has progressed beyond the possibility of twinning, it cannot be considered an individual prior to that.

In this situation, the authors do not see the puzzle or “problem” posed by the cellular divide. It is a form of asexual reproduction—unusual and uncharacteristic in human gestation, but possible and actual. Twinning does not developmentally establish individuality where none had previously existed. Twinning does not involve the division of an individual in half. Early undifferentiated cells on an individual human growth trajectory experience, for reasons unknown at this time, an extrinsic division of a small number of cells that continue to grow on a separate individual human growth trajectory.

Modern embryology, Lee and George argue, clearly supports the preimplantation organism as a group of cells evidencing purpose and trajectory toward individuality, and neither implantation nor twinning represent any kind of significant embryological change in the biological (and therefore, moral) status of the human organism.

When Law and Ethics Collide—Why Physicians Participate in Executions, Atul Gawande. *NEJM*, March 23, 2006: 1221-29.

Periodically an article will appear concerning capital punishment in the US and physician activity associated with carrying out the death sentence. This article begins on that familiar track but makes a novel turn that sets it apart as very interesting reading.

Gawande recounts recent court rulings that order physician supervision of executions by lethal injection (Ninth Circuit Court of Appeals, 2006). Since capital punishment was resumed in 1976, lethal injection has come to be the universal preferred method. But this method medicalizes the procedure and requires some degree of professional skill to carry out. Stanley Deutsch, MD developed a protocol of anesthesia agents and dosages that were widely accepted.

However, in 1980 the AMA passed a resolution

against physician participation in capital punishment as ethically unacceptable. In fact, virtually all participation—from prescribing the medication, supervising placement of the IV, to pronouncing death—was prohibited. The American Nursing Association also adopted a prohibition. And the Society of Correctional Physicians has the strictest ban of the three.

However, today, of the thirty-eight states using lethal injection, thirty five states allow physician participation, and seventeen require it (Ohio is not listed as one of them). So the question is: Who are these physicians/nurses involving themselves in capital punishment against the ethics codes of their professions? This is where Gawande’s report becomes quite interesting. He identified fifteen participating professionals; but only four physicians and one nurse agreed to an interview. As a group they had helped with forty-five or more executions.

What follows are the often personal and detailed stories of the participants. Some were quite afraid of being identified and spoke cautiously; some kept their activity secret from colleagues and even family members. No one had any great enthusiasm for the executions. But because the nature of lethal injection is specifically *medical*, most felt an obligation to ensure that it was done correctly and with appropriate expertise. One physician who opposes the death penalty still participates. He views it in terms of end-of-life care: ensuring that the dying process is without pain and suffering.

Gawande is struck by the competence-comfort-compassion argument, but in the end, he finds it unpersuasive. He is more than troubled that professional codes of ethics are being assaulted by government fiat. He believes all medical professionals should be banned by law from participation in executions. ∞

BOOK NOTICES

Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, Albert Jonson, Mark Siegler, William Winslade. 6th Edition, McGraw-Hill Medical Publishing Division, 2006: 227pp. paper \$29.95.

Mind Wars, Brain Research and National Defense, Jonathan Moreno. Dana Press, 2006:193 pp.

The Limits of Medicine, Andrew Stark. Cambridge, 2006, 264pp. \$25.99 paper.

The Baby Business: How Money, Science, and Politics Drive the Commerce of Conception, Debora L Spar. Harvard Business, 2006, 320pp. \$26.95.

Belmont Revisited: Ethical Principles for Research With Human Subjects, James F Childress, et al, (Eds.) Georgetown University Press, 2005: 279pp

BOOK REVIEW

By Joseph P. DeMarco, PhD
Cleveland State University

BIOETHICS BEYOND THE HEADLINES: WHO LIVES? WHO DIES? WHO DECIDES?

(Rowman & Littlefield Publishers, 2005), 209 pages
Albert R. Jonsen

Albert R. Jonsen, the author of *Bioethics beyond the Headlines*, is one of the founders of bioethics. His influential book, *Clinical Ethics*, written with Mark Siegler and William J. Winslade, should be required reading for anyone with deep interest in bioethics. Though I don't agree with his position on casuistry, I also much admire his book, *The Abuse of Casuistry* was written with the well-known philosopher Stephen Toulmin. My respect for Jonsen led me to read *Bioethics beyond the Headlines: Who Lives? Who Dies? Who Decides?* Additionally, the title raised speculation about the book's content. I imagined, perhaps idiosyncratically, that the book is about day-to-day bioethics, for example, what a bioethics consultant encounters in a large hospital setting. Although I'm an academic, I've been around practicing bioethicists enough to know that they often encounter cases where someone lives or dies due to moral decision making. Who decides? Who better to get the answer from than Jonsen?

