

*Health Care Law*

*Mid-Atlantic Ethics Committee Newsletter*

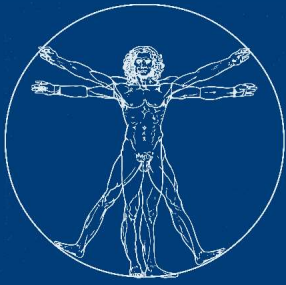
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Mid-Atlantic Ethics Committee  
Newsletter, Spring 2018

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# MID-ATLANTIC ETHICS COMMITTEE

## NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia  
Published by the Law & Health Care Program, University of Maryland Francis King Carey  
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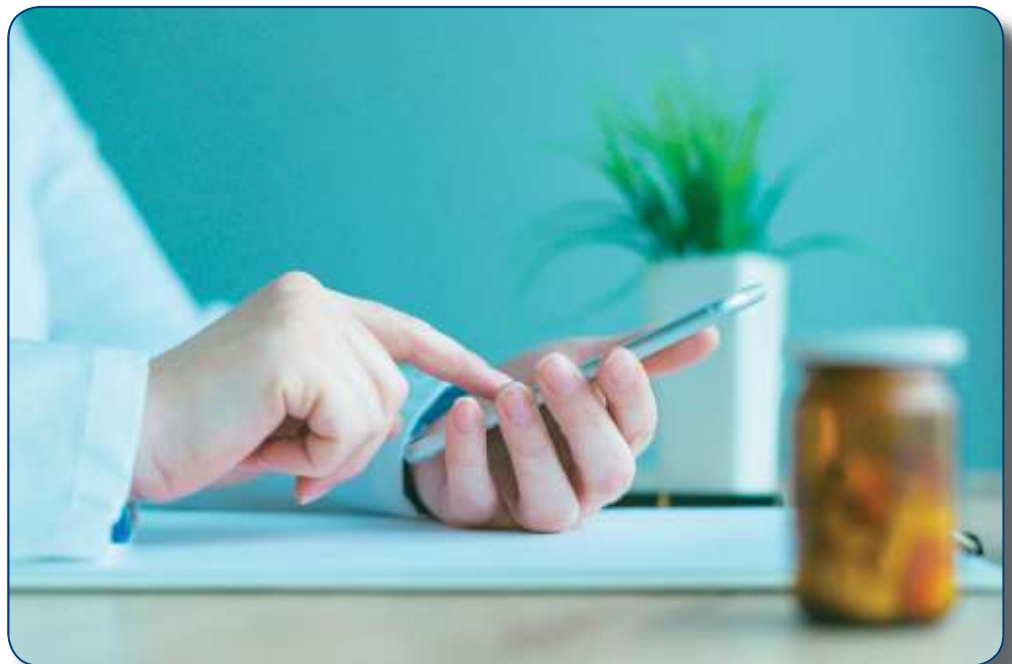
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## SOCIAL MEDIA AND HEALTH CARE: WHAT IS THE ROLE OF THE ETHICS COMMITTEE?



For better and worse, social media has become an essential part of our lives. According to the Pew Research Center, nearly 70% of Americans use some type of social media with Facebook and YouTube being among the most popular platforms.<sup>1</sup>

As social media use has become more widespread, it has presented healthcare providers, institutions and patients with unique opportunities for connection. For providers, online platforms can facilitate continuing education, disseminate research findings, foster connections with experts and allow clinicians to solicit advice from colleagues regarding patient issues. In addition, these networks can provide critical peer support for clinicians by providing a forum “to share workplace experiences, particularly those events that are challenging or emotionally charged.”<sup>2</sup> The appeal of these networks is evidenced by their growing membership rosters. According to Doximity, one of the leading online clinician networks, more than 70% of U.S. doctors are members, with more physician members than the American Medical Association.<sup>3</sup>

The *Mid-Atlantic Ethics Committee Newsletter* is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland Francis King Carey School of Law’s Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

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## **Social networking sites for clinicians**

- [Doctorshangout.com](http://Doctorshangout.com)
- [Sermo.com](http://Sermo.com)
- [Doximity.com](http://Doximity.com)
- [Figure1.com](http://Figure1.com)
- [WeMedup.com](http://WeMedup.com)
- [MomMD.com](http://MomMD.com)
- [AllNurses.com](http://AllNurses.com)

At the organizational level, social media can be a highly effective mechanism for enhancing a health care entity's visibility and developing relationships with surrounding communities. Many hospitals and medical centers now have Facebook pages and Twitter accounts as well as YouTube channels. For patients, social media platforms have enabled improved communication with providers, strengthened patient involvement in care, and fostered online communities of patients, such as PatientsLikeMe, that allow for information sharing and social support.

Despite these benefits, there are also significant risks associated with the use of social media in the healthcare context. We have all seen the headlines – an employee at a health care entity photographs a patient in a vulnerable moment and shares the photos with friends via social media applications such as SnapChat or Facebook. A ProPublica analysis, updated in June 2017, identified 65 instances since 2012 where inappropriate patient images were posted to social media by employees of long-term care facilities.<sup>4</sup> This past September, two employees from a naval hospital were removed from patient care roles after posting a video where they mishandled an infant and referred to babies as “mini-Satans.”<sup>5</sup> In December, a woman filed suit against her hospital employer in

connection with photos of her genitals taken by a nurse while she was undergoing surgery and later shared with co-workers.<sup>6</sup>

These incidents concern us not only as individuals and patients but also as members of health care ethics committees. They also raise important ethical concerns related to confidentiality, informed consent, and professionalism.<sup>7</sup>

Problems arise, in part, because of the conflict between the prevailing norms of health care settings and those for social media platforms.<sup>8</sup> In the health care context, laws and codes of conduct emphasize privacy, confidentiality, and professionalism. In contrast, in the social media realm, there are no such formal strictures and the prevailing values emphasize sharing, transparency and informality. It has become increasingly clear that health care providers and facilities must take a proactive approach to address the use of social media in the health care context or risk becoming the headline.

## **Legal Considerations**

Apart from the negative publicity, misuse of social media can have serious legal ramifications for health care providers and institutions. HIPAA, the federal Health Insurance Portability and Accountability Act, sets standards for the disclosure and use of individually identifiable health information (IIHI). IIHI includes any information that relates to the past, present or future physical or mental health of an individual or provides enough information that leads someone to believe that the information could be used to identify an individual (e.g. date of birth, social security number, etc.).

