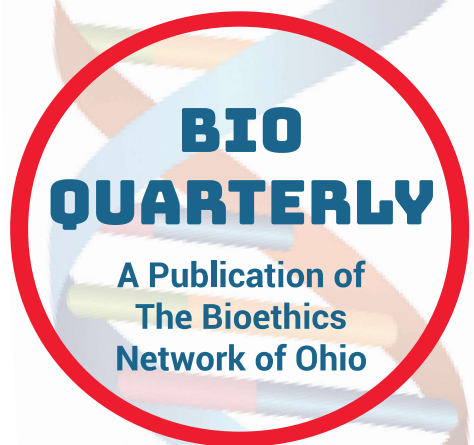


BEN

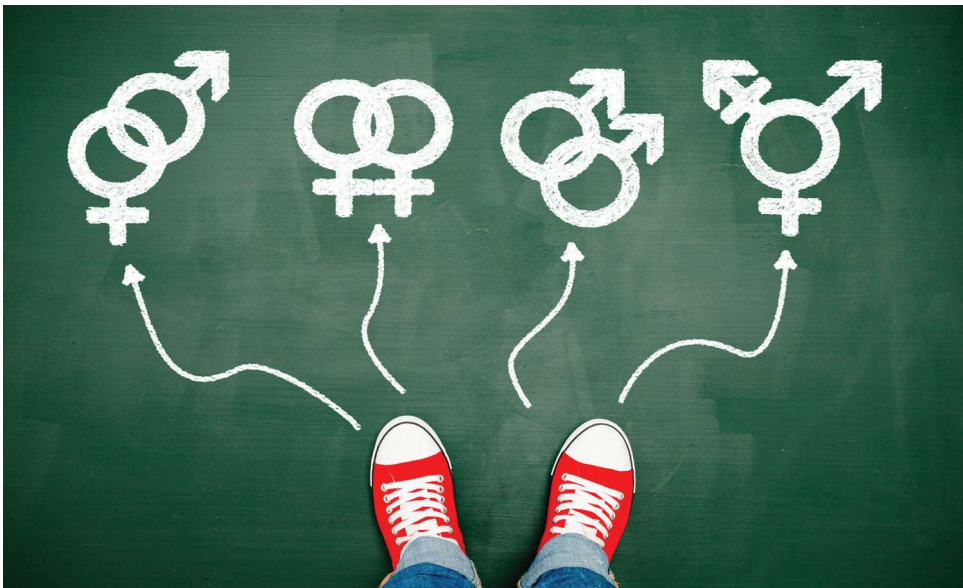


A Case for Caution: *Rethinking Approaches to Intersex Medical Care*



Debra Beight holds BAs from the Ohio State University in Communication Analysis and Women's, Gender, and Sexuality Studies, an MSc in Public Health from Lund University in Sweden, an MA in Bioethics, also from Ohio State, and she is entering her second year as a PhD student in Bioethics at Case Western Reserve University.

A 2013 South Carolina court case involving an intersex child provides an opportunity to examine the current complexities of medical management for intersex/DSD (Differences of Sex Development). The child referred to as M.C., was a ward of the state and had gender-“normalizing” surgery on his ambiguous genitals, assigning him as female. Post surgery, M.C. was adopted and after realizing M.C. identified as a boy, his family sued the physicians, hospital administrators, and state officials in charge of M.C.’s care. The case cited their actions “violated M.C.’s rights to bodily integrity, procreation, liberty, and privacy”. [1] Considering the influences of socio-cultural aspects of sex and gender, along with the historical evolutions of medical decision-making for intersex children, provides an overview of the present challenges families and healthcare providers face in determining goals of care for these patients.



continued on page 3...

CONTENTS

- 2** Greetings from the President
- 5** Leveraging Rural Strengths: Beyond a Deficit Model in Rural Healthcare
- 7** Online Educational Opportunities
- 8** New Board Members Book Review
- 9** Educational Opportunities Member Spotlight

Bio Quarterly

is published four times a year by
Bioethics Network of Ohio
22425 Canterbury Lane
Shaker Heights, OH 44122
PH 216-403-2430
www.BENOethics.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 info@benoethics.org 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 editor of the purpose of volume copying. We are interested in what you are doing.

Josh Crites, PhD
President

Kathleen Grannan, RN-C, MSN
Anna Meurer, BA, MPH

We welcome your Charitable Contributions

Your financial contribution to BENO, a qualified 501(c) (3) organization, is considered tax deductible. We appreciate all contributions to help further our mission and educational efforts. Contributions can be made by check or on our website, www.BENOethics.org. A receipt is available upon request.



President's Greetings

Welcome to the Summer Issue of BioQuarterly.

Our parents were right: time does speed up as we move through the years! It seems as though we were just finalizing plans for the BENO Annual Conference and now September is knocking on the door. Whether you're transitioning into a new academic year or just continuing the good clinical work that's year-round, spend time doing the things you love most with the people who give you energy.

