

# BENO



## From the PRESIDENT

*Donna F. Homenko, PhD*



**W**e are quickly approaching another season; fall, with all of its many sights and sounds..... like football. When I think of football, I think of teamwork, something most of us experience daily in the delivery of medical care. And when I think of teamwork, I'm excited to welcome our new Board members (see pages 5, 6) health care professionals currently working in different roles that address bioethics in the clinical environment. I am certain they will bring the depth of their experiences to BENO as we strategize to advance the continuing mission of our association.

We are also underway with our educational programming in Ethics Consultation and the next BENO Annual Conference on Friday, May 2, 2014. Mark your calendars now—details will be posted on our website very soon.

***A message of professionalism and ethics, constantly reinforced throughout an individual's career, is essential for licensed medical providers.***

Part of my role as President is to share BENO activities with other health care organizations. I will be attending an advisory council of educators in Washington DC next month. The participants for this event are responsible for the formal curriculum in postsecondary institutions in the areas of ethics and clinical training. I hope to glean information about current methodologies

for teaching ethics consultation, required certifications and the role of bioethics in clinical facilities. Throughout my tenure in academe, I have seen the transition that must occur with our medical graduates from their college coursework to internships, residency and fellowships. Some allied health care graduates move directly from the university to a clinical or private practice setting. Gatekeepers within the regulatory agencies who license these graduates must 'bridge' that gap from school to the real world of patients. A message of professionalism and ethics, constantly reinforced throughout an individual's career, is essential for licensed medical providers. *BENO can be an ongoing forum for both the recent graduate as well as seasoned practitioners.*

Look forward to updates as we continue to reach our 'field goals' in bioethics throughout the coming year.

**CONTENTS**

- The Editors' Desks** 2
- New Board Members** 5
- Antipsychotic Treatment** 7
- Presymptomatic Genetic Testing** 8

# New The Editors' DESKS

**Pedro Weisleder, MD, PhD**

Division of Child Neurology  
Co-Chair of Nationwide Children's Hospital's Integrated Ethics Committee



## ● Immunizations Do Not Cause Autism

**W**e recently learned that Jenny McCarthy will join the panel of ABC's daytime show "The View" in September. As a pediatrician and parent of two boys, I find ABC's decision ill-advised. You see, Ms. McCarthy has helped spread the dangerous myth that immunizations can cause autism. And my worry is that ABC has just given her a platform to continue spreading wrong information. I respect the rights of parents to make decisions for their children. In this case, however, science continues to win the argument.



Ms. McCarthy's unfounded ideas come from the fact that her son developed some of the symptoms associated with autism, and she found immunizations to be a good scapegoat. In reality, and based on publicly available information, Ms. McCarthy's son has a neurological condition called Lennox-Gastaut syndrome. This illness is

characterized by difficult-to-control seizures and cognitive impairment. And while Ms. McCarthy has acknowledged the fact that her son does not have autism, it has not changed her opinion on immunizations – a very dangerous stance.

In the late 1990's, concerns that children vaccinated with products that contained the preservative Thimerosal™ could receive doses of mercury above those considered acceptable were raised. At the same time, the number of children diagnosed with conditions that fall under the umbrella of autism spectrum disorders was on the rise. But the authors of well-designed and scientifically rigorous research studies demonstrated, and continue to demonstrate, that there simply is no association between immunizations and the apparent rise in the incidence of autism.

Vaccines are among the most effective prevention tools available to clinicians. High immunization coverage has resulted in drastic declines in vaccine-preventable diseases. And for those who cannot be immunized because of other

***...the low incidence of vaccine-preventable diseases has led some to wrongly believe the conditions have been eradicated – we have become victims of our own success.***

illnesses, "herd effect" – the phenomenon by which a disease is squeezed out of a community due to a lack of hosts capable of transmitting it – offers a potentially lifesaving option. Unfortunately, the low incidence of vaccine-preventable diseases has led some to wrongly believe the conditions have been eradicated – we have become victims of our own success.

Use of immunizations is good medicine and good healthcare policy. It helps protect individuals today. And in the long-run, it will decrease the cost of providing care to those who might be afflicted by preventable conditions. It is the proverbial "win-win" situation. A popular aphorism states that "an ounce of prevention is worth a pound of cure." In the case of immunizations, this simple and safe precautionary measure not only prevents illnesses, it saves lives.

A new study evaluating parents' concerns of "too many vaccines too soon" and autism has been published online in the *Journal of Pediatrics*. It adds to the conclusion of a 2004 comprehensive review by the Institute of Medicine (IOM) that there is not a causal relationship between certain vaccine types and autism. The results provide relevant data for the current childhood immunization schedule.