I was wrong. That is not at all what the book is about. "Who Lives? Who Dies? Who Decides?" are questions that are rarely explicitly raised in the body of the text.

A reviewer shouldn't complain that a book isn't what the reviewer expected or wanted. Jonsen tells us what the book is meant to be: "*Bioethics Beyond the Headlines* is a primer in bioethics, an introduction to the topics and discussions that engage bioethicists. But a primer is not merely a first book; it should also 'prime' the interest of the reader, prepare the mind for a more expansive venture into these issues by starting with a small dose." (p.3) Of course, he presents a worthy goal. Honestly, I'm still debating whether he accomplishes his goals. If he doesn't, his book does come close. Regardless, the reader should be cautioned that it isn't an introduction to bioethics, such as one would get in a college course or textbook; the claim is that it is an introduction to

topics and discussions in bioethics, something very different.

Jonsen also believes the book is for everyone; he lists patients, their families and friends, doctors, nurses, social workers, judges, lawyers and legislators. I suspect that his style is too academic for much of the intended audience. Jonsen tends to drop a lot of names. Knowing something about the person he mentions helps to add interest. For example, in discussing assisted reproduction, he quotes Joseph Fletcher's approval and Leon Kass's disapproval. Picking these people makes sense in a way that many of the intended readers, I suspect, are likely to miss. Here is probably the most egregious, but fortunately not at all typical, example of "name dropping." "In England, Thomas Hobbes, John Locke, Lord Shaftsbury, Bishop Butler, David Hume, Jeremy Bentham, and John Stuart Mill, in Europe, Benedict de Spinoza, Immanuel Kant, Georg Hegel, Arthur Schopenhauer, and Friedrich Nietzsche produced masterpieces of ethical reasoning." (p. 12.) Nothing more is said about most of these philosophers. Instead, Jonsen gives an unexplained endorsement for G.J. Warnock's view that ethics is about amelioration of the human condition. So all in all the book is not going to be easy reading for the uninitiated. Those who know a lot about bioethics will have an easier time and will probably more appreciate Jonsen's historical insights. However, the initiated will also cover lots of familiar ground.

Aside from introductory comments and three appendixes (which I don't recommend), the book is divided into three parts, with fifteen topics covering a total of 160 pages. Each topic is succinct; for example, "Organ Transplantation" covers seven pages plus a page for references and a bibliography for future reading. In each topic "Beyond the Headlines" makes sense and illuminates his work. Bioethical concerns do make headlines; think of the coverage of the Terri Schiavo case. Most of Jonsen's topics begin with a headline. "Defining Death" opens with "Brain Dead Woman Dies after Fifteen Years." (p. 26)

I particularly like the opening material of the "Neuroscience" topic, dealing with rhesus monkeys controlling a computer cursor by thinking about it; the citation is from *The New York Times* article, "Monkey Think, Robot Do." (October 13, 2003)

After the headline story is explained, Jonsen typically turns to bioethical debate, involving pros and cons. In "Neuroscience" a good part of the debate is over the legitimacy of neurological human enhancement. The debate is beyond the headlines but says little about who decides on life and death. The chapter ends with some speculation on what philosophers call the "mind/body problem." Are we merely a "pack of neurons," as Sir Francis Crick ar-

gued? Jonsen raises questions, wondering, for example, whether Crick thought he deserved his Nobel Prize or received it as a function of his neurons? Jonsen adds, "Or, in a moment of humility, might he admit that, as Paul Ricoeur told Changeux, 'In the last analysis, we are dealing with two discourses of the body.'" (p. 125) The phrase picks up on an earlier paragraph (p. 116) that cites the conversation as an exception to the general silence about the new field of neuroethics.