It has been a productive summer for BENO. After a very successful conference, the BENO Board of Trustees held annual elections and is welcoming both new and returning members. Please join me in congratulating Craig Dove, M.Div., PhD (Vice-President); Julie Aultman, PhD, MA; Kathy Grannan, RN, MSN; Cristie Cole Horsburgh, JD; Amanda Lang, MPH, MA; and Carl Mullins, M.Div. I'm very excited to be working with these folks on the Board.

BENO also hosted its first educational session earlier this summer, with an excellent presentation from Board Member Keren Tanguay, PhD, M.Div. This was the kickoff to renewed efforts to provide high-quality education for our members and the broader bioethics community in Ohio. The next session in the series will be facilitated by former BENO Vice-President, Alan Murphy PhD in November. Watch for additional details about how to participate.

Content in this issue is both timely and I believe of value to our members. In addition to running content highlighting art, humor, Board Member bios, and upcoming educational opportunities, Board member Alex Perry writes about how bioethicists can become better leaders when it comes to advocating for patients with substance abuse disorder. Debra Beight, a PhD student at CWRU, offers an ethical assessment of a range of issues tied to medical care for patients who are intersex. Here, too, better understanding of the experiences of patients who are intersex allows for better support and advocacy for appropriate medical care from bioethicists and our clinical colleagues.

In the same way I close each President's Letter in BioQuarterly, I want to remind our members that BENO's mission is to support the work of bioethicists and clinical ethicists across the state. The Board of Trustees would love to hear from you! Please consider sending along ideas for future webinars or web-based content that would amplify the good work that you all do everyday.

My Best,

Josh



FOLLOW BENO ON:



Caution continued from page 1...

Assigned male at birth, M.C. had ovotesticular DSD, male and female internal reproductive organs, elevated testosterone, a small sized phallus and a small vaginal opening with scrotalized labia. [2] Physicians determined M.C. could be reared as either a boy or a girl, advising he needed an assigned gender and correction of his ambiguous genitals. One of M.C.'s surgeons noted the risks of performing an "irreversible feminizing surgery.... would be devastating.... on a child who might ultimately identify as a boy" [3], but still, at sixteen months old, M.C.'s genitals were feminized, and he was re-assigned female.

M.C.'s adoptive family initially raised him as a girl; however, it became obvious that he was developing a male gender and by age seven, M.C. was living as a boy. The resulting lawsuit, the first of its kind, cited that his care providers failed to thoroughly evaluate the risks of surgery or to explore alternatives and options. The suit was to validate that M.C.'s rights had been violated, and to prevent this from occurring again. [4]

Intersex/DSD manifests as variations in genetic, hormonal, and/or physical traits that don't fit into the binary categorization of male or female. Up until the mid-1960s, intersex interventions applied to adults who could prove obvious intersex traits. In 1965 psychologist Dr. John Money, working from his gender theory studies on children, determined gender identity was moldable up until 18 months of age. [5] To prevent psychological incongruity and emotional instability, "normalizing" surgeries shifted from intersex adults to intersex children. The primary concern was not a medical emergency but a social emergency concluding that a child born with intersex traits would not only be harmful to the future adult but also to the present child's parents. [6] Since the 1990s, adult intersex activists have pushed back against unnecessary and harmful childhood surgeries. Their extensive work resulted in surgical interventions approached more cautiously, but not eliminated.

Medical and social understandings of sex and gender identity have evolved, impacting the application of our ethical values to standard practices. Over the last ten years, this evolution of under-

standing, along with continued engagement from adult intersex activists has resulted in more support for postponement or elimination of "normalizing" surgeries. The DSD-Life study in the EU, the Global DSD Update Consortium, intersex organizations such as InterAct and IHRA (Intersex Human Rights Australia), along with autobiographical books and movies from intersex adults, all challenge as-

"Performing these surgeries on infants and young children restricts the patient's ability to engage in the decision-making process."