Under HIPAA, a covered entity such as a health care provider or facility may not use or disclose protected health information unless

such disclosure is expressly permitted under the HIPAA regulations (e.g. for treatment, payment for services rendered, quality assessment/improvement) or the individual patient or their representative authorizes the disclosure in writing. Although HIPAA does not specifically reference social media, the HIPAA Privacy Rule prohibits unauthorized disclosure of IIHI in “electronic” form. In order to share patient information on a social media platform in a HIPAA-compliant manner, the patient must provide written consent or the information must be de-identified to prevent any reader from identifying the patient.

**Consider the following case:**

Jamie, a nurse, has been working in hospice care for the last six years and one of her patients, Maria, maintained a hospital-sponsored communication page to keep friends and family updated on her battle with cancer. One day, Maria posted about her depression. As her nurse, Jamie wanted to provide support, so she posted, “I know the last week has been difficult. Hopefully the new happy pill will help, along with the increased dose of morphine. I will see you on Wednesday.” The site automatically listed the user’s name with each comment. The next day, Jamie was shopping at the local grocery store when a friend stopped her to ask about Maria’s condition. “I saw your post yesterday. I didn’t know you were taking care of Maria,” the friend said. “I hope that new medication helps with her pain.”

While the nurse’s actions are well intended, her post constitutes a breach of confidentiality and a HIPAA violation that puts the hospital at risk for fines and other penalties.

**Professional Standards**

Recognizing the risks presented by clinician use of social media, several professional organizations have issued guidelines regarding its ethical use. The American Medical Association (AMA), the American Nurses Association (ANA), the National Council of State Boards of Nursing (NCSBN), among others, have issued guidance to help providers navigate social media while maintaining protections for patient privacy and confidentiality. Results of a 2010 survey of state medical boards illustrate the need for these professional standards. According to the survey, more than 90 percent of medical boards received reports of violations of online professionalism. These violations include inappropriate contact with patients via the internet, inappropriate prescribing, and misrepresentation of credentials or clinical outcomes. Both the Maryland Board of Physicians and Board of Nursing have disciplined licensees for unprofessional behavior involving misuse of social media.

**Professional Standards**

With slight variation, the various professional standards emphasize the following:

1. Clinician responsibility to maintain legal and ethical standards of privacy and confidentiality
2. Prohibitions against posting identifying information about patients online
3. Vigilance regarding online privacy settings and safeguarding patient information
4. Distinct boundaries between personal and professional online presence
5. Consistent, appropriate standards for patient-provider interactions



## **Ethical Considerations**

In addition to the legal implications, there are important ethical considerations about use of social media. Issues of confidentiality, a core ethical principle for health care providers dating back to the Hippocratic Oath, patient privacy, informed consent, professionalism and trust should all be given careful consideration in any interactions or activities involving social media.<sup>8</sup>

As the NCSBN notes, many times inappropriate disclosure of patient information is unintentional and may be the result of a lack of understanding on the part of providers. For example, clinicians may mistakenly believe that their communication or post is private. As the American Medical Association notes, “privacy settings are not absolute...once on the Internet, content is likely there permanently.”<sup>9</sup> Providers are likely to encounter various ethical challenges as they navigate social media in the care context.

### **“Friending” a patient**

The American College of Physicians discourages physicians from accepting “friend” requests from patients and recommends limiting online interactions to discussions involving the patient’s care in the context of secure, approved electronic media such as MyChart. The NCBSN also urges caution for nurses regarding online interactions with patients and recommends consultation with employer policies for guidance.

### **Employing social media and search engines during course of treatment**

While the appropriate response to “friend” requests might seem clear-cut, there may be less clarity when it comes to health care provider use of sites like Facebook or Google to glean additional information about

patients. Professional organizations have not taken a strong position against so-called “patient-targeted Googling,” in part because it may be necessary under certain circumstances, such as attempts to identify unconscious patients.<sup>10</sup>

Guidelines from the American College of Physicians and the Federation of State Medical Boards, however, advise caution in the use of online sources to obtain information about patients, warning of the risk that such use may veer into “curiosity, voyeurism, and habit” and blur personal and professional boundaries. Such “digital tracking” may also undermine the trust a patient has for their provider if the patient discovers that a physician has engaged in these types of searches.

### **Visitors posting pictures of patients or identifying information**

As cell phones have proliferated, so has the tendency to document moments and events with their built in cameras. Although a visitor wanting to take a picture of a friend or family member’s new baby is understandable, such photos may be problematic if they include other patients in the background. While visitors are not considered “covered entities” in terms of HIPAA, many institutions have instituted policies regarding cell phone use in order to meet their ethical obligations to protect patient privacy and confidentiality. Stanford Hospital’s policy, for example, prohibits visitors and patients from photographing other patients, visitors, staff or physicians without permission. The hospital reserves the right to remove or destroy any photo taken in violation of the policy and requires consultation with hospital security and risk management if an individual refuses to comply. Even when a policy is in place, however, enforcement remains a challenge.

## **Implications for Ethics Committees**

In many of the cases involving healthcare provider use of social media, the behavior at issue falls squarely into the category of unethical, inappropriate and, in some cases, illegal engagement with social media. There are many cases, however, where a definitive determination is much more challenging. Such cases present an opportunity for health care ethics committees to provide guidance.

Ethics committees might consider leading efforts to develop social media policies and guidelines for health care institutions that have yet to adopt formal policies. Policies governing provider and employee use can emphasize the ethical obligations to patients, clearly outline prohibited behaviors regarding use of patient information on social media, and incorporate key input from stakeholders such as legal counsel and information technology personnel.

For institutions that have initiated the process or implemented policies, the ethics committee may have a role in the periodic review of the policy to ensure that it is comprehensive and up-to-date. There is also the potential for ethics committees to take an active role in the review and adjudication of cases involving potential violations of social media policy. Ethics committees might also facilitate training activities following adoption of a social media policy, working with providers and other health care entity staff to review and implement standards.