Dr. Weisleder, serves as Associate Editor for *Neuroethics* for the *Journal of Child Neurology*, and is Co-Editor of *BENO's BioQuarterly*.

## Robert M. Taylor, MD, FAAN, FAANHPM

Associate Professor of Neurology  
Associate Professor of Clinical Medicine, Division of Palliative Medicine, Department of Internal Medicine  
Co-Chair, OSUWMC Bioethics Committee  
The Ohio State University Wexner Medical Center



### ● Care-based Ethics and Feminist Ethics: Alternatives to Principlism

The most commonly employed approach to clinical ethical analysis is the Principle approach (sometimes referred to as Principlism), popularized by Beauchamp and Childress in their book: *Principles of Biomedical Ethics*. They propose four universal principles that they assert must be considered in all ethical dilemmas: Respect for autonomy, Beneficence, Nonmaleficence, and Justice.

One of the most important challenges to Principlism comes from the work of Carol Gilligan and Nel Noddings, who argue that the Principlism approach excessively values traditionally male perspectives and devalues traditionally feminine perspectives, reflecting historical male domination of academics and medicine. Gilligan's work was based on studies exploring the differences in moral development of boys and girls. Lawrence Kohlberg had studied moral development in children and concluded that they evolve through six universal stages, from the lowest stage of "punishment and obedience orientation," through stages of "good boy – good girl orientation" (stage 3) and "law and order orientation" (stage 4). Those who achieve the highest moral stage (stage 6) develop a "universal ethical principle orientation."

This analysis supports the Principlism approach as representing the highest level of moral development. However, Gilligan was troubled by the fact that Kohlberg's experimental data suggested that males were much more likely than females to develop the highest levels of moral insight and wondered if these stages were truly universal or whether, instead, they were biased toward a male perspective. Her studies indicated that girls do develop differently, focusing on interpersonal relationships. She identified three stages of feminine moral development: Stage 1 focused on self-interest; stage 2 overemphasizing the interests of others, reflecting a desire to please others; and stage 3 wherein they attempt to balance the interests of themselves and others as a relational unit. Gilligan's work

led to an ethical perspective based on relationships and caring for others.

Some have argued that "caring" is essentially another word for "benevolence," but the emphasis on the primacy of relationships distinguishes these two concepts. Whereas benevolence focuses on the physician-patient interaction, care-based ethics incorporates the complex web of relationships in which the patient is embedded and considers the perspectives of all those who truly care for the patient. Indeed, the connection among family members (broadly defined) ordinarily supersedes the connection between patient and physician and, furthermore, the burden and gratification of caring for the patient fall most heavily on the family. Thus, from the perspective of care-based ethics, the family has a much stronger interest and responsibility for decisions about the patient's care than typically understood in more traditional ethics, such as Principlism. One can see why the care-based perspective has been identified as a "feminine" perspective, emphasizing the importance of relationships and de-emphasizing patient "rights" as well as the role of the physician, in contrast to the "masculine" perspective of Principlism which emphasizes patient autonomy and justice, as well as the importance of the physician's role, while de-emphasizing family and relationships.

#### Feminist Ethics

Feminist ethics incorporates the ideas of "feminine" ethics in that it tends to note the gender-based differences in perspectives on caring and relationships (e.g. see Tong and Williams 2012). But it goes further in emphasizing the importance of power and control in medical relationships (e.g. see Allen, 2011, and Sherwin, 1992). From the feminist perspective, the primacy of Principlism in medical ethics is mostly a result of the relative power differential of males and females in medicine. Historically,

*continued...*



## Care Based Ethics *continued...*

physicians have mostly been male, whereas nurses and family caregivers have traditionally been predominantly female (one may note that nursing ethics has traditionally been more care-based than physician ethics). Thus the assertion that an ethic which reflects a traditionally male perspective is actually a universal ethical perspective serves the interest of a male-dominated enterprise (i.e. medicine) while serving to maintain a gender-based imbalance of power. It is worth noting that the care-based perspective was proposed by women and has gained traction as women have gained parity in medicine.

***Integrating feminine and feminist perspectives into our understanding of medical ethics provides a broader view of the moral landscape of modern medicine.***

However, the insights of feminist ethics regarding the importance of power relationships are not limited to understanding the significance of gender relationships. Once one begins to look at medical care (especially within the modern hospital) through the lens of power relationships, one begins to see the impact in many different ways. For example, patients in the critical care unit are physically powerless and almost entirely dependent on physician decisions. Families of these patients have very limited power and often search for ways to obtain greater power. This can lead to very destructive behaviors, including being excessively demanding, avoiding meetings, and even threats of lawsuits. When these kinds of behaviors are understood as attempts to redress a perceived imbalance of power, they become both more understandable and potentially more manageable.

