

BENO

BIO Quarterly

A Publication of
The Bioethics
Network of Ohio

● BENO involvement in state DNR, Living Will regulatory review



Alan Murphy, PhD is a Clinical Ethicist at OhioHealth, Vice President of BENO, and Co-editor of Bio Quarterly.

Because regulatory work is not the year-to-year focus of the Bioethics Network of Ohio, newer members may be surprised to read that the Ohio Revised Code (ORC) mandates BENO's participation in the regular five-year review of the state's Do Not Resuscitate (DNR) regulations. The revisions to the regulations in the Ohio Administrative Code (OAC) concerning DNR orders and Living Wills (OAC 3701-62) cannot change ORC 2133, which organizes both DNR orders and Living Wills. This means that, for example, the Ohio Department of Health cannot use the regulatory review process to replace or supplement Ohio's DNR orders



with Physician Orders for Life Sustaining Treatment [1]; neither could the regulatory review process expand or contract the scope of Ohio's Living Wills to

allow patients more or less autonomy than is afforded them in ORC 2133. All the regulatory review can do is specify things that remain vague in statute and clarify how the statute is to be applied.

Even with this comparatively limited scope, there is much to specify through regulation. Statute does not establish the concrete details of the Do Not Resuscitate protocol, so this falls to the regulatory review process. And the language about Living Wills in routine use does not exactly

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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 stephanie.fabbro@osumc.edu and alan.murphy@ohiohealth.com for consideration. Quarterly deadlines are the 15th of February, May, August and November.

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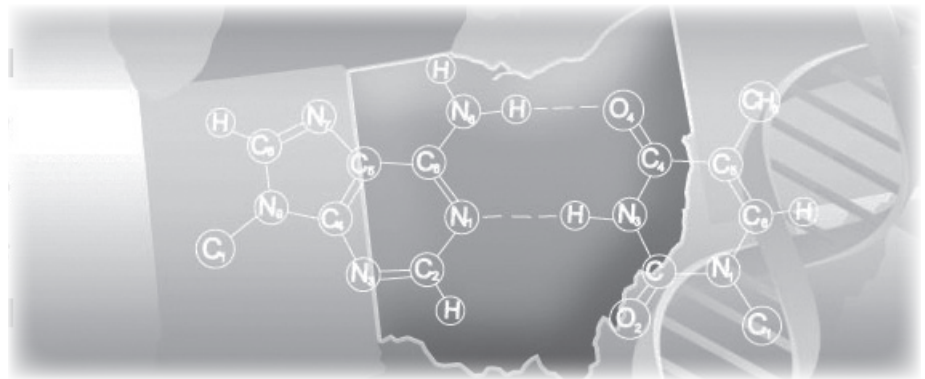
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Cassandra D. Hirsh, DO
President

Stephanie Fabbro, MD
Alan Murphy, PhD
Editors

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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.



**● From the President
Cassandra Hirsh, DO**

I am thrilled to start my second year as the president of BENO.

Our last year was full of excitement and changes. We said goodbye to some wonderfully-dedicated board members, who just recently rotated off of the board: O. Mary Dwyer, Anne Lovell, Lynn Maitland, and Curt Sheldon. Thank you for all your hard work.

It was great to see so many of you at our conference at the end of April! It was a special day where we were able to share the expertise of members of the bioethics community, to network, and to collaborate.

Over the summer, we held our yearly elections where many individuals expressed interest in becoming members of the board. I'd like to welcome our new members: Robert Guerin, Ali Jahan, Lea Ann Morris, and Alexandra Perry and I look forward to their energy, good ideas and fresh viewpoints. We have already met this year and started planning the year ahead. We've begun discussions and preliminary planning around a new bioethics certificate course based on your comments at the conference. We have also started to work on our 29th annual conference. Save the date for Friday, April 26th, 2019!