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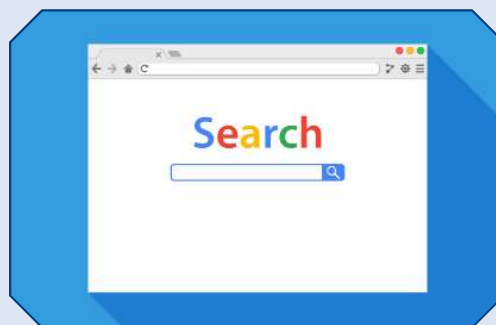
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## IS IT EVER OK FOR CLINICIANS TO GOOGLE THEIR PATIENTS?

This is a question that has been posed as an ethical issue for some physicians. In the publication *Psychiatric News*, a psychiatrist wrote in:

“We have learned that our psychiatry residents routinely Google their patients. On one recent occasion, the resident discovered that an inpatient was on a most-wanted list in another state for arson despite having denied a history of illegal behavior. Is it ethical to do a Google search on your patient's name?”

APA's Office of Ethics responded that “Googling” a



patient is not necessarily unethical but “it should be done only in the interests of promoting the patient's care and well-being and never to satisfy the curiosity or other needs of the psychiatrist. Also important to consider is how such information will influence treatment and how the clinician will ultimately use the information.”

The APA ethicist goes on to say that, “The standard of practice for learning about a patient's medical condition is through face to face interviews and this information may be supplemented by collateral information, for example, medical records or family members. Refusal or inability by patients to provide important historical information is not uncommon; in this circumstance, collateral data may assume an important role.”

Zilber (2014), cited above.

# INTEPROFESSIONAL, INTERFAITH ETHICS FORUM ON SUBSTANCE USE DISORDERS

*On November 7, 2017, MHECN partnered with the University of Maryland Schools of Law, Medicine, Nursing, Pharmacy, and Social Work, the UMB Graduate School, and the Institute for Jewish Continuity to present the 4th annual interprofessional forum on ethics and religion in health care. Prior topics have included end-of-life care, aging, and organ donation and transplantation. This fourth forum explored the topic of substance use disorders (SUDs). To view archival presentations, visit: <http://www.nursing.umaryland.edu/academics/pe/events/interprofessional-forum-on-ethics-and-religion-in-healthcare/>*

## TRANSTHEORETICAL MODEL OF INTENTIONAL BEHAVIOR CHANGE

In the opening plenary session, Dr. Carlo DiClemente, PhD, recounted a story from a New York Times article<sup>1</sup> about a woman who was having dinner with a friend. When asked if she would like wine with dinner, the woman responded, “Not for me ... I’m celebrating 10 years of sobriety this weekend.” At the end of the meal, to her amazement, the wait staff came to her table with a dish of ice cream garnished with a burning candle, singing “Happy Birthday” to recognize her recovery accomplishment. While this story signals progress in efforts to de-stigmatize drug addiction, there are many other stories of individuals with substance use disorders (SUDs) who routinely face others’ scorn, blame, and intolerance.

DiClemente, a Professor of Psychology at the University of Maryland Baltimore County, is known for his work developing and applying the Transtheoretical Model of Intentional Behavior Change to those with SUDs. This model describes stages of change both into addictive behavior (e.g., regular use of and dependence on a drug in harmful ways) and into recovery from that addiction. Moving through the stages (Precontemplation, Contemplation, Preparation, Action, and Maintenance) takes time, is not linear, and is influenced by various risk and protective factors, such as shared beliefs (e.g., “drinking alcohol is cool” or “using heroin is OK as long as you don’t shoot it into your veins”). Many people take opioids to manage pain and do not become addicted. Addiction in SUD involves both drug dependence (when the body gets used to a drug such that suddenly stopping it will cause physical symptoms of withdrawal) and abuse. A person in this maintenance stage of addiction is in precontemplation for addictions recovery. As with the journey through the stages of addiction, moving through the stages of addictions recovery takes time, is not linear, and is influenced by a host of factors that influence whether an individual will overcome the barriers to behavior change.

Examples of the many barriers individuals with SUDs face include neurobiological adaptation (i.e., the brain adapts to frequent exposure to the addictive substance, which can sometimes cause permanent brain damage), the tendency to associate with others with SUDs, and loss of social supports from immoral or illegal behaviors aligned with finding more drug to avoid the emotional and physical pain of withdrawal. Thus, while individuals may start using a substance to experience pleasure, they keep using it to avoid pain. This impairs self-regulation and increases impulsivity, making it even more difficult to exercise the control needed to stop using. As the addicted individual’s world narrows, maintaining the drug use becomes more highly valued and meaningful and takes over the person’s life.

Telling someone to “just stop using” is meaningless without walking them through the stages of change and providing appropriate supports along the way. DiClemente likens helping someone through the steps of recovery to a parent holding the hands of a toddler just learning to walk. He urges health care providers to appropriately evaluate SUD severity and treat the whole person, rather than SUD in isolation. For example, a person with SUD who also has attention deficit hyperactivity disorder (ADHD) has a higher risk of relapse due to even further reduced self-regulation (i.e., a weakened “self-control muscle”). Accordingly, rehabilitation from severe SUD often takes many months, as individuals need to build self-control and confidence. This comes from small steps, like making a bed or cleaning up after a meal.

Re-integration into society requires systems level changes. Putting someone into a three week recovery program and sending them back to the same environment and expecting them to resist the temptation to use again is not a formula for success. Research shows that one year after being diagnosed with diabetes, only about 20% of patients adhere to the prescribed diet and lifestyle recommendations they were given. Just as we continue working with these patients to help them manage their disease, we owe the same to persons with SUDs. Successful recovery occurs over a long period of time, involves multiple interventions, and requires an integrated, interprofessional, collaborative approach that treats the whole person rather than a disease.

## Addictions Medicine Specialists

**Christopher Welsh, MD**, Associate Professor in the Department of Psychiatry at the University of Maryland School of Medicine and an addictions treatment specialist reviewed the milestones leading up to the current opioid overdose epidemic, including a focus on undertreatment of pain and pharmaceutical industry lobbying and marketing efforts accounting for a dramatic increase in opioid prescribing in the 1990s and 2000s. (New prescribing guidelines hope to thwart inappropriate over-prescribing, such as the Centers for Disease Control's guidelines at <https://www.cdc.gov/drugoverdose/prescribing/guideline.html>.) Some of the many who received such prescriptions were predisposed toward addiction based on their genetics (accounting for about 60% of drug addictions) and life circumstances (e.g., poor and unemployed persons, or victims of prison system injustice). The trend of purchasing opioids online is partly to blame for the increased fatal overdoses, as these are much more potent formulations. Some small towns are spending the majority of their public health budgets on providing opioid antagonists like naloxone to prevent overdose deaths, with little left to spend on effective addictions prevention and treatment programs.