Likewise, much of the moral distress experienced by nurses and medical trainees can be explained by an imbalance of power between them and the attending physician(s). Both nurses and medical trainees are obligated to carry out the directives of the attending physician(s), yet they have their own individual moral obligations toward patients and families. If they believe that these dual obligations are in conflict, they have limited options to resolve them. Ideally, such a conflict would be addressed by in-depth conversations about the ethical issues and the moral responsibilities of each individual practitioner. However, that rarely happens, nor is it practical for that to occur routinely. Instead, those in positions of inferior power must find ways to deal with their moral distress. Possible responses to such distress can take many forms, including side conversations with family members, passive-aggressive behaviors toward the physician(s), or requesting an ethics

consult. Few institutions have acknowledged this source of moral distress, much less attempted to create constructive mechanisms for addressing it.

Integrating feminine and feminist perspectives into our understanding of medical ethics provides a broader view of the moral landscape of modern medicine. Furthermore it can help those involved in medicine to understand the biases and limitations of “traditional” perspectives on medical ethics. This, in turn, can enhance respect and open channels of communication among the various professionals involved in medical care and between medical practitioners and patients’ families.

## REFERENCES

- Allen A. “Feminist Perspectives on Power”, *The Stanford Encyclopedia of Philosophy (Spring 2011 Edition)*, Zalta EN (ed.). URL = <<http://plato.stanford.edu/archives/spr2011/entries/feminist-power/>>. Accessed 9 September 2012.
- Beauchamp TL, Childress JF. Principles of biomedical ethics, 5th ed. New York City, NY: Oxford University Press; 2001.
- Gilligan, C. In *A Different Voice: Psychological Theory and Women’s Development*. Cambridge, Mass.: Harvard University Press, 1982.
- Noddings N. *Caring: A Feminine Approach to Ethics and Moral Education*. Berkeley: University of CA Press, 1982.
- Pellegrino ED, Thomasma DC. *For the Patient’s Good: Toward a Restoration of Beneficence in Health Care*. New York: Oxford University Press; 1988.
- Sherwin S. *No Longer Patient: Feminist Ethics and Health Care*. Philadelphia, Temple University Press, 1992.
- Tong R, Williams N. “Feminist Ethics”, *The Stanford Encyclopedia of Philosophy (Summer 2011 Edition)*, Zalta EN (ed.). URL = <<http://plato.stanford.edu/archives/sum2011/entries/feminism-ethics/>>. Accessed 9 September 2012.

# NEW Board Members

**Ashley K. Fernandes, MD, PhD**

Asst. Professor of Community Health & Pediatrics  
Wright State University School of Medicine  
Dayton, OH

I see the mission and future of BENO as one of practical co-operation—bringing together people of diverse, multidisciplinary talent to support one another, build consensus for bedside and policy issues which reflect the importance of human dignity, and, where consensus cannot be reached, engage in respectful debate with each other in order to make medicine more humane.

During my term, I will help to make this vision a reality by encouraging increased BENO visibility among hospitals and academic communities, advancing diversity of thought and respectful dialogue, improving communication outlets for members, promoting multidisciplinary networking, and continuing the increased rigor of BENO publications and conferences. Thank you for this opportunity.



**Cassandra Hirsh, DO**

Palliative Care Physician  
Akron Children’s Hospital  
Akron, OH

As a pediatric palliative medicine physician who works at Akron Children’s Hospital, I care for children with chronic, complex, and at times, life-threatening illnesses. The nature of the work has given me many opportunities to look at patient situations from both a medical and ethical vantage point. Often times, I find these cases to be the most challenging, but also the most rewarding. I am privileged to sit on the Ethics Committee at our institution. I hope to collaborate with others in the region, and that my particular expertise and perspective, and those of the colleagues with whom I collaborate, might be valuable to the board, especially as pediatric palliative care is an evolving and rapidly growing specialty.

**Asma Mobin-Uddin, MD**

Staff Pediatrician  
Nationwide Children’s Hospital  
Columbus, OH

BENO has a long history of serving the community by fostering education, collaboration, and advocacy. I look forward to expanding and developing BENO’s impact in the field of bioethics and will work hard to contribute to the success of this organization. I have served on OhioHealth’s Joint Ethics Advisory Committee (JEAC) for the past four years. I also serve on the Clinical Ethics Competency Task Force, a subcommittee of OhioHealth’s JEAC that educates and trains hospital and community based personnel to be effective members of medical ethics committees. My personal interests in ethics include end-of-life care and issues relating to cultural diversity. As a pediatrician in central Ohio, I work both at Nationwide Children’s Hospital clinics and at a private pediatric practice.