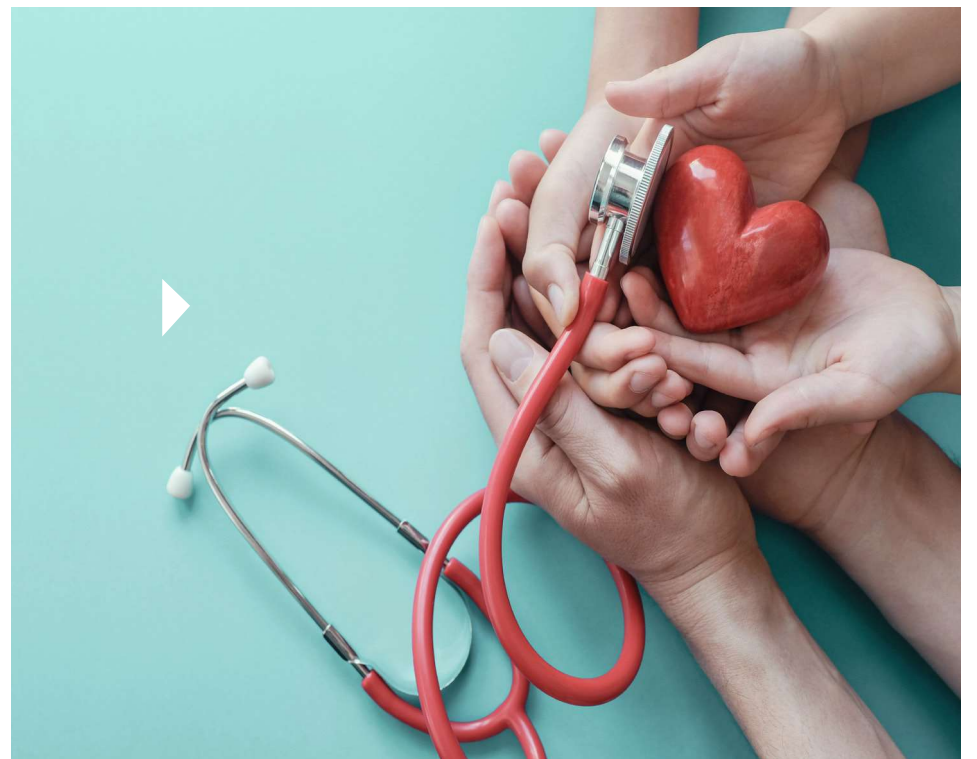
sumptions surrounding present medical care standards for intersex children. [7] An example of the impacts of these re-evaluations to intersex medical management was that in 2020, Boston Children's Hospital and the Ann and Robert H. Lurie Children's Hospital of Chicago, decided to cease certain cosmetic genital surgeries on intersex children [8] and explore different avenues of support for intersex patients and their families. This support can be medical, such as hormonal therapies, or psychosocial, such as familial counseling and mental health care. [9]

However, more work is needed in education and advocacy. In the most recent edition of the standards of care guide

from WPATH (World Professional Association for Transgender Health), the use of interdisciplinary teams to guide parents in determining care goals for intersex children is recommended, but it still presents intersexuality as a problem to be fixed and managed rather than a natural form of human variation. [10] Providers and parents experience gaps in knowledge around intersex realities and the way information is presented can either reinforce narratives of wrong bodies needing to be made right or to embrace these variations and navigate medicine outside of gendered binaries.

Looking back at the case of M.C., the main argument is that M.C.'s autonomy was not respected due to the surgery being performed without his consent. Performing these surgeries on infants and young children restricts the patient's ability to engage in the decision-making process. It is generally accepted that the legal and ethically permissible choice for decision-making for minors is to respect the preferences of parents or guardians. However, limiting a minor's participation may run the risk of placing parental desires or fears above the child's autonomy and right to bodily integrity. For the most part, parents or guardians do act in the best interests of their child. Yet for the medical management of intersexuality, a condition with

continued on page 4...



Caution continued from page 3...

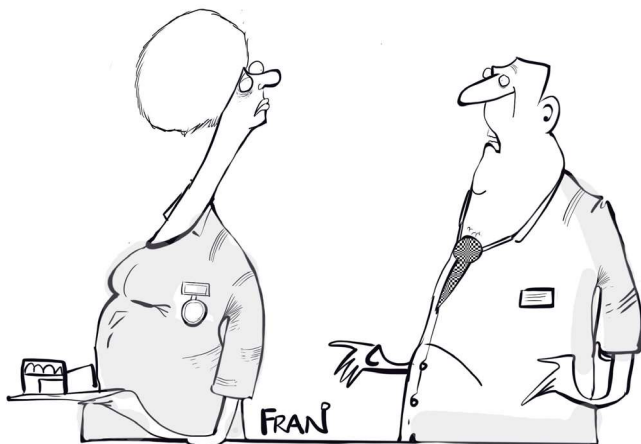
limited information, education, and support, it ought to be approached more cautiously with a stronger emphasis on protecting the child's autonomy and well-being, both present and future. Deferral of surgery, at least until the minor can provide appropriate contributions to these decisions, would bolster these protections.

M.C.'s case is a maelstrom of principles in tension. His operation was performed without the benefit of a pre-operative hearing or ethical review board. The question must be posed that if a hearing had been convened or a board consulted and the same conclusion was drawn, does that suddenly make it justified and the entirety of this case moot? Decisional authority, what constitutes benefit and what constitutes harm, and how was justice served for this vulnerable patient, are aspects intertwined with the fact that M.C. was at the mercy of a system entrenched in sex/gender binaries. The gender theory studies conducted by Dr. Money have been debunked for some time and our understanding of gender identity has expanded greatly and yet, the need to correct M.C.'s body was seen as an absolute necessity. M.C.'s case was settled out of court in 2017, with no admission of wrongdoing by any plaintiff, and no change to hospital policy that initiated the surgery in the first place.[11] While progress is being made in pediatric DSD care, many intersex activists state not nearly enough is being done.