The fascinating neuroethics topic is part of a genuine strength in Jonsen's book. He wants to expand the horizons of bioethics. He takes seriously that 'bio' in 'bioethics' comes from the Greek word *bios* that means life. Thus, all life issues should be of concern in bioethics. Jonsen's final topic is "Environmental Ethics." He appropriately notes that the environment has an enormous impact on health; he also points, in passing, to the toxicity of health care itself. Nevertheless, bioethics is not environmental ethics, and the topic reads more like a brief introduction to environmental ethics than one focusing on its overlap with bioethics. The topic headline, "Farmers Oppose Genetically Engineered Crops" is on the right track, but too many words, in the few pages allotted, are spent on basic environmental ethics debate, for example about the moral status of ecosystems. I'm not saying this isn't important. It is. I'm saying that it would have been more helpful, in making the point about extending bioethics, to stick with the direct impact of the environment on human health. The topic is an excellent overview of environmental ethics that bioethicists should read.

I'm still wondering about how strongly to recommend Jonsen's book. I certainly benefited from it, even though I guess it wasn't written for me. I appreciate the starting assumption: bioethics is in the headlines and there's much more beyond them. Jonsen's topics do cover life and death issues. Also, I think Jonsen is right that everyone should know more bioethics. Jonsen's short book is a good beginning for many but not all. Perhaps the book is right for those of us who are as pleased to read a paragraph about the conversation between Ricoeur and Changeux as we are to learn about Donald "Dax" Cowart's desire, in 1973, to end treatment for his severely burned body, the headline story of the topic "Autonomy of the Patient." ∞

IN THE NEWS

Lori Kusterbeck
Cleveland State University

Error Sparks Stem Cell Debate Confusion

The Associated Press
September, 2006

An advance in stem cell research that was intended to resolve moral differences over the promising but controversial field has ignited fresh conflict instead. Because stem cells can turn into virtually any type of human tissue, they hold promise for treating a host of human maladies. But critics have argued that creating the cells for research is wrong because it requires the destruction of human embryos in their earliest stages.

Scientists say the field's progress is seriously hampered by federal funding restrictions that are motivated by those moral objections. The California biotech company Advanced Cell Technology has proposed a way out of the impasse. Writing in the scientific journal *Nature*, ACT researchers described a way to make stem cells from single cells that had been removed from embryos. Because fertility doctors routinely remove single cells from embryos for genetic testing and then successfully implant them, the technique could in theory be used to create stem cells without destroying human embryos.

In reality, however, the embryos used by the company were destroyed in the course of developing the method. The researchers removed an average of five to six cells from each embryo rather than one to improve their chances of success. Removing that many cells at such an early stage of development effectively destroys an embryo.

Sterile Victims Stand Up, Decry Legacy of Eugenics

Chicago Tribune
September, 2006

It is hard for Elaine Riddick to talk about how the state of North Carolina sterilized her without her knowledge at the age of 14, changing her life forever. After Riddick became pregnant from a rape, doctors on the Eugenics Board of North Carolina decided in 1968 that she was too "feeble-minded" to ever be a good mother and wanted to ensure that she never would get pregnant again. So doctors tied her tubes and didn't tell her.

Thirty-eight years later, Riddick, 52, has emerged as a voice for thousands of victims of state-

sponsored sterilizations that were part of the eugenics movement in the United States from the 1920s to the 1970s. Riddick and others are coming forward and forcing states to address their roles in a controversial social experiment that went awry.

The idea behind eugenics, a concept embraced by Nazi Germany, was to wipe out future poverty, crime and other social ills believed to result from genetic flaws. By sterilizing the feeble-minded, mentally retarded, insane and epileptic, eugenicists believed they would ensure that undesirable traits would not continue through generations.

North Carolina had one of the most active and long-running programs. At least 7,500 poor African-Americans and whites, many of them welfare recipients, were tricked or forced to undergo sterilizations from 1929 to 1975. Throughout the United States, an estimated 65,000 people—overwhelmingly women—were involuntarily sterilized.

Though state boards ordered thousands of sterilizations, experts said many more occurred during that time, though not part of state-mandated programs. Many women still don't know whether they were affected. In North Carolina, the official records of the program are sealed in state archives. No states now have eugenics programs.

More Couples Screening Embryos for Gender

The Associated Press

September, 2006

Almost half of U.S. fertility clinics that offer embryo screening say they allow couples to choose the sex of their child, the most extensive survey of the practice suggests. Sex selection without any medical reason to warrant it was performed in about 9 percent of all embryo screenings last year, the survey found.

Another controversial procedure—helping parents conceive a child who could supply compatible cord blood to treat an older sibling with a grave illness—was offered by 23 percent of clinics, although only 1 percent of screenings were for that purpose in 2005.