# NEW Board Members



**Ryan Nash, MD, MA**  
 Director, The OSU Center  
 for Bioethics  
 Wexner Medical Center  
 Columbus, OH

I have recently been recruited to lead the new Ohio State University Center for Bioethics. In that role, I will be engaged in bioethics projects and collaborations that are aimed to not only serve the Ohio State community but also the region and state. The Bioethics Network of Ohio's mission aligns with the mission of the OSU Center for Bioethics. Serving with colleagues at BENO will afford me the opportunity to form meaningful relationships and collaborations. I will surely learn much from the combined experience of those involved with BENO. In turn, I will bring a decade of administrative, clinical, and educational leadership experience. I will strive to help maintain and strengthen BENO's current effective programs as well as explore potential for meaningful expansion, including but not limited to involvement of students and trainees. I welcome the opportunity to serve Ohioans through the combined efforts of BENO and the OSU Center for Bioethics.

**Steven J. Squires, MEd, MA, PhD**  
 East Market Mission Leader  
 Mercy Health Anderson Hospital  
 Cincinnati, OH

There are three priorities I would like to identify for BENO to the BENO board. First, it is imperative to continue the wonderful programming and publications of BENO. The conference is excellent, and my uninformed, informal opinion is that BENO is one of the few and more active state ethics groups. Being a reliable source of quality programs and publications always lends itself to BENO's credibility. Second and related to the first, BENO needs to continue to be relevant to its membership. A method of doing this is to frequently assess what is of value to BENO members. Third, exploring possible means of integration between BENO and other ethics organizations is important. Given my history and experience, I could serve as a bridge between BENO and other state-wide networks and I look forward to this more formal role in BENO.



**Kathryn Westlake, RPh, MA, PharmD**  
 Oncology Pharmacist  
 Case Western Reserve University  
 Cleveland, OH

As a long-time member of BENO, I have maintained an interest in interdisciplinary approaches to medical ethics practice and education with my practical experience as a pharmacist in a variety of hospital and community settings. I am interested in opportunities to expand BENO's constituency to other allied health care professionals, as well as to represent viewpoints that would expand alliances and perspectives. I have found membership in BENO to be valuable to me as I learn about current ethics topics at our meetings, and network with others in the Ohio bioethics community. I would like to help further the mission and expand the membership of BENO through contribution of time and effort on the board. I look forward to participating in, and serving with the BENO board.

## ● Encouraging Concurrent Evolution of Antipsychotic Treatment & Right to Refuse Standards

### Hilary Homenko, JD

Associate in the Healthcare Practice Group,  
Womble Carlyle Sandridge & Rice, LLP  
Case Western Reserve University School of Law, Class of 2012

When cases involving a civilly committed individual's right to refuse medication began to navigate their way through the appellate process in the 1980s, medical considerations about antipsychotic medications played a limited role in court opinions. Initially, the focus of judicial decision-making was on determining whether a patient had a constitutional right to refuse treatment with antipsychotic medication and if so, what the legal basis was for such right. However, once courts universally recognized a civilly committed individual's constitutional right to refuse medication, the courts began to turn their focus to the procedural aspect of the right. In other words, the courts began to develop standards or tests in order to determine when physicians are permitted to override an individual's right to refuse treatment with antipsychotic medication.

One approach, taken by federal courts, is to defer to the opinions of treating physicians. This approach is known as the "professional judgment" standard, which places the burden of weighing the risks and benefits of antipsychotic medication on medical professionals. Under the "professional judgment" standard, the court asks whether a decision such as forcible use of antipsychotic medication is a "substantial departure from accepted professional judgment, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment."<sup>1</sup> Judge Adams writing the concurrence in *Rennie v. Klein*, 720 F.2d 266, explained that a physician treating patients in a state mental hospital "must, at the very least, consider the side effects of the drugs, consult with other professionals and investigate other options available before that physician can be said to have discharged full professional judgment."<sup>2</sup> Judge Seitz added in a separate concurrence that determining whether to administer antipsychotic medication against a patient's will is "by its nature fact-specific."<sup>3</sup> In jurisdictions that have retained a "professional judgment" standard, federal courts themselves do not have to consider in detail the risks and benefits of antipsychotic medications. Rather, they defer to the judgments of medical professionals.