We appreciate your feedback and are always looking for more ways to engage. If you have ideas to share, or needs that we can assist with, please do not hesitate to contact us. I look forward to another rewarding year where we can work together to continue to grow BENO!

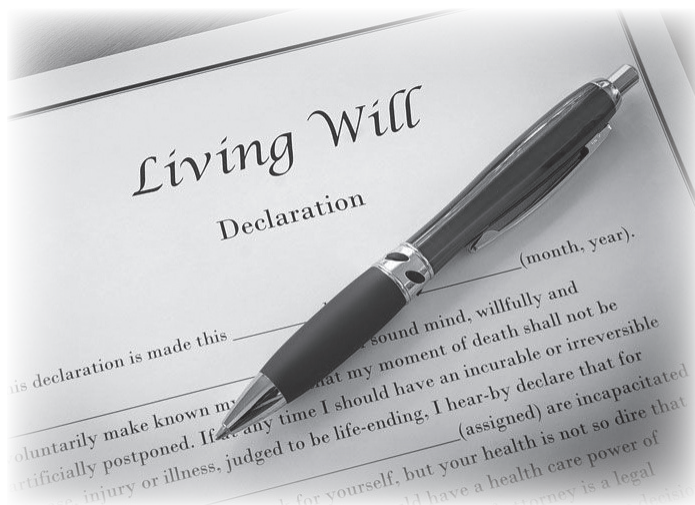
mirror the language of statute, so regulation serves to clarify the relationship between statutory language and everyday usage. Since late 2017, Margot Eves and I have participated on BENO's behalf in several meetings hosted by the Ohio Department of Health in Columbus to propose revisions to the regulations surrounding both Living Wills and Do Not Resuscitate orders. In addition to BENO, the stakeholder group included hospital representatives, emergency medical services, hospices, healthcare lawyers from across the state, and representatives of several state government agencies. The proposed revisions were open to public review and comment from mid-September until mid-October 2018; the Ohio Department of Health will now review public comments and finalize the proposed revisions with the aim of implementing them in 2019.

With regard to the DNR protocol, the most notable clarification offered by the proposed revisions concerns biPAP and CPAP. Under the current, active regulations, it is somewhat ambiguous whether outpatients who are DNR should receive non-invasive mechanical ventilation (biPAP or CPAP) when the DNR protocol is active. The proposed, revised regulations would explicitly allow for use of biPAP and CPAP as medically indicated for outpatients who are DNR-Comfort Care or DNR-Comfort Care-Arrest.

The proposed revisions were open to public review and comment from mid-September until mid-October 2018...

Incidental to the DNR regulatory review, it came to light that many companies selling DNR identification jewelry to Ohio residents were selling products that did not include the required state of Ohio DNR logo, the absence of which might lead to persons who are DNR receiving CPR and other high-intensity interventions because of invalid identification. The Ohio Department of Health followed up with one of

the largest such jewelry vendors, which has already fixed its merchandise and issued new, compliant DNR jewelry to its past customers, reportedly free of charge.



BENO's influence is particularly felt in the proposed revision of OAC 3701-62-10, which includes the regulations intended to clarify the order of priority among advance directives and other expressions of patients' preferences in end-of-life care. By general agreement among the governmental and non-governmental stakeholders involved in the review process, the existing regulations are not especially clear. Together with attorneys from several Ohio government agencies, Margot Eves and I drafted what we believe would be a clearer expression of what all agreed was the intended order of priority. Expect more detail on these revisions in a future *BioQuarterly* if the proposed revisions survive the final reviews and go into effect next year.

[1] See <http://polst.org>



● Marty Smith: Professionalization of Ethics Revisited



Marty Smith, STD, is a past President and former board member of BENO and former editor of *BioQuarterly*.