Survey results were published by the medical journal *Fertility and Sterility*. The survey was led by Susanna Baruch, a lawyer at Johns Hopkins University's Genetics and Public Policy Center in Washington, D.C., with the cooperation of the reproductive medicine society. It involved an online survey of 415 fertility clinics, of which 190 responded.

They were asked about pre-implantation genetic diagnosis, or PGD, which can be done as part of in vitro fertilization, when eggs and sperm are mixed in a lab dish and the resulting embryos implanted directly into the womb. In PGD, a single cell from an embryo that is three to five days old is removed to

allow its genes and chromosomes to be analyzed.

About 1 of every 20 in vitro pregnancy attempts in the United States last year used PGD, the survey found. Two-thirds of the time it was to detect abnormalities that would keep the embryo from developing normally and doom the pregnancy attempt.

In 12 percent of cases, PGD was used to detect single-gene disorders like those that cause cystic fibrosis. Three percent of cases were to detect problems that mostly affect males, because they have only one copy of certain genes.

However, these cases are different from those done purely for gender preference. Forty-two percent of clinics that offer PGD said they had done so for non-medically related sex selection. Nearly half of those clinics said they would only offer sex selection for a second or subsequent child.

Many countries ban PGD or restrict its use to the prevention of serious inherited diseases. Many people from foreign countries travel to the United States to obtain it, especially from countries like China and Canada.

Feds: HIV Testing Should be Routine for Americans

The Associated Press

October, 2006

Millions of Americans may soon undergo their first HIV test—not because of any high-risk behavior, but because federal officials believe testing should be routine for all Americans ages 13 to 64.

The U.S. Centers for Disease Control and Prevention (CDC) officials said they aim to prevent the further spread of the disease and prompt needed care for an estimated 250,000 Americans who have the AIDS virus but don't know it.

The recommendations aren't legally binding, but they influence what doctors do and what health insurance programs cover. However, some doctors' groups predict the recommendations will be challenging to implement, requiring more money and time for testing, counseling and revising consent procedures.

The recommendations were endorsed by the American Medical Association, which urged doctors to comply. The CDC said it's difficult to predict how many doctors will.

Previously, the CDC recommended routine testing for those at high risk for catching the virus, such as intravenous drug users and gay men, and for hospitals and certain other institutions serving areas where HIV is common. It also recommended testing for all pregnant women.

Under the new guidelines, patients would be tested for the virus as part of the standard tests they get when they go for urgent or emergency care, or

even during a routine physical. The CDC recommends everyone get tested at least once, but annual testing is urged only for people at high risk.

Consent for the test would be covered in a clinic or hospital's standard care consent form. Patients would be allowed to decline the testing. The CDC's guidelines say no one should be tested without their knowledge. Doctors should tell patients anonymous testing is also available, if they'd rather choose where they want to get HIV testing.

The cost of the new policy is not clear. A standard HIV test can cost between \$2.50 and \$8, public health experts say. New rapid tests cost about \$15. If an initial result is positive, confirmatory tests can cost another \$50 or more. Treatment for HIV can cost more than \$10,000 a year.

The CDC has been working on the guidelines for about three years, and got input from more than 100 groups, including doctors' associations and HIV patient support groups.

Face Transplant Recipient Doing Extremely Well
Medical News Today,
November 2006

Isabelle Dinoire, who had a partial face transplant a year ago, can go out without people noticing her scars, said her doctor, Professor Devauchelle, Centre Hospitalier Universitaire, Amiens, France. Isabelle says she is now able to smile.

Devauchelle was interested to hear that people who had only seen her before her face was mauled are starting to recognize her—meaning she is beginning to look like her old self. It was expected that a face transplant recipient would look different—neither like her/his old self nor the donor.

Devauchelle said she does have scars, but they don't stand out. He added that she still occasionally experiences minor inflammations near wires deep beneath her skin. With a bit of make-up, he added, the scars are hardly noticeable.

Her face has restored its sensitivity to touch and temperature. She can drink and eat without difficulty now.

Since her operation, there have been two occasions when her body started to reject the foreign tissue. However, this was successfully treated with immunosuppressant drugs. Even though doctors advised her to give up smoking, Isabelle continues to smoke. She lost parts of her face when her dog tried to revive her during a suicide attempt.