## Perspectives from the lens of religion and spirituality

**Rabbi Shmuel Silber**, the founder and Dean of the Institute for Jewish Continuity and Rabbi at Suburban Orthodox Congregation Toras Chaim in Baltimore, Maryland, shared insights from the Jewish faith tradition. In Judaism, people are considered inherently good, even when they behave badly. To address SUD, the source of a person's pain would be explored. Often there is

prior trauma that requires healing or acknowledgment. Sometimes, a person traces his substance addiction to a feeling that his life is not going the way he expected; he is not happy and turns to substance use to change that. This might stem from a belief that one has a right to always be happy and content. Yet, true happiness can't come from something you pop into your mouth or veins; it is a byproduct of efforts and accomplishments that bring meaning to one's life. Religious leaders must educate those looking to them for support that despite there being valid reasons for some to succumb to substance addiction, individuals must own their own circumstance, rather than giving away power by seeing themselves only as victims. "If we want people to heal," Rabbi Silber implored, "we must empower them with the realization that change is possible, and that it's okay to fail" (quoting Proverbs 24:16, "for though the righteous fall seven times, they rise again"). In Judaism, righteousness is not in avoiding failure, but being willing to learn and grow from it, and get back up again. Rabbi Silber encouraged an approach of accepting and loving people as they are while believing in their capacity to change and grow, and not reducing a person to his or her addiction or destructive behavior.

**Rev. Milton Emanuel Williams, Jr.**, the founder and pastor of New Life Evangelical Baptist Church in East Baltimore and President of the Turning Point Methadone Treatment Clinic, gave a moving address about his own experiences serving individuals seeking recovery from addiction. The Turning Point clinic is one of the first faith-based, and the nation's largest, methadone treatment center. Rev. Williams has lost friends and church members over his decision to provide SUD treatment within the walls of his church. His life has been threatened by drug

dealers who view him as a threat to their revenue stream. He doesn't care. As he watches individuals moving through the stages of addictions recovery, he sees whole family units being reassembled. Rebuilding the family is at the root of addressing SUD at its core. This starts with a message of love: God's love for each person. Whether one is religious or spiritual, one can start from this place of loving another and offering hope for change.

**Kathi Storey, MA**, a chaplain at the University of Maryland Medical Center, reiterated the message of dwelling from a place of love and forgiveness through spirituality. Spirituality is the belief in something greater than oneself. It gives a person strength in difficult situations. It gives life meaning. For some people, there is great overlap in their spirituality, religion, and morality. But just because someone is not religious or doesn't believe in God doesn't mean the person is not spiritual. Non-religious individuals active in traditional 12-step recovery programs may interpret "God" and "prayer" in non-religious ways (although courts have deemed such programs to be "religious" and thus unconstitutional for judges to mandate). Chaplain Storey's experiences ministering to patients and families challenged by drug addiction have taught her that religion can both nurture and thwart the spiritual transcendence necessary to overcome addiction. She recalled one patient whose wife insisted that her husband simply go to church and "stay clean" rather than get help outside of the church for his alcoholism. However, Storey's own husband enjoyed 14 years of continuous sobriety before he died, largely due to support from Alcoholics Anonymous, his church, and his employer. The common thread throughout Rev. Milton's, Rabbi Silber's, and Chaplain Storey's remarks was that healing from



addiction requires love and support from multiple sources, and that hope for positive change lies in community and the power of faith.

## Multiple perspectives on ethics and SUDs

A panel addressed interprofessional perspectives on ethical issues arising in addressing SUDs, including analysis of a case study.<sup>2</sup> Sorting through the ethical issues involves weighing harms and benefits and identifying what comprises “fairness.”

### Pharmacist’s perspective

**Bethany Dipaula, PharmD,** psychiatric pharmacist and director of the University of Maryland Psychiatric Pharmacy Residency Program, reviewed medication-assisted treatment (MAT) options for patients with opioid addiction (naltrexone, buprenorphine, and methadone). There are three medications approved to treat alcohol addiction (naltrexone, acamprosate, and disulfiram). Barriers to effective MAT use include limited treatment locations due to licensing restrictions and limited prescribers, lack of availability of medications in pharmacies, and stigma associated with opioid use and treatment (e.g., 12-step programs that require drug abstinence and attitudes that substance addiction is a character flaw rather than a chronic disease requiring a long-term treatment approach with MAT as a necessary component). Dipaula advises patients to establish routine care with a knowledgeable medical team that tailors care to each individual and treats the whole person rather than each disease or condition in isolation. MAT prescriptions should ideally be filled at the same pharmacy.

### Physician’s perspective

**Anika Alvanzo, MD,** Assistant Professor in the Division of General Internal Medicine at Johns Hopkins University School of Medicine, described the mission of the SUD consultation service she directs at Johns Hopkins Hospital as improving the health and quality of life of patients with SUD by providing non-judgmental, comprehensive and patient-centered care and education. Each patient’s plan of care is informed by an assessment that uses a motivational interviewing framework based on DiClemente’s Stages of Change model. She points to stigmatizing language often used to refer to persons with SUD (e.g., referring to them as “addicts,” “alcoholics,” “drug abusers,” “clean,” or having “relapsed”). Health care professionals often see a biased sample of persons with severe SUD so become pessimistic about recovery potential, which impairs their ability to develop rapport. They under-appreciate how awful it feels to withdraw from substance use (what some have described as the “worst flu you’ve had, times 10”), and dismiss legitimate pain as “drug seeking.” Dr. Alvanzo looks for “teachable moments” where she can enlighten staff about what effective SUD interventions look like and how they can transform lives.