In contrast, some state courts apply a "least restrictive means" test or a "best interest of the patient" standard, where the burden is on the court to assess the medical risks and benefits of treatment by antipsychotic medication before deciding whether to override a patient's refusal of the treatment. In 2000, the Ohio Supreme Court heard

*Steele v. Hamilton County Community Health Board*,<sup>4</sup> where it articulated the procedural aspect of the right to refuse as allowing a court to issue an order permitting forcible medication, without finding that a patient is dangerous, when the court finds by clear and convincing evidence that: (1) a patient lacks the capacity to give informed consent to the treatment; (2) the medication is in the best interest of the patient; and (3) no less intrusive treatment will be as effective in treating the mental illness.<sup>5</sup> The second and third prongs of the test are the most significant, since they require the court to make medical considerations about antipsychotic medication.

As one might expect, under the state standard, the judges in *Steele v. Hamilton* dedicate a significant part of the opinion to the medical implications of treating a patient with antipsychotic medication. The Ohio Supreme Court has explained that administering antipsychotic medications to patients against their wishes is "particularly severe" since the drugs alter the chemical balance in a patient's brain, which changes his or her cognitive processes.<sup>6</sup> The court further stated that the alterations and other negative side effects associated with the drugs could be "severe and/or permanent."<sup>7</sup>

Over the years, state courts have repeatedly applied the legal standards in the context of patients who have been prescribed first- or second-generation antipsychotics. However, as the field of medicine evolves, a third generation of antipsychotic medication has been introduced into the clinical setting. It is quite possible that

**...as medicine changes, state courts responsible for weighing the risks and benefits of antipsychotic medications should rebalance the factors that determine the "best interest of the patient" or the "less intrusive treatment."**

this third generation of antipsychotic medicines will no longer target dopamine, but rather serotonin, which is a chemical known to affect an individual's mood.<sup>8</sup> This means that as medicine changes, state courts responsible for weighing the risks and benefits of antipsychotic medications should rebalance the factors that determine the "best interest of the patient" or the "less intrusive treatment."

In order to facilitate this transition, the state courts should consult only the most current and credible resources to guide their analysis. For example, it is important to include psychiatrists in the court's decision-making process. In some state cases the testimony of psychiatrists have educated the judges on the types of drugs currently

1 *Rennie v. Klein*, 720 F.2d 266, 271 (3rd Cir. 1983) (citing *Youngberg*, 457 U.S. at 318-19).

2 *Id.* at 272 (Adams, J., concurring).

3 *Id.* at 271 (Seitz, J., concurring).

4 *Steele v. Hamilton Cnty. Cmty. Mental Health Bd.*, 736 N.E.2d 10 (Ohio 2000).

5 *Id.* at 15.

6 *Id.* at 16 (citations omitted).

7 *Id.* at 16-17 (citations omitted).

8 *Third Generation Antipsychotic Drugs: Partial Agonism or Receptor Functional Selectivity*, 16 CURRENT PHARMACEUTICAL DESIGN 488, 500 (2010).

## Antipsychotic Treatment *continued...*

prescribed to mental health patients, which is essential to a court's analysis, when newer drugs were not even in existence at the time cases such as *Rennie v. Klein* were decided in the federal courts. However, the drawback of having psychiatrists testify is that they have a bias towards using antipsychotic medication to treat mental health patients.<sup>9</sup> In order for the court to have testimony representative of the entire mental health profession, the court should have encouraged input from psychologists, too, because they tend to be less willing to advocate for treatment by medication.<sup>10</sup>

Courts should also consider requesting amicus briefs on an antipsychotic medication at issue in a right to refuse case. Ideally, the briefs would be submitted by professional organizations with members involved in the practice of medicine, specifically the treatment of mentally ill patients. As mentioned with regards to testimony, courts have to be aware of the potential for bias. For example, in the amicus briefs submitted to the Court in *Washington v. Harper*, the American Psychiatric Association submitted a brief bolstering the therapeutic benefits of antipsychotic medications, while the American Psychological Association submitted a brief emphasizing the negative side effects of antipsychotic medications.<sup>11</sup> The risk of bias should not stand in the way of a court reviewing the briefs and using them to support its analysis, as long as the judges believe that the briefs were prepared in close proximity to the case and are supported by reliable scientific studies.

In conclusion, while both federal and state courts recognize a civilly committed individual's right to refuse treatment by antipsychotic medication, the courts have adopted different tests or standards to determine when it is appropriate to override the patient's right. In federal courts, judges employ the "professional judgment" standard, which allows the court to defer to medical professionals as long as they adequately weigh the risks and benefits to the patient. In state courts, judges consider whether treatment with antipsychotic medication is the "least restrictive means" and within the "best interest of the patient," despite the patient's refusal. This second approach requires that the court consider the risks and benefits associated with the treatment. In order to ensure that state court analyses continue to develop concurrently with medicine, judges must consider testimony by medical professionals and amicus briefs submitted by professional organizations.