Interview conducted by Stephanie Fabbro, MD and Alan Murphy, PhD

Marty Smith, STD, was significantly involved in BENO throughout his career and edited the *BioQuarterly* for several years spanning two separate runs. This year at the BENO Annual Conference, Dr. Smith accepted the Founder's Award in honor of his service to BENO. In 2014, Dr. Smith published an article in *BioQuarterly* discussing the future of professionalization of ethics; in this interview, we reprise his predictions and discuss potential issues surrounding certification of ethics consultants, as well as discuss Dr. Smith's thoughts on the role of *BioQuarterly* going forward.

SF: In your article from 2014, your prediction for the future of professionalization of ethics consultants over the next 5-10 years included a standardized certification process put in place with the backing of a regulatory agency, as well as all ethics consultation services being required to have at least one certified ethics consultant. How does that line up with where we stand in 2018?



MS: Some elements of the article are beginning to come true: ASBH has now developed a voluntary certification exam, a first step of what I was foreseeing. I was on the ASBH Board when that certification process was being debated and approved, and at least at

that time (2016) there was a lot of energy and enthusiasm to move the certification process forward. The other components of certification are still to be determined, one of which is whether a regulatory board such as CMS or the Joint Commission will regulate the certification process.

Some elements of the article are beginning to come true: ASBH has now developed a voluntary certification exam, a first step of what I was foreseeing.

The other element of my prediction was that there would be a requirement for ethics committees to have at least one certified member. That in some ways was wishful thinking. I don't think every ethics committee member in our community hospitals will be able to go forward with the certification process, and we don't want that to impede their ability to offer consults at their institutions. An achievable goal would be to have at least one member of the service to be certified, which might be intertwined with Joint Commission regulation if and when that day comes.

SF: Let's talk more about the ASBH's new certification process you mentioned, called the Healthcare Ethics Consultant Certified (HEC-C) program, which is available for the first time this year. To be eligible, applicants must have a bachelor's degree and 400 hours of healthcare ethics experience (working consults and gathering and analyzing data about them) within the past 4 years. As you mentioned, there is also an exam associated with getting the certification. Once you are certified, it's valid for 5 years. [1] What do you think of the application requirements?

MS: Having a bachelor's degree was highly debated; some thought higher education such as a master's would be necessary. I was a proponent of a bachelor's rather than a master's, and certainly not a doctorate, which would rule out thousands of people sitting on ethics committees today. I have met many, many skilled ethics consultants who

are nurses or other clinicians who are quite savvy when it comes to ethical activities and interfacing with patients and families. A doctorate seemed like too strong of an academic criterion.

400 hours of working consultations over the last 4 years seems somewhat steep. Breaking that down, 100 hours a year would be needed, and even a very dedicated, energized ethics committee member may have difficulty putting in that much time.

AM: One thing that kept coming up at the ASBH this year was that for smaller institutions, there simply may not be enough consults for even the most involved consultant to get 100 hours a year. Do you feel the application requirements should be different for those at smaller institutions?

MS: Maybe fewer hours should be required of everybody so we don't make exceptions for one group versus the other. I would hope that some of the other experiences would be included, such as participating in self-education or in the ethics committee at the institution. Maybe making sure a broad set of experiences that qualify and a smaller number of hours would be helpful so you don't end up just certifying people who are in academic medical centers.

With regard to the exam, my concern lies here: in the core competencies we talk about not only the knowledge needed to be a good ethics consultant, but also the skills. But how can we test skills with an objective, multiple choice, non-simulated exam? The response from the testing company [Castle Worldwide] was that there are ways of developing questions that can touch on some of the skills that the core competencies expect people to have. In some ways this is an issue of trusting that there are people who know how to develop a valid exam that can test both knowledge and skills and that ASBH has partnered with such a group.