### Social worker’s perspective

**Michelle Tuten, MSW, PhD,** Assistant Professor at the University of Maryland, Baltimore, School of Social Work and Adjunct Assistant Professor at Johns Hopkins University School of Medicine, has 20 years of experience in the treatment of SUDs through her work as a clinician and SUD treatment program director. One particular issue she has explored is what happens to women with a SUD who become pregnant. Society reserves harsh

judgment for such women, despite pregnancy not being a cure for SUD. While there is already a concern about insufficient availability of SUD treatment programs and poor insurance coverage, this is even more pronounced when searching for SUD recovery programs equipped to treat a mom and fetus/newborn dyad. Moreover, these women are often shamed and threatened with criminal prosecution (in some states), so they delay seeking treatment, fearing they may lose their parental rights if their SUD is discovered. The conflicting duties to treat the mom’s chronic relapsing disorder while also looking out for the best interests of the child presents an ethical dilemma. Yet, treating the mom with compassion and competent care rather than blame and judgment is more likely to benefit both her and her child.

### Health lawyer’s perspective

**Richard Boldt, JD,** faculty member at the University of Maryland Francis King Carey School of Law, has researched drug policy and the legal issues surrounding drug use disorders. He believes that reliance on the criminal justice system as a way of addressing drug addiction is ethically flawed. For example, the President’s Commission on the opioid crisis recently recommended use of drug courts, where teams of lawyers, judges, case managers, social workers, and other SUD treatment specialists work to meet the needs of individuals with SUD who enter into the criminal justice system. The thinking is that SUD recovery aims can be furthered by leveraging the coercive authority of the court. However, treatment-punishment hybrids often become debased; the punishment ultimately overrides the treatment component. Racial minorities and lower risk offenders are disproportionately targeted, mental health services

offered are substandard (sometimes drug courts disallow medication-assisted treatment), and those who “fail” end up with longer sentences. Instead, policy makers should prioritize community-based addictions treatment programs that are accessed upstream, rather than diverting individuals to treatment after they enter the criminal justice system. One promising model is when law enforcement provides “safe spaces” for drug-addicted persons, or Seattle’s program where police officers divert those with substance addictions to community programs. Decriminalizing drug addiction and funding its treatment as a chronic disease is supported both by public health outcomes and ethical standards.

### **Perspective from an addictions nurse**

**Katherine Fornili, DNP**, Assistant Professor at the University of Maryland School of Nursing and President-Elect of the International Nurses Society on Addictions, shared sobering statistics about the opioid crisis and its roots. For example, despite the death toll from opioid overdose topping 52,000 in 2015, only one in ten people who suffer from SUD receive any type of treatment. Various federal initiatives are being implemented to prevent drug use, promote early intervention, and integrate treatment for SUD across healthcare disciplines. The Department of Health and Human Services has identified three priority areas: (1) improved opioid prescribing practices, (2) expanded distribution and use of naloxone to reverse effects of opioids and prevent overdose fatalities, and (3) expansion of medication-assisted treatment options. Unfortunately, politics, ignorance, and bias have thwarted efforts to properly fund and prioritize interventions that would reduce SUD prevalence and improve access

to recovery and harm reduction programs (e.g., needle exchange, test kits to allow persons to verify what drugs they are using, and access to safe injection sites). Since addiction is a chronic illness characterized by alternating periods of substance use and abstinence, a plan must be devised to anticipate this trajectory. Attention to the social determinants of health is paramount. Unfortunately, gains made under the Affordable Care Act (e.g., health coverage for mental health services, limits on out-of-pocket spending, and expanded prescription drug coverage) may be lost given the current budgetary and political climate. Bills recently passed (the Drug Addiction Treatment Act, the Recovery Enhancement for Addiction Treatment Act of 2015-16, and the Comprehensive Addiction Treatment Act of 2016) did not come with funding. The Substance Abuse and Mental Health Services Administration’s website (<https://www.samhsa.gov/>) is a good starting point for those looking for SUD resources. But clearly, more advocacy work is needed to create policies and foster attitudes that help those in active addiction and at risk for addiction to get the help they need and deserve.

### **NOTES**

1. Hilgers, L. (2017, November 4). Let’s Open Up about Addiction & Recovery. *The New York Times*. Retrieved from: <https://www.nytimes.com/2017/11/04/opinion/sunday/drug-addiction-recovery-alcoholism.html>
2. See The American Journal of Bioethics January 2018 issue (Volume 18, Issue 1) for the case and related ethical commentaries.

### **NEW BOOK: Courageous Conversations by Shahid Aziz, M.D.**

If you search on Amazon for topics related to death and dying, you will retrieve over 20,000 titles. If you are looking to hone that search, here is a new title to explore: *Courageous Conversations on Dying - The Gift of Palliative Care: A Practical Guide for Physicians, Healthcare Providers, & All the People They Serve* by Shahid Aziz, M.D. Dr. Aziz is a long-time friend and supporter of MHECN as well as former chair of MHECN’s Education Committee. In his work as a pediatrician and as Harbor Hospital’s ethics committee chair, he became intimately familiar with the shortcomings of how clinicians communicate about death and dying with patients and families. These communication missteps and missed opportunities have fueled a majority of the ethics consultation requests that ethics committees receive. This inspired Dr. Aziz to switch his professional focus and obtain board-certification in hospice and palliative care medicine. He now concentrates in palliative and end-of-life care. Dr. Aziz developed a particular approach to advance care planning that moves away from a checklist approach toward a goals-of-care approach. After teaching this approach in workshop format to hundreds of individuals, he now shares it more broadly in his book. *Courageous Conversations* walks the reader through the steps of effective advance care planning conversations and how to document these, and contains numerous helpful insights, tips, and case studies. While end-of-life care experts are needed, all health care providers must play a role in facilitating advance care planning. Dr. Aziz’s book is a roadmap for how to get there.

# CASE PRESENTATION

*One of the regular features of this Newsletter is the presentation of a case considered in an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. We may also change facts to protect confidentiality. Cases and comments should be sent to MHECN@law.umaryland.edu.*

## CASE STUDY - PARENTAL REFUSAL OF LIFE-SUSTAINING INTERVENTIONS IN A NEWBORN

Boy L was born full term to a married Nigerian couple visiting family in the U.S. The baby's mother did not have any pre-natal exams so she and the delivery team did not know that the baby had Down syndrome. The baby required some respiratory support at delivery warranting a NICU admission. The clinicians noted a cleft palate and suspected other congenital anomalies such as duodenal atresia. Before the NICU team could finish the complete diagnostic work-up, the parents requested that no further testing be performed. They explained that in their country, a child with these conditions has no meaningful chance of a good quality of life. They requested that the child not be given any further medical treatments, including intravenous nutrition and hydration, and that the infant be allowed to die. The NICU team wondered whether this would constitute medical neglect. They consult the ethics committee for guidance.