Some hospitals are making the move towards surgical cessation; however, no US state has legal prohibitions against them. Unfortunately, providers, parents, and intersex individuals are also being confronted with additional, politically motivated obstacles. In the wake of anti-transgender initiatives, current legislative shifts that seek to limit or eliminate transgender care for youth have sought to enshrine unnecessary "normalizing" surgeries for intersex children under specific surgical provisions for their medical management. [12] Where trans youth is deterred from exploring their own gender identity, intersex infants and children are having an identity externally affixed onto them.

If all intersex surgeries ceased today, healthcare providers would still be obliged to provide assistance to their patients

HUMOR



We're a bit understaffed today, could you be 6 people?

CartoonStock.com

and their families for navigating through a world that is gendered and expects a clear response to the question, is it a boy or a girl? More education, more support resources, and more advocacy engagement would benefit not only the parents and guardians of intersex children, but also clinicians, ethicists, and policy makers working with intersex populations. Organizations such as InterAct, the Intersex Justice Project, OII (Organization Intersex International), and IHRA have online education and support resources. Activists such as Pigeon Pagonis, Sean Saifa Wall, River Gallo, and Alicia Roth Weigel, all featured in the 2023 documentary *Every Body*, address providers and policy-makers with narrative discussions on their experiences in healthcare, offering insight and recommendations on how to best serve their community.

REFERENCES

- [1] **M.C. v. Aaronson et al.**, U.S. District Court for the District of South Carolina, Charleston Division, 2:13-cv-01303 (2013).
- [2] **Debra Beight**, "The Case of M.C. – An Argument for Legal, Medical, and Social Recognition of Ambiguity," *Sprinkle: An Undergraduate Journal of Feminist and Queer Studies*, 8 (2015): 39-51.
- [3] **I.A. Aaronson**, "The Investigation and Management of the Infant with Ambiguous Genitalia: A Surgeon's Perspective," *Current Problems in Pediatrics*, 31 (2001): 168-194.
- [4] **M.C. v. Aaronson et al.**
- [5] **Debra Carroll-Beight**, "Medicine, Intersex, and Conceptions of Futurity: Examining the Intersections of Responsibility and Uncertainty" (MA thesis, Ohio State University, 2021).
- [6] **Carroll-Beight**, "Medicine, Intersex."
- [7] **Nat Mulkey, Carl G. Steed, and Barbara M. Chubak**, "A Call to Update Standards of Care for Children with Differences in Sex Development," *AMA J Ethics*, 23-7 (2021): E550-556. doi: 10.1001/amajethics.2021.550.
- [8] **Mulkey, Steed, and Chubak**, "A Call to Update"
- [9] "ISNA's Recommendations for Treatment" Intersex Society of North America | A World Free of Shame, Secrecy, and Unwanted Genital Surgery | Intersex Society of North America. Accessed August 9, 2023. <https://isna.org/node/138/>.
- [10] **E. Coleman et al.** *Standards of Care for the Health of Transgender and Gender Diverse People*, Version 8. WPATH, (2022). <https://doi.org/10.1080/26895269.2022.2100644>.
- [11] **Azeen Ghorayshi**, "A Landmark Lawsuit About An Intersex Baby's Genital Surgery Just Settled For \$440,000." *BuzzFeed News*, (July 2017). <https://www.buzzfeednews.com/article/azeenghorayshi/intersex-surgery-lawsuit-settles>.
- [12] **Alicia Roth Weigel**, "The Intersex Community is Fighting for Every Body," *Time Online*. (June 2023). <https://time.com/6291609/intersex-community-every-body-essay/>.

Leveraging Rural Strengths: Beyond a Deficit Model in Rural Healthcare



Alexandra Perry, Ed.D., M.Ed. is the interim Dean of the McDonough Center for Leadership and Business and an Associate Professor of Leadership and Ethics at Marietta College. She is also a clinical ethicist with OhioHealth. She is currently working on a book that looks at end-of-life care in American Hospitals, and projects surrounding the opioid epidemic, and rural and indigenous healthcare.

As an industry, healthcare tends to focus on diagnosis and repair more than wellness or even prevention. Public health professionals are engaged in an ongoing discussion about the value of deficit vs. asset approaches to public health research and intervention. [1] Anyone who has been a consumer of healthcare has probably experienced this: the lab values and examinations that are intended to look for deficits rather than an appraisal of what strengths the patient has, or what wellness strategies they engage in. Still, the reality is that while the discourse might be shifting in some areas, research on rural health is still very much viewed through the lens of deficit. Earlier this year, I published an article in BioQuarterly that emphasized the challenges highlighted by current research in public health which often emphasizes rural health weaknesses rather than rural health strengths. I hope that this article will be a refreshing pivot, and while acknowledging that challenges exist, it will focus on the strengths that rural communities can draw upon to address challenges, thereby creating more ethical and sustainable solutions for rural patient populations.