<sup>9</sup> See generally Brief of the American Psychiatric Association and the Washington State Psychiatric Association, *Washington v. Harper*, 494 U.S. 210 (1990) (No. 88-599), 1989 WL 1127132, at \*10 (advising that antipsychotic medications are the "treatment of choice for large numbers of persons suffering from the most severe forms of mental illness").

<sup>10</sup> See generally Brief of the American Psychological Association in Support of Respondent, *Washington v. Harper*, 494 U.S. 210 (1990) (No. 88-599), 1989 WL 1127142, at \*5 (warning that the prevalence, permanence, and severity of antipsychotic drugs is underestimated by recent research).

<sup>11</sup> See *id.* at \*10; see also Brief of the American Psychological Association, at \*5.

## ● Commentary: Presymptomatic Genetic Testing in Children

### Chantal N. Kelly, MS, CGC

Certified Genetic Counselor  
Duke University Medical Center  
Division of Maternal Fetal Medicine

As a genetic counselor, I am often tasked with the interpretation of genetic screening or test results for my patients, and attempt to provide answers to questions such as "What does having this mutation mean to me?" Or, "My amniocentesis results show that my baby will have Down syndrome? What can I expect for her?" And while answering these questions is vital, I believe the most important and difficult part of my interaction with patients occurs prior to them undergoing genetic testing.

I often talk with them about their "risk" or potential of having a genetic condition themselves, or, in a prenatal context, the "risk" for their unborn child to have a genetic condition. This may be a chromosome condition, such as Down syndrome, or a single gene condition, such as cystic fibrosis. I ask them to imagine how they might feel if their baby, indeed, has the condition, and they learned of the diagnosis early in the pregnancy. I ask them to consider how the same situation may feel different if they learned of the diagnosis after the baby was born. They have the opportunity to imagine, and on some level, experience these feelings prior to having to accept the information from the genetic testing. I then ask them to decide if this is information they will benefit from, or if it is something that the baby may benefit from directly. I ask them to consider if this information has the potential to cause them more distress than do any good.

In order to answer these questions, one must consider the idea of a derived benefit more closely. A benefit is something that is advantageous or good, that can result from a specific action or choice. If medical care for the patient or the pregnancy will change as a result of the information learned, there may be a direct benefit. If nothing will change for the better, either from a medical management standpoint, or with regard to a patient's emotional well-being, there may not be a benefit. Similarly, if one is likely to undergo significant psychological stress from learning about a diagnosis, this may cause harm rather than provide direct benefit. By asking my patients to imagine both scenarios, I have them weigh perceived benefits against potential harms in a way that they aren't typically asked to do. This is a fairly sophisticated intellectual endeavor, and something that many of my patients are not used to doing.

Typically, if the health care provider "recommends" a test, most often it is accepted by the patient with no further questions or thoughts about the future that those results might bring. My role and ethical responsibility as

a genetic counselor is to assist my patients as they navigate the decision-making process, and help them understand how their decision, and information to be gained, fits into the context of their life. As is written in the National Society of Genetic Counselors Code of Ethics, it is the obligation of genetic counselors to "...respect their client's beliefs, inclinations, circumstances, feelings, family relationships, and cultural traditions; enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives, and anticipated consequences."

Genetic testing is also undertaken to find the underlying cause for a person's set of symptoms, to put in place a treatment plan, to identify other complications or medical problems arising from the underlying diagnosis, or to initiate surveillance for a specific complication or presenting symptom. In this case, although the information learned may be distressing, managing the medical condition appropriately may potentially alleviate some stress about the unknown, thereby tipping the balance in favor of benefit over risk or harm.

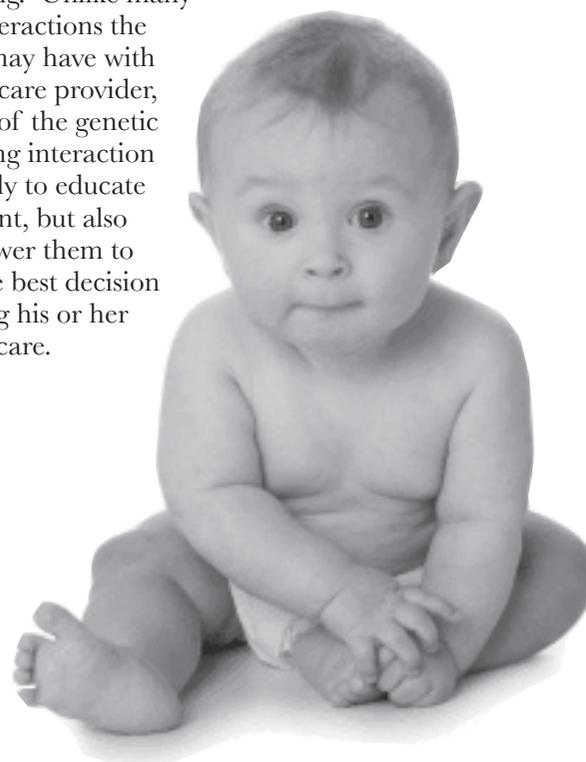
The question of benefit vs. harm may be more difficult when it comes to pre-symptomatic genetic testing, but the concepts and guiding principles for decision making remain the same. Instead of thinking about the near or immediate future, a patient will need to consider what it will feel like to know that a specific medical condition is in their future, but not knowing when the symptoms or