## COMMENTS FROM A NICU NURSE, NEONATOLOGIST, AND NEONATAL NURSE PRACTITIONERS

As the nascent field of Neonatology has evolved, so have opinions and policies regarding the medical, legal, and ethical care of newborn infants, especially those born with congenital anomalies and genetic syndromes such as Trisomy 21. As evidenced by widely publicized cases at Johns Hopkins and Yale in the 1960s and 1970s, it was "ethically acceptable" to forego surgical interventions for such infants, and allow natural death to occur.<sup>1</sup> These decisions were paternalistic in nature, and largely based on the belief that the parents' future burden in taking care of an infant with complex medical issues was paramount. The "right to die" as well as a parental right to choose for their infant (parental authority) were the dominant ethical principles.<sup>1</sup>

The 1980s saw a significant paradigm shift toward "life-at-all-costs," which began following public awareness of the Baby Doe case. Baby Doe was born in 1982 in Indiana, and was diagnosed with Trisomy 21 and tracheoesophageal fistula. The obstetrician informed the family that developmental outcomes were dismal for children with Trisomy 21, and counseled the family to withhold surgical intervention. Other physicians disagreed, and petitioned the court. The Indiana State Supreme Court ruled that the child's parents had a right to choose the baby's treatment and the infant died without surgery. This case galvanized right-to-life advocates within the Reagan Administration to pass the "Baby Doe Laws," to ensure that all infants received life-sustaining interventions, regardless of diagnosis. This effectively removed the consideration of "quality of life," and minimized parental authority.<sup>2</sup>

Over the past 35 years, the pendulum has swung back toward an ethical middle ground. Shared Decision Making (SDM) between parents and the health care team is emphasized and endorsed by The American Academy of Pediatrics (AAP). In the SDM model, parental authority is prioritized and respected, with guidance based upon the experience and expertise of the medical team.<sup>3</sup> In 2017, the AAP Committee on Bioethics published a policy statement titled, "Guidance on Forgoing Life-sustaining Treatment." This policy statement emphasizes both parental authority and promoting the best interest of the child ("best interest standard"), with efforts aimed toward interventions that sustain life. Collaborative communication and SDM between healthcare providers and families regarding the benefits and burdens across a range of treatment options is vital to these ethically-based decisions.<sup>3</sup>

In Trisomy 21, there is an extra copy of chromosome 21, increasing the total number of chromosomes from 46 to 47. This extra copy of chromosome 21 is responsible for development of congenital anomalies, including characteristic facial features and cognitive impairment. The spectrum of congenital anomalies often includes hearing loss, congenital heart disease, and gastrointestinal (GI) malformations such as duodenal atresia. Although a wide range in degree of cognitive impairment occurs, severe impairment is less common and quality of life for children with Trisomy 21 is generally achievable.<sup>4</sup> Thus, surgical interventions that sustain life are thought to be in the best interest of the child. While in the 1970s fewer than 50% of physicians recommended surgical interventions for Trisomy 21, it is now considered standard of care.<sup>5</sup>

Would withholding surgery in this infant be considered medical neglect? Medical neglect occurs when parents fail to provide adequate treatment for their child, possibly resulting in harm or death.<sup>6</sup> In this case, parents declined further diagnostic testing or treatment of known medical conditions, which could be considered medical neglect. The cleft palate may hinder feeding and optimal language development, and requires surgical repair. Duodenal atresia requires surgical

intervention to sustain life. In the United States, the morbidity and mortality associated with this procedure are negligible, and the benefits of surgery outweigh the risks. Thus, both surgeries would be offered to infants with Trisomy 21, especially in the absence of life-limiting comorbidities. In fact, surgical repair of more severe cardiac malformations and treatment of conditions such as leukemia associated with Trisomy 21 are routinely offered based on modern ethical opinions of the quality of life associated with this condition. Quality of life, however, is highly subjective, especially in the case of infants who cannot speak for themselves, and therefore parents are traditionally seen as the best advocates for their child. Cultural influences, religious beliefs, personal experiences, and biases drive parents' perspectives of quality of life. When caring for infants with life-limiting diagnoses, focusing on goals of care can help lend understanding of parents' desires for their infant and their definition of quality of life.

In this case, the parents have expressed a desire that the child be allowed to die, which in their opinion is in the infant's best interest. Thus, there is conflict between the parents' and the medical team's guiding principle of right to life and their definition of quality of life for infants with Trisomy 21. This case is further complicated by the fact that the parents are planning to return to Nigeria. Several questions then arise: 1) What information was provided to the parents by the medical team regarding prognosis and natural history of Trisomy 21? 2) What is preventing a good quality of life for this child in Nigeria (for example, resources, social stigma) and can those conditions be altered? 3) Should the medical team seek assistance from the legal system in order to determine next steps, complete diagnostic testing and perform surgeries without parental consent? 4) Would the infant be subsequently placed in the U.S. foster care system or would the parents be allowed to resume custody and return to Nigeria? 5) Should custody be taken from the parents, and the "best interest standard" followed, to meet the U.S. medical system's definition of quality of life for children with Trisomy 21 and ultimately preserve life? Right to life and quality of life, as perceived by the medical team, would be obtained at a price. This includes loss of parental authority and sacrifice of parents' right to raise their child within their value system. These concepts require further examination and exploration prior to any decisions regarding the outcome of this case.

Respect for autonomy dictates that the choices of the patient with decision-making capacity be honored. Parental authority is a similar but unique concept. As surrogate decision makers, parents are expected to make decisions that are in the best interest of their child. In certain conditions, it may be permissible and even obligatory to override parental decisions based on the best interest standard.