In a healthcare climate where primary care is being held up as a key component of reducing poor health outcomes, there is no question that rural health systems have an advantage given that small communities value relationships and have the ability to invest time in them. Rural health, despite facing unique challenges, possesses several strengths that contribute to the well-being of individuals living in rural areas. These strengths are often the result of close-knit communities, resourceful approaches, and dedicated healthcare professionals. Here are some of the key strengths of rural health.

Strong Sense of Community

Rural areas are known for their tight-knit communities, where individuals often have strong social connections and a sense of collective responsibility. This sense of community can play a vital role in promoting health and well-being, as neighbors and community members support each other during times of illness or adversity.

Personalized Care

In rural settings, healthcare providers often develop strong relationships with their patients. The smaller patient loads allow for more personalized care, enabling doctors and healthcare professionals to understand individual patient needs better. This personalized approach can lead to improved patient outcomes and higher patient satisfaction.

Lower Cost of Living

Rural areas often have a lower cost of living compared to urban centers. This can translate to more affordable healthcare services, making it easier for residents to access medical care without facing significant financial barriers.

Reduced Stress and Pollution

Rural environments typically offer a slower pace of life with less pollution and noise. This can contribute to improved mental health and overall well-being for residents, potentially reducing the prevalence of certain stress-related health issues.

Innovations in Telemedicine

Due to the challenges of distance and limited access to specialists, rural health systems have embraced telemedicine solutions. Telemedicine enables rural residents to consult with specialists remotely, reducing the need for long-distance travel and enhancing access to specialized care. Telehealth is a growing approach to outpatient consultations across all geographic environments. Because rural healthcare providers have relied on telehealth consultation longer, they have greater experience making good use of telehealth and negotiating its pitfalls. At least for now, rural health may be more proficient with this 'cutting edge' healthcare intervention than are urban providers.

Resilience and Self-Reliance

Rural communities often possess a strong sense of resilience and self-reliance. In the face of challenges like limited resources and infrastructure, residents and healthcare providers develop innovative solutions to deliver healthcare services effectively.

Opportunities for Research

Rural health settings offer unique opportunities for research on various health issues, such as agricultural-related illnesses, environmental impacts on health, and disparities in healthcare access. These studies can contribute valuable insights to the broader field of public health. This strength requires a caution, of course, because it would be easy to allow rural communities to serve as a subject of research without any benefit to offset participation. Research should not use rural communities in a strictly instrumental way.

Interdisciplinary Collaboration

In rural healthcare settings, healthcare professionals often collaborate across different specialties due to the limited number of providers. This interdisciplinary approach can lead to more comprehensive and holistic care for patients.

Greater Focus on Prevention

With limited healthcare resources, rural health systems often emphasize preventive healthcare measures. This focus on prevention can lead to better health outcomes and reduced healthcare costs in the long term.

continued on page 6...

Opportunities for Medical Students and Professionals

Rural health offers unique opportunities for medical students and healthcare professionals to gain diverse clinical experiences and contribute meaningfully to underserved communities. Many professionals find working in rural settings rewarding and fulfilling, making it a positive career choice for some.

While rural health faces its share of challenges, it is essential to recognize and build upon its strengths to ensure that residents of rural areas receive the care and attention they deserve. By understanding and leveraging these strengths, healthcare systems can work towards providing equitable and effective healthcare services to all populations, regardless of their geographic location. In the next section, I highlight an initiative that I have been engaged in at Marietta College, located in rural southeastern Ohio, on the border of West Virginia.

Substance Use Recovery Leadership Development

In Spring 2023, the McDonough Center for Leadership and Business at Marietta College partnered with an alliance of WV leaders who are focused on innovation in addiction recovery. We partnered to create a substance use recovery leadership development program designed to empower individuals in recovery from substance use disorder (SUD) to become effective leaders in their communities and advocates for positive change in the field of addiction and recovery. The program aims to use leadership development as a public health intervention by implementing peer leadership to address the opioid crisis in rural Appalachian communities where resources are often scarce and opioid addiction has become a public health emergency. The program promotes personal growth, and equips participants with the knowledge and tools to make a meaningful impact on the lives of others struggling with addiction.

The program will meet in person once per month and will rotate between rural WV counties so that participants can become familiar with community engagement work in those areas, and the resources available in rural counties. The initiative will expand to cover additional regions of Appalachia after its first year.



Key components of the substance use recovery leadership program include:

1. Leadership Training: Participants receive training in leadership principles and techniques, including communication skills, conflict resolution, decision-making, and team building. The curriculum is delivered through workshops, seminars, and interactive learning experiences, and is all based on the McDonough Center's approach to leadership education which is guided by the Five Components of Leadership Model², and bridges leadership theory and practice.

2. Advocacy and Education: Participants learn about addiction and recovery-related issues, policies, and advocacy efforts. They are encouraged to use their personal experiences to advocate for improved access to treatment, recovery support services, and reduced stigma surrounding addiction.