***The question of benefit vs. harm may be more difficult when it comes to pre-symptomatic genetic testing, but the concepts and guiding principles for decision making remain the same.***

condition will occur. Decision making in this scenario requires the ability of the patient to think in an abstract fashion, not about something that is happening, but that may happen someday. In the era of the "\$99 genome" this information is readily available, with very little oversight. Consumers have the opportunity to undergo genetic testing that is touted to identify one's genetic status for over 200 different traits and conditions. The consumer is able to collect a specimen for testing in the privacy of their own home, with no consideration for informed consent, the age of patient, indication for testing, etcetera. The results are reported back to the patient who provided the contact information with the order, with no specific requirements or recommendations that they seek the counsel of a physician or genetic counselor to help interpret the results. With no advanced discussion of the anticipated consequences of the results, there is great potential for the patient to be put into a very difficult situation, one that they could not anticipate. There is also no specific requirement

in place to ensure that the information released to the account holder was determined based on a sample from that particular person. This means that parents have the opportunity to collect a saliva sample from their children, and can learn about genetic conditions and predispositions that may impact their children 20, 30 or 50 years into the future – a time when the patient's parents, who ordered the test, might have already passed. If parents are choosing to uncover this information for their children there is no way to anticipate what benefit the child may have, or even if they mature into the type of person who is going to derive benefit from the information. This type of long-range thinking requires a level of emotional and intellectual maturity that many adults have to summon, and that by nature of the stages of emotional development, many children do not yet possess. For this reason, as evidenced by the recent policy statement from the American College of Medical Genetics, presymptomatic genetic testing for children should be discouraged, except in the rare case where the child may be able to have a treatment or change in their medical management that would prevent the condition from manifesting. Even in such cases, assent of the child should be obtained, if possible.

As with all scenarios involving genetic testing, presymptomatic, diagnostic, or for adults or children, the involvement of a genetic counselor may aid in the interpretation of results, to reduce the emotional burden to the patient, and identify the next best steps based on the patient's unique view of the situation. Without this advocacy, the patient may otherwise need to navigate the complexities of genetics and the implications of results, both medical and emotional, drawing only on their own skill set and resources. Certified genetic counselors are trained in various types of counseling theory and medical information pertaining to their particular specialty, with an overarching focus on non-directive and patient-centered counseling. Unlike many other interactions the patient may have with a health care provider, the goal of the genetic counseling interaction is not only to educate the patient, but also to empower them to make the best decision regarding his or her medical care.



### **Bio Quarterly**

is published four times a year by Bioethics Network of Ohio, 2653 Ramsay Road Beachwood, OH 44122 PH 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 [bioquarterly@gmail.com](mailto:bioquarterly@gmail.com) for consideration. Quarterly deadlines are the 15th of February, May, August and November.

### **Reprint Permission**

is granted to BENO members for professional/educational purposes unless otherwise indicated in the article. As a courtesy, please inform the editors of the purpose of volume copying. We are interested in what you are doing.

*Donna F. Homenko, PhD*  
President

*Pedro Weisleder, MD, PhD*  
Co-Editor

*Robert M. Taylor, MD, FAAN, FAANHPM*  
Co-Editor



## **BENO is Unique!**

We are the only statewide organization serving Ohio as an educational resource in health care ethics. If you share this interest, we invite you to become a member and...

- **Network** with experienced ethicists statewide.
- **Earn** continuing education credit.
- **Participate** in our projects.
- **Better serve** your organization and community.
- **Polish** skills and learn new ones.

**BENO** provides a unique opportunity for continuing education and for networking with colleagues across the state. If you might consider membership in BENO, please see the membership application on page 11.

## **Welcome New Members**

**BENO** welcomes the following new members and thanks them for joining the Network and contributing to the work of the organization.