Similar sentiments are echoed within the Constitution of the Federal Republic of Nigeria. Civil and criminal laws aim to preserve the right to life. According to the Nigerian Child Rights Act, ethical decision making should focus on the best interest of the child; every child has the right to protection of his/her well-being, and the right to health and health service. In extreme cases, however, it is acceptable to withhold or withdraw treatment.<sup>7</sup>

In this difficult case, it is likely that the medical team would feel obligated to treat. However, medical providers should make every effort to respect parental authority, and remain sensitive to cultural values and the belief of the patient's family. Continued efforts aimed at collaborative and transparent communication may aid in mutual understanding and lead to development of an acceptable treatment plan.

**Lucy Rose Davidoff RN, Dawn Mueller-Burke PhD, NNP-BC, Nikki Brandon MS, NNP-BC, Alison J. Falck MD, Division of Neonatology & Neonatal Intensive Care Unit, University of Maryland Medical Center**





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1. Boyle, R. (2004). Paradigm cases in decision making for neonates. NeoReviews. *American Academy of Pediatrics*, 5, e477.
  2. Mercurio, M. (2009). The aftermath of Baby Doe and the evolution of newborn intensive care. *Georgia State Law Review*, 25(4), 835-863.
  3. Weise, K.L., Okun, A.L., Carter, B.S., Christian, C.W. (2017). American Academy of Pediatrics Committee on Bioethics, Section on Hospice and Palliative Medicine and Committee on Child Abuse and Neglect. Guidance on forgoing life-sustaining medical treatment. *Pediatrics*, 140(3), 1-9.
  4. Bull, M.J. (2011). American Academy of Pediatrics Committee on Genetics. Health supervision for children with down syndrome. *Pediatrics*, 128, 393.
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  6. Jenny, C. (2007). American Academy of Pediatrics Committee on Child Abuse and Neglect. Recognizing and responding to medical neglect. *Pediatrics*, 120(6), 1385-1389.
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## COMMENTS FROM CLINICAL ETHICS CONSULTANTS

In the case of Baby Boy L, there is a range of intersecting interests and obligations implicated including: 1) the interests of the patient himself; 2) the interests of his parents as his parents; and 3) the correlated obligations of the medical team and our society in protecting the interests of individuals who cannot protect themselves, especially children, and specifically children with disabilities. Based on these interests, we describe and rank the ethical acceptability of various potential resolutions for the dilemma this case presents.

### The ethical issue

The morally laden choice facing the care team is whether to honor the parents' request and allow the patient to die, or to overrule the parents' wishes and save the patient's life. The ethical dilemma is whether to affirm the parents' interests as parents while respecting their construction of their child's future interests, and letting the patient die, or to overrule the parents' choice and substitute our society's construction of the child's interests,

and subsequently act to save the child's life.

### Reasons to honor the parents' request

The care team ought to consider honoring the parents' request out of respect for their autonomy and inherent right to care for their son as they believe to be best. Parents have an interest and a correlated societal right to care for their children without unnecessary interference from others. Hospitals have an obligation to respect the autonomy and dignity of parents as caregivers and guardians for their children. The societal boundaries of the parental right to raise children as the parent sees fit end where abuse and neglect begin. Absent clear showings of harm, it's unethical and inappropriate to substitute the community's judgment for a parent's choices in matters regarding childrearing.

In our society we tolerate potentially suboptimal parenting behavior due to a commitment to respecting parental rights and autonomy. This is ethically

appropriate for several reasons. First, people should be able to construct their personal relationships and families consistent with their own cultural norms and values. Second, in most cases, the people that are best positioned to maintain and promote a child's best interests are his or her parents. The default societal position that parents have an inherent right to raise their children as they see best should only be overturned in extenuating circumstances where clear harms can be demonstrated. The question here is where to draw the line in defining these extenuating circumstances.

### Reasons to overrule the parents' wishes and operate on the patient

There are two arguments for overruling the parents' wishes and saving the patient's life. First, children have an interest in their own health, and the opportunity to live out their future interests as their own person. Death extinguishes those interests.

Second, communities have an interest and a correlated obligation and authority to protect and promote

the interests of individuals who cannot act on their own behalf. This is especially true for children and individuals who have certain impairments and disabilities, or who are a member of a historically disadvantaged class. This interest and obligation is reflected in child protection and disability rights law. The Baby Doe Rules are an example of an explicit policy designed to protect the interests of children like Baby L. Whether or not the Baby Doe Rules apply in this case is unclear; however, the rules create an obligation on healthcare providers to intervene and care for a child in circumstances where a child's welfare would be harmed on the basis of an inappropriate discrimination against a disabled child. If Baby L's parents are making the decision to allow him to die of an otherwise survivable condition on the basis of discrimination against children with Down syndrome, then it would be ethically appropriate and consistent with regulatory requirements to intervene and save the patient's life.

### **Possible Resolutions**

There is a range of potential resolutions to this ethical dilemma that vary in their practicability and ethical acceptability.

We suggest that the best option would be to save the patient's life while preserving the integrity of the family. An ideal variation of this option might involve supporting the family if they desire and are able to stay in the U.S.. However, this presents a challenge if the parents must return to Nigeria, given the pervasive negative attitudes there toward persons with disabilities, and few affordable resources to allow Baby L to thrive. Although Baby L's life is preserved and his family remains intact, his life in Nigeria will probably involve challenges

that reduce his quality of life. This case epitomizes the weight of moral residue accompanying ethical dilemmas involving both cultural relativism and inequality in the distribution of wealth and resources across the world.

Thus, the next best option may be to explore adoption with the parents. If they consented to the surgical intervention to allow the baby to feed and grow, they could then agree to place the child up for adoption if they decide they do not want to parent the child. This affirms the patient's interests, and is consistent with the parents' interests to the extent their choices are voluntary. This solution is practicable, but also depends on the child being adopted by a caring and supportive family.

Two other options remain; however, these result in harms to persons that are ethically problematic.

The first of these is to obtain a court ruling to proceed with surgical intervention to save the baby's life, along with involuntary termination of the parents' rights and placement of the child in the foster care system for adoption. This affirms the patient's interests in life, but harms the parents' interests as parents of the patient.

The final option is to honor the parents' wishes and allow the patient to die; however, this harms the patient's interests in a future life. This also potentially undermines the societal institutions and norms for the protection of children with disabilities.