3. Community Engagement: The program emphasizes community involvement and encourages participants to engage with local organizations, recovery groups, and healthcare providers to raise awareness about addiction and promote recovery resources and to learn what elements make an organization successful and sustainable in order to inform the development of their own leadership projects.

4. Empowerment and Self-Efficacy: Participants are encouraged to identify their strengths and unique abilities to make a positive impact on others in recovery.

5. Peer Support: The program fosters a sense of camaraderie among participants, creating a peer support network where individuals can share challenges, celebrate successes, and offer encouragement to one another.

6. Personal Growth and Wellness: The program addresses holistic well-being, promoting physical, emotional, and spiritual health. Participants are encouraged to set personal goals and work towards achieving overall wellness.

7. Recovery-Oriented Projects: Participants engage in projects that support recovery and wellness within their communities. These projects could include organizing recovery events, conducting educational workshops, or developing nonprofit resources for individuals in recovery.

8. Skill-Building Workshops: Workshops on various practical skills, such as public speaking, advocacy strategies, and strategic planning, equip participants with the tools needed to lead successful recovery-oriented initiatives.

The program aims to use leadership development to create a ripple effect, where empowered individuals in recovery inspire and support others, contributing to a more recovery-friendly and supportive society. By promoting leadership and advocacy skills, participants help to reach resource-barren communities to address addiction as a public health problem. The program will help to break the stigma surrounding addiction and highlight the potential for positive change and growth in recovery journeys, thereby impacting families

Rural continued from page 6...

struggling with active addiction.

This program also creates opportunities for undergraduate students to develop and hone leadership skills through curriculum development, project planning and management, program implementation, and volunteering. For students interested in careers in healthcare, this program is a chance to engage with the non-clinical aspects of public health, and to gain experience working with a patient population that represents one of the most underserved and in-crisis sectors of the regional community. This meaningful experiential education aims to align with the College's initiative to become more student-ready as the demographics of students enrolling in institutions of higher education shift.

An Ethical Transformation

Developing community engagement programming such as the substance use recovery initiative is critical to addressing challenges in rural health in an ethical way. Leveraging the strengths of rural communities in order to empower them to decide how to best meet their needs allows for the prioritization of the autonomy of each community in much the same way that medicine ought to prioritize the autonomy of each patient.

Understanding rural communities and the values espoused by the patients served by rural healthcare systems is critical to developing leadership frameworks that adequately address the needs of patients, providers, and the regions that they operate within. It would be easy to understand rural health challenges as simply requiring economic solutions. Increased resources and centralized administrative and legal services can certainly address the fragility that rural healthcare systems experience. In fact, the steady pace of small rural hospitals and healthcare systems being acquired by large hospital systems suggests that economic solutions are very effective at allowing rural hospitals to continue serving their communities, however they often address economic challenges while ignoring the values-based dilemmas. If community-based providers and clinics are essential to a patient's experience of seeking healthcare, an acquisition might be enough for that patient to cease seeking care at their local clinic or hospital.

What other strategies can communities use to bridge the gap between existing healthcare resources and policy and rural health settings? To start, they can broadly promote dialogue on how healthcare systems can build on the existing strengths of rural communities. Often these communities have strong support for the organizations that call them home and are willing to engage in finding creative ways to support them. Using medical education and residency programs to introduce students to rural communities and rural healthcare systems can help to alleviate the challenge of recruiting and retaining a workforce in rural communities, and can create opportunities for students to pursue careers after graduation.

Identifying and amplifying the strengths of rural healthcare can be a focus of advocacy. For the substance use recovery program, this meant engaging communities on what supports they needed to continue fighting against the opioid epidemic. The lived experience these communities have make them far more effective at developing strategies than those in communities who have not been as impacted by the epidemic. Finally, communities can create partnerships with academic institutions, including medical schools and public health programs, to incorporate rural health education into their curricula and encourage students to pursue careers in rural health. By building upon the strengths of their communities, rural health systems can empower leaders who are equipped to address the unique challenges faced by rural patient populations, and can work collaboratively towards improving healthcare access, quality, and outcomes.

REFERENCES

[1] Morgan A, Ziglio E. Revitalising the evidence base for public health: an assets model. *Promot Educ.* (2017) 14(2_Suppl.):17-22.

[2] McManus, R.M., & Perruci, G. (2015). *Understanding Leadership: An arts and humanities perspective* (1st ed.). Routledge.

<https://doi.org/10.4324/9781315851525>

ONLINE BENO VIRTUAL EDUCATIONAL OFFERINGS

BENO Educational Series:

“State of Ohio DNRs and Advance Directives”

- Alan Murphy, PhD, HEC-C
- November 14 at 4:00pm EST
- Flyer coming soon with registration information



NEWLY ELECTED BOARD MEMBERS

JULIE M. AULTMAN, PhD, MA – Julie serves at NEOMED (Northeast Ohio Medical University) as Dean of the College of Graduate Studies, Professor of Family and Community Medicine, College of Medicine and Director for Medical Ethics and Humanities. She also serves four clinical hospitals and community centers as a clinical ethicist, as well as holding leadership positions withing and external to NEOMED.