### **INSTITUTIONS**

**Acclaim Hospice & Palliative Care**  
Dayton, OH

**Lima Memorial Health System**  
Lima, OH

### **INDIVIDUALS**

**David A. Simpson, MA**  
Akron, OH

**Julie A. Landoll, LSW**  
Willard, OH

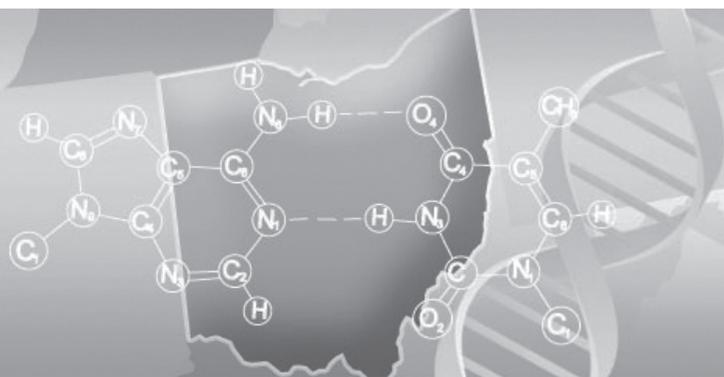
**Julie D. Hayde, MSW, LSW**  
Dayton, OH

**Asama Mobin-Uddin, MD**  
Dublin, OH

**Ashley K. Fernandes, MD, PhD**  
Dayton, OH

**Cassandra D. Hirsh, DO**  
Akron, OH

Serving Ohio as an  
Educational Resource  
in Healthcare Ethics



BIOETHICS NETWORK OF OHIO • **2013 MEMBERSHIP FORM**

**Individual Membership Levels:**

\$ \_\_\_\_\_ **INDIVIDUAL, Professional: \$50, 1 year**

\$ \_\_\_\_\_ **INDIVIDUAL, Professional: \$90, 2 years**

\$ \_\_\_\_\_ **INDIVIDUAL, Student: \$25, 1 year**  
(include copy of student ID)

• Individual Member benefits include a subscription to BIO QUARTERLY, discounted registration fee for the annual conference and access to special course offerings.

\$ \_\_\_\_\_ **ADDITIONAL GIFT** in support of  
BENO programs & activities\*

\$ \_\_\_\_\_ **TOTAL Enclosed.**

**Institutional Membership Levels:**

**Hospital Systems**◇, \$1500/yr.

For health care systems with 2 or more facilities. Members receive 3 complimentary registrations at the Annual Conference plus a discount on all other registrations, 25 copies of the Bio-Quarterly and a certificate of membership.

**Institutions, \$350/yr.**

For clinical, non-clinical, health care or academic facilities. Members receive a discount for the Annual Conference, 15 copies of the Bio-Quarterly and a certificate of membership.

\$ \_\_\_\_\_ **TOTAL Enclosed.**

..... **Please make checks payable to "BENO".....**  
**Mail to: MA Marketing Communication, 2653 Ramsay Rd., Beachwood, OH 44122**

*(Please print all information)*

Name or Contact Person \_\_\_\_\_ Degree(s) \_\_\_\_\_

Title \_\_\_\_\_

◇ Institution \_\_\_\_\_

Address (Circle work or home) \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ / \_\_\_\_\_ FAX \_\_\_\_\_ / \_\_\_\_\_ Email \_\_\_\_\_

◇ List all hospitals in your organization \_\_\_\_\_

Yes, you may use my information in the website password-protected directory

**Please contact [ljmarket@ma-marketing.net](mailto:ljmarket@ma-marketing.net) if you have any questions or want to verify your membership status.**

\* Your gift to BENO may be tax-deductable to the extent allowed by law.

**Bioethics Network of Ohio**  
2653 Ramsay Road  
Beachwood, OH 44122

Non-Profit Org  
U.S. Postage  
PAID  
Berea, Ohio  
Permit No. 333

Return Service Requested

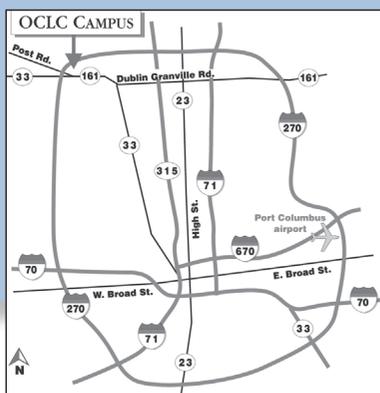
*Serving Ohio as an educational resource in healthcare ethics.*

## Save The Date!

Bioethics Network of Ohio  
Annual Conference

**Friday, May 2, 2014**

**"Bioethics in the Future Tense"**



**The Conference Center at OCLC**  
6565 Kilgour Place, Dublin, OH 43017-3395