### **Culture and contextual considerations**

Given the patient and family's national and cultural background, it is important to consider the historical context for the involuntary termination of the parental rights of persons who are not members of the dominant culture in our society. In

this case, the option of involuntarily terminating parental rights implicates additional concern regarding racial inequities in power and privilege in the U.S. Historically, the substitution of a societal construction of a child's interests as a basis to involuntarily terminate parental rights has occurred at disproportionately higher rates in minority families. This includes a history of systematically terminating the parental rights of Native American/American Indian families, and an ongoing discrepancy in the rates of terminations of parental rights in minority families. Although it may be ethically appropriate in the individual case, it's important to consider that this choice may be embedded in a broader history of supremacy where a dominant culture invalidates the parental interests of minority parents under a justification that the dominant culture's values have greater weight or validity.

### **Conclusion**

An ethical resolution of this case ought to take into account the interests and obligations of all stakeholders. It is essential that the analysis extend beyond the narrow question of whether the withholding of treatment constitutes medical neglect.

Additional considerations should include the parents' interests as parents, the patient's future interests in health and quality of life, and our society's interest in protecting vulnerable individuals. The relative importance of these considerations remains debatable; our society's values and commitments regarding the government's role in protecting children and intervening in private family affairs will vary and continuously evolve. We suggest that the best option would be to save the patient's life while preserving the integrity of his family.

We would also maintain that there is an ethical obligation to systematically pursue the best options first, and proceed through the next best option, before considering options resulting in ethically problematic harms.

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#### **In Memoriam: Bob Roby, M.D.**



March 15th marked the one-year anniversary of the death of Dr. Robert (“Bob”) Roby, geriatrician and devoted advocate of services for the elderly. Dr. Roby graduated from University of Maryland Medical School and completed Postgraduate Medical Training in internal medicine at Maryland General Hospital (now University of Maryland Medical Center Midtown Campus – UMMC Midtown). He was Chief of the Emergency Department at Maryland General for over 25 years. From 2004 until his death, Dr. Roby served as Coordinating Physician for Geriatric Physician Services at UMMC Midtown. He joined that hospital’s ethics committee in 1994 and MHECN’s Education committee in 2001. Dr. Roby was also active in geriatric and nursing home and assisted living medicine from 1979 until his death in 2017. He served as medical director at multiple Baltimore area nursing homes over many years. Dr. Roby also held leadership positions, including serving on the Executive Council for the National Nursing Home System’s National Medical Director Advisory Board. In 2008, he was nominated for National Medical Director of the Year by the American Medical Directors Association (now called AMDA – The Society for Post-Acute and Long-Term Care Medicine). His extensive experience and encyclopedic knowledge of emergency medicine and long-term care made him a tireless advocate for improving patient care. His co-workers, students, and mentees recognized him as a true leader and role model. One year after his death, his dynamic presence and ethics advocacy is still missed.

# CALENDAR OF EVENTS

Spring 2018

## MAY

10-11

Brain-based and Artificial Intelligence: Socio-ethical Conversations in Computing and Neurotechnology, Organized by the Center for the Study of Ethics in the Professions, Illinois Institute of Technology, Chicago, IL. Visit: <http://ethics.iit.edu/BrainAIWorkshop>

## JUNE

4-7

Foundations of Bioethics, sponsored by The Interdisciplinary Center for Bioethics at Yale University, New Haven, CT. Visit: [bioethics.yale.edu/summer](http://bioethics.yale.edu/summer). (Longer program also available June 1-July 21.)

4-14

Summer Institute in Bioethics, sponsored by the Johns Hopkins Berman Institute of Bioethics. Visit: <http://www.bioethicsinstitute.org/summer-institute>

- PH.700.600 Basics of Bioethics (2 credits)
- PH.700.702 The Ethics of Making Babies (2 credits)
- PH.221.656.11 Conceptual and Evidential Foundations of Health Equity and Social Justice (4 credits)

8-11

Clinical Ethics Immersion, sponsored by the Center for Ethics at MedStar Washington Hospital Center, Washington, DC. Visit: <https://www.medstarwashington.org/our-hospital/center-for-ethics/clinical-ethics-immersion/#q={ }>

13 (8am-12pm)

Practical Clinical Ethics: Addressing the Suffering of Mind, Body and Spirit, sponsored by Harbor Hospital's Ethics Committee, Harbor Hospital, Baltimore MD. MHECN members can register at a reduced rate (MedStar Harbor Associates' rate). Visit <http://www.law.umaryland.edu/MHECN> and click on "Conferences" for registration information.

21-23

The 14th Annual International Conference on Clinical Ethics & Consultation (ICCEC), hosted by the Institute of Medical Ethics, Oxford, UK. Visit: [iccec2018.org](http://iccec2018.org)

Bioethics and Being Human, sponsored by The Center for Bioethics & Human Dignity, Deerfield, IL. Visit: <https://cbhd.org/conf2018>

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## RECURRING EVENTS

Johns Hopkins Berman Institute of Bioethics Seminar Series, either at Sheik Zayed Tower Chevy Chase Conference Center (1800 Orleans St.) or Feinstone Hall, E2030, Bloomberg School of Public Health (615 N. Wolfe St.) Baltimore, MD. 12N-1:15PM. Visit: <http://www.bioethicsinstitute.org/educationtraining-2/seminar-series>

**May 14 speaker:** Understanding the potential of state-based public health genomics programs to mitigate disparities in access to clinical genetic services, Laura Senier, PhD, MPH (Zayed)

**May 21 speaker:** Risk and benefit for pediatric Phase I trials in oncology: a meta-analysis and ethical implications, Marcin Waligora, PhD (Deering Hall, Lower Level)



**The Law & Health Care Program  
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University of Maryland  
Francis King Carey School of Law  
500 W. Baltimore Street  
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*The Maryland Healthcare Ethics Committee Network* (MHECN) is a membership organization, established by the Law and Health Care Program at the University of Maryland Francis King Carey School of Law. The purpose of MHECN is to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. The Network attempts to achieve this goal by:

- Serving as a resource to ethics committees as they investigate ethical dilemmas within their institution and as they strive to assist their institution act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

MHECN appreciates the support of its individual and institutional members. MHECN also welcomes support from affiliate members who provide additional financial support.

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