KATHY GRANNAN, RN, MSN – Kathy is a retired nurse who, for the past three years, has served as an editor of the BENO BioQuarterly, during which time she helped to diversify its content and ensure its timely production. She believes BioQuarterly is undeveloped as a networking tool and has ideas to continue its growth.

CRISTIE COLE HORSBURGH, JD – Cristie is a Staff Ethicist in the Center for Bioethics at the Cleveland Clinic and Clinical Assistant Professor in the Cleveland Clinic Lerner College of Medicine. She is responsible for directing ethics programming and managing the ethics consultation services at four community hospitals within the Cleveland Clinic system, Co-Director of the Cleveland Fellowship in Advanced Bioethics, Associate Director of the Nursing Ethics Program and Associate Director of the Clinical Ethics Immersion Program.

AMANDA LANG, MPH, MA – Amanda is currently a PhD student at Duquesne University for Healthcare Ethics as well as an employee at Cleveland Clinic Akron General.

CARL MULLINS, M. Div. – Carl is staff chaplain with Bon Secours Mercy Health at St. Vincent Hospital in Toledo, where he has served for the past 5 years, and was ordained in 2012 as an Anglican priest. Carl is currently attending Loyola University, pursuing a Masters in Bioethics.

CRAIG DOVE, M. Div, PhD. – Craig works as a hospice chaplain at OhioHealth in Columbus and is currently the chair of Ohio Health's Ethics Advisory Committee for Community-Based Services. His background combines academic experience with a sensitivity to religious issues, which allow him to bring a unique perspective to BENO and now as its Vice President.

BOOK REVIEW



The Measure by Nikki Erlick | Reviewed by Kathy Grannan

Nikki Erlick has used a creative approach to a topic that impacts every human being at the deepest level: the measure of a life. In writing this review, I want to convey the depth of thought the author explores through each character, without spoiling the read! The novel is set in current times. As the book opens, every human being in the entire world receives a box at the same moment from an unidentified sender. Many choose to open the box, but not all do. The content of the box is a string, the length of which varies from person to person. The author relates the stories of characters from different backgrounds, cultures, and socioeconomic situations who struggle as they come to terms with the source and meaning of this gift. Their lives move through moments of discovery, introspection, and discernment of values with an altered perception of the time they have remaining and how they should spend the time they have in light of this gift. The choices they make have a profound impact on their lives and relationships going forward.

This book is a different genre from the usual book reviews featured in the Bioquarterly. Compared to the issue-oriented or academic books we have presented in previous reviews, this could be considered a lighter read. While the book has some humor, the premise on which it is centered and the way each character considers the value of their lives will give the reader pause to reflect on the values we live by.

The decisions the characters face have parallels to the ethical issues we often face in practice as well as in life. There are many ways an author might choose to write about the meaning of life. A science fiction novel was probably not the first genre that would occur to you in considering this; it is not usually the genre I seek when looking for a book to enjoy. Nikki Erlick has chosen an unusual, perhaps unlikely premise for this novel that turns out to be thought provoking on personal and professional levels. We all live with some "what-ifs" in life, to which we may give some thought or put on a shelf for later consideration. The Measure will take you down the road a bit with some of your own life questions. I invite you to explore the meaning of life "with a twist".

UPCOMING EDUCATIONAL OPPORTUNITIES

Center for Bioethics 10 th Anniversary One-Day Conference: "Engaging Ethics in a Polarized World"

- September 21st all day, hybrid (in person and livestream), free and open to all
- [U.osu.edu/bioethicsconference](https://u.osu.edu/bioethicsconference)
- Keynote speakers:
 - 7:00am – Christine Grady, PhD, MSN
 - 12:00pm – Larry Churchill, PhD

Harvard Surgical Ethics Conference

- Zoom -- <https://bioethics.hms.harvard.edu/about/harvard-ethicsleadership-group/harvard-dinical-ethics-working-groups/surgical-ethics>
- September 5th – *Ethical Considerations in Pig-to-Human Xenotransplants*
- September 12th – *Challenges to the Patient-Surgeon Relationship*
- September 19th – *Ethical Implications of New Biomedical Technologies in Neuroscience*
- September 26th – *How Non-medical Factors Affect Surgical Decision-making and Patient Care*

ASBH Annual Conference

- October 11-14, 2023
- Baltimore, MD
- <https://asbh.org/annual-meeting/bioethics-humanities-meeting>

OSU Bioethics Grand Rounds – Jada Wiggleton-Little, PhD

- November 8th, 2023
- Zoom and in person
- More info and full Grand Rounds schedule at go.osu.edu/bioethics