FDA Primed To Help Dying Patients Gain Easier Access To Unapproved Drugs

by Food and Drug Law Institute
Medical News Today,
January 2007

In 2007, terminally ill patients are expected to gain expanded access to unapproved medications. As soon as its proposed guidelines become final later this year, the Food and Drug Administration (FDA) will proactively assist physicians in getting experimental drugs in the hands of their dying patients.

The FDA is taking action on the controversial issue of access to unapproved drugs as the landmark case of Abigail Alliance v. von Eschenbach heads toward a possible showdown in the U.S. Supreme Court. On March 1, the U.S. Court of Appeals for the District of Columbia will hear FDA's rehearing petition on its May 2006 ruling that terminally ill patients have a constitutionally based right to access to experimental drugs not fully approved by the agency.

Six months after the ruling by the three-judge appeals court panel, FDA published a proposal for "significant regulatory changes" to expand access to unapproved drugs.

The agency is currently evaluating public comment on those guidelines and is not expected to issue final rules for several months. However, after FDA publishes those final rules, it is committed to making sure that physicians who want to get unapproved medications for their patients have all the information they need to process their applications.

Although patients will be able to apply through their physicians for expanded access to unapproved drugs, FDA has no authority to compel them to do so, emphasizes Cruzan. "As the preamble to the proposed rule says, 'FDA cannot compel a drug manufacturer to provide access to investigational drugs for treatment use.'" Whether pharmaceutical firms make such medications available will be their decision, Cruzan explains.

No matter what happens with the final FDA rule and the Abigail Alliance case, the decades-long debate over expanded access is not likely to end soon. ∞

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“From Cruzan to Schiavo: What Have We Learned?”

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An intensive four-hour graduate course connected to the symposium will begin on June 18 at Hiram. It will conclude June 24, except for the research paper. For more information, contact mais @hiram.edu or call 330-569-6111.

The Summer Symposium is supported in part by a challenge grant from the
National Endowment for the Humanities

BOOK REVIEWS

By John A. Gallagher, PhD
Catholic Healthcare Partners
Cincinnati OH

THE KNIFE MAN: BLOOD, BODY SNATCHING, AND THE BIRTH OF MODERN SURGERY

Wendy Moore
(New York: Broadway Books, 2005), 341 pages

THE GHOST MAP

Steve Johnson
(New York: Silverhead Books, 2006), 299 pages

Wendy Moore's *The Knife Man* is a biographical account of the career of John Hunter, an 18th century English surgeon and student of human anatomy. Hunter lived in an era when the science of human anatomy was in its infancy and its significance for the practice of surgery was unrecognized. John Hunter learned his craft as a student of his brother William, with whom he worked for most of his career. Rivalry eventually drove the brothers apart and only relatively late in life were John Hunter's accomplishments recognized.

As one reads this fascinating study, one needs to set aside scruples about body snatching and grave robbing. John Hunter did not work in the antiseptic surrounding of a morgue or anatomy lab, but rather in rooms sequestered away in the basements of his homes. He and his students conducted their research only in the colder months of the year when it was somewhat possible to preserve their specimens. Hunter's research is enshrouded in the macabre and grotesque.

An ethicist reading the *The Knife Man* does face the question, can the end justify the means? There are accounts of surgery narrated in this work that border on butchery, accounts of surgeries performed by surgeons with little or no knowledge of muscle structure or the pathways of nerves, to say nothing of the lack of anesthesia; one can only marvel that any patients survived. John Hunter's genius, with whatever other modifiers one might deem appropriate, was in beginning to compile the information concerning human anatomy essential to the high success rates of modern surgery. One conclusion that can be drawn is that ethical dilemmas are not new to the practice of medicine and human subjects research.

Steven Johnson's *The Ghost Map* is a study in 19th century epidemiology. In an effort to detect the source of a cholera epidemic in London, the physician John Snow mapped the sites of the homes of victims. The map enabled him to identify a water pump as the source of the disease.

The Ghost Map presents a much different ethical issue than any of those posed by *The Knife Man*. The ethical issue that confronted Snow was how to change the cultural mind set, shared by physicians, public officials and journalists, that cholera was an air-borne disease. Perhaps residents of the 21st century are more willing and more able to embrace new scientific theories.

Both of these books make interesting reading for anyone interested in the history of medicine. The common reminder that weaves its way through both books is that modern medicine is a very young discipline and that contemporary standards of medical practice and even basic presumptions of the science of medicine need to remain open to further questioning. ∞

**To these recent new members of BENO, we want to say
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Individuals

Barbara A. Matlak, RG
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