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SF: There has been some pushback against the concept of professionalization of ethics. Larry Churchill, a prominent ethicist, wrote in the 1970s that he was concerned professionalizing ethics might limit the "scope of accountability" because it undermines "the personal

resources of ethical reflection." [2] Similarly, it could create problems similar to those physicians face with maintenance of certification and expensive boarding processes. Do you think the same thing could happen in clinical ethics? As a reference, the current fees to apply to the HEC-C program are \$450 for ASBH members and \$650 for non-ASBH members. [1]

MS: There is a delicate dance going on. ASBH put up a few hundred thousand dollars of seed money, like a grant to the process, out of its own reserves, without an expectation to recoup it, but hoping that maybe in a few years the process could be self-sustaining. We need a critical mass of consultants to apply for certification year after year so that the cost is not too high, and to get enough people it can't feel too expensive. In time, ASBH likely won't be able



to carry this expense, and it may be a good idea to make the certification process independent as quickly as possible. ASBH was the clear organization to initiate the process, and we're still in the initial stages, so they still have a lot of skin in the game due to the initial money put forward, but eventually ASBH should create the infrastructure, and then not be involved with the process going forward.

AM: Although you concluded that some sort of certification process was desirable, of the principled arguments against certification, which did you find most compelling?

MS: Going all the way back to the '60s and '70s, the egalitarian view of bioethics has been that no one group or profession really controls or owns it, and that that's a good thing. But as soon as you say certain people are certified, you've put a stamp of approval on certain individuals and you've begun to exclude others, to the detriment of what has been a multidisciplinary, open discipline. To me, that has been an argument that at least needs to be listened to. I relate it to the criteria for even sitting for the exam: there were a number of people involved in the debates who

said, “You need to have at least a master’s degree.” Okay. But as soon as you say that, think of all the hundreds, if not thousands, of people you’ve just excluded who are frontline healthcare providers. I wanted, and still want, a delicate balance that recognizes that unqualified individuals doing ethics consultation could lead to tragic outcomes, and that at the same time, if we become too steep in our qualifications, we’re going to exclude lots of very good people who know how to do this.

AM: If this whole process succeeds and credentialing for ethics consultants ensures a minimum standard of competence in ethics consultation, are there other interventions that you think ethics consultants, once credentialed, ought to provide? Jeffrey Spike has suggested from time to time that ethics consultants could assess decision making capacity. [3] Another example might be ethics consultants billing for advance care planning.

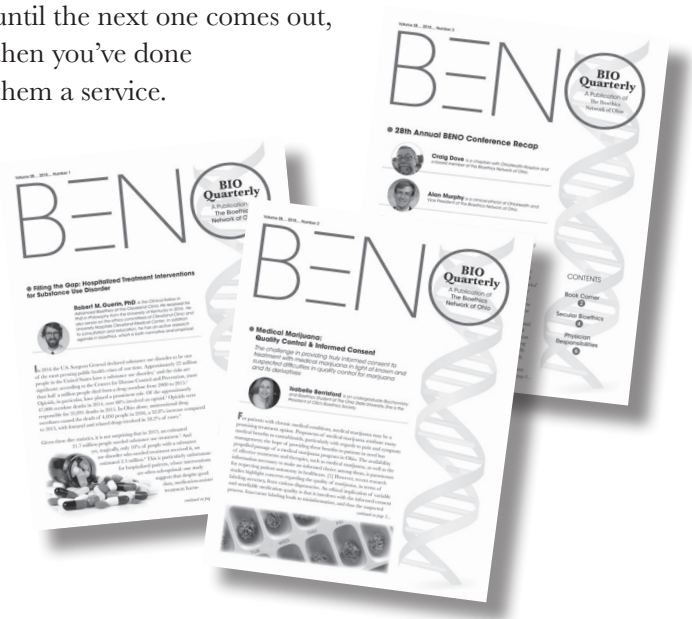
MS: Right now, I would say no. I think that assessing decision making capacity requires a particular set of skills, and while there may be clinical ethicists who know how to do that, certification in ethics consultation does not in and of itself say that you have the particular skills needed to assess capacity. In my almost 30 years of doing ethics consultation, I always viewed myself as having information or facts that could contribute to the process of assessing decision making capacity, but that the ultimate responsibility for that belongs somewhere else, and not with ethics consultants. I’m probably a little more comfortable with clinical ethicists doing advance care planning. We, as clinical ethicists, need to know about end-of-life issues, advance directives, DNR orders, and helping people understand different scenarios that they or their families might be facing.

SF: Do you envision clinical ethicists’ practice changing in other ways?

MS: I don’t envision the practice of individual ethicists changing, assuming the certification process is built on appropriate knowledge and skills as articulated by ASBH and others. I could see certification changing who at an organization or institution does consultation, depending on whether we expect everybody who participates in an ethics consultation service to be certified. That’s where the certification process may change how a service is run. But I’m not seeing certification changing how an individual provides ethics consultation.

AM: You did a fair bit of time in editorial roles for BioQuarterly in addition to your many other services to BENO. Going forward, what do you see as the role for a periodical such as BioQuarterly?

MS: BioQuarterly has a very important role: to continue to give ethics committees and the individuals who serve on those committees guidance on what are the issues, what are some good articles that I should be reading or cases that I should be thinking about. There is so much information out there, not just globally but about bioethics and clinical ethics. The nurses, the chaplains, the physicians like you, Stephanie: you and your colleagues have enough to do already just trying to keep up with your own discipline and all the other expectations that you have within your organization. I would see those individuals welcoming the service of paring the literature down, so that even if the only thing that the front line clinician or ethics committee member does is read *BioQuarterly* until the next one comes out, then you’ve done them a service.



[1] HCEC Certification Commission. Healthcare Ethics Consultant Certified (HEC-C) Examination Candidate Handbook. 1 June 2018. Handbook online: http://asbh.org/uploads/certification/HEC-C_Candidate_Handbook.pdf; accessed 26 October 2018.

[2] Churchill, Larry R. “The professionalization of ethics: Some implications for accountability in medicine.” *Soundings* 60, no. 1 (Spring 1977): 40-53.

[3] Spike, Jeffrey P. “Informed consent is the essence of capacity assessment.” *Journal of Law, Medicine and Ethics* 45, no. 1 (Spring 2017): 95-105.

● Narrative Ethics: How A Doctor Grieves



Ali Jahan, MD, is a new board member of the Bioethics Network of Ohio and is Board Certified in Critical Care and Anesthesia. He is a faculty member at University Hospitals Ahuja Medical Center in Cleveland, Ohio.

I came into work as any regular day, driving 30 minutes no matter what time I left as the eastside was poorly designed to get downtown. I had now been a “critical care staff” at a tertiary care center for over 2 years. At 7:30 every morning all the residents, fellows, and other ICU staff would gather in a small room to review the events that occurred overnight and make patient care assignments for that day. The residents and fellows would start doing the grunt work in preparing to present details of the cases to me. My resident, nervous and hoping to impress, told me the story of an 18 year old kid we had in room 17; I’ll never forget the room. It was one of three rooms in this archaic ICU that was essentially a cave; it was not only small but had no windows and was quite dark. This type of room would not be allowed to be an ICU room in modern times but was “grandfathered-in.”

This experience along with caring for the critically ill and dealing with personal challenges (life) has helped me develop what I call “emotional maturity...”

The resident went on to say “this boy had acute liver failure and is currently on the liver transplant list.” Just before I was about to start “pimping” her — shorthand for the standard, malignant approach used to teach, yet terrify trainees — about the medical implications of “acute liver failure,” I asked her “what do we think is the cause of his liver failure?” She replied, “We don’t know. He was on spring break in Florida and when he came back he just wasn’t feeling well and became jaundiced”, (yellow from an increase in a toxin that the liver usually manages). I’m thinking, “That’s weird.” Usually in the States the cause of acute liver failure is due to taking too much acetaminophen, (best known as Tylenol)....on purpose,

and on occasion someone eats poisonous mushrooms