BENO Educational Series: "State of Ohio DNRs and Advance Directives"

- Alan Murphy, PhD, HEC-C
- November 14 at 4:00pm EST
- Flyer coming soon, more info at <https://www.benoethics.org/>

4th International Conference on End-of-Life Law, Ethics, Policy, and Practice (ICEL4)

- Salt Lake City, Utah
- March 6-9, 2024
- www.icel4.org

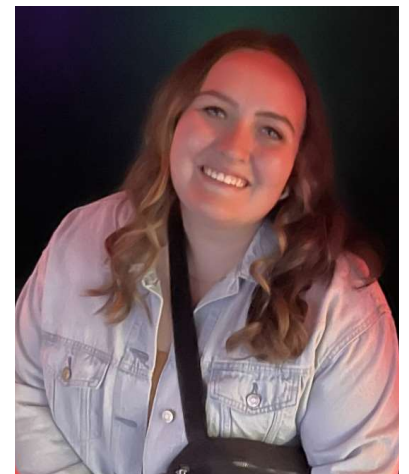
MEMBER SPOTLIGHT

Amanda Lang M.A. PhD Student at Duquesne University Patient Access Representative at Cleveland Clinic Akron General

I have been a member of BENO for a little over a year, joining shortly after receiving my Master's degree in Healthcare Ethics from Duquesne University. My journey towards healthcare ethics has been a winding path. In my undergraduate studies I knew I wanted to go into healthcare, but also knew that the hands-on side of healthcare was not for me. I decided to get my Bachelor's degree in Integrated Health Studies with a focus on Business Administration from Kent State University in 2019. One of my mandatory classes for my undergraduate degree was healthcare ethics. This class opened my eyes to healthcare ethics and the possibilities it offered as a career path. I took a year to truly solidify that I wanted to continue my schooling between undergraduate and graduate and then started applying to healthcare ethics programs in the beginning of Spring 2020. I committed to Duquesne University to obtain my Master's and PhD in Healthcare Ethics and began my journey in Fall 2020.

One of my proudest moments was a joined opportunity to be able to participate in clinical rounds and cases with both UPMC in Pittsburgh and Cleveland Clinic in Cleveland and Akron. I wanted to be able to experience various ethical cases in multiple hospital settings to expand on my experiences and knowledge. Fall of 2021 found me commuting between Ohio and Pennsylvania to do clinical rounds at UPMC which included going to different medical units for ethical cases, as well as the opportunity to shadow specific positions held in UPMC; for example I shadowed a palliative care doctor for a few weeks. A few months throughout 2022 I had the opportunity to shadow bioethicists at Cleveland Clinic and actively participate with ethical cases. I am grateful for the time I spent at both UPMC and Cleveland Clinic for allowing me to see and be part of current ethical cases which will help me in the future.

A fun fact about me is that I have been to 8 different countries (6 during a 23-day excursion): Canada, England, France, Switzerland, Italy, Greece, Turkey, and Amsterdam. Many of my friends and coworkers at Cleveland Clinic are always wondering where my next adventure will take me, whether it is for vacation, concerts, or day trips.



ART SPOTLIGHT

Picasso's "*Science and Charity*" (1897) portrays a dispassionate physician measuring a pulse and an empathetic nun providing patient and family care, bringing sustenance, holding the infant and casting a tender glance toward a patient juxtaposed between them. This composition highlights the differences between two approaches to care. Medical knowledge was limited at the time, so physicians often presented a posture of scientific authority and professional distance to gain prestige in the public eye. This distance, a promoted attribute for doctors, increasingly came into question in the 20th century, within and outside of the profession. In 1927, Dr. F.W. Peabody famously bucked the trend, writing "the secret of the care of the patient is in caring for the patient." (Peabody FW. The care of the patient. JAMA. 1927; 88(12):877–82.)

That debate continues today. The modern physician must balance authority and compassion, simultaneously accepting their evolving role as interprofessional team members and mastering conflicts between electronic medical records and attentive care. A modern version of *Science and Charity* might have the nun at bedside and the physician at a distance scrambling over a computer keyboard—the newest tool of professional mastery, authority, and distance. Katz, J., Khoshbin, S. "Picasso's *Science and Charity*: Paternalism Versus Humanism in Medical Practice: [doi: 10.1093/ofid/ofw056](https://doi.org/10.1093/ofid/ofw056)



Changes in health care administration in recent years have added additional layers to this juggling act. Promoting quality, implementing best practices, and controlling costs have increased the role of insurers, administrators, and legislators in decision making. Reimbursement is limited for time spent on Picasso's "charity". In outcome-driven health care, productivity is easier to measure than the impact of humanistic care.

Picasso recognized the power of symbolism and metaphor to stimulate the imagination. The awards received for this painting, one of his last "traditional" paintings, launched him into further education and professional exposure in the art world. (Marilyn McCully. Picasso: The early years, 1892–1906. National Gallery of Art, Washington (1997) P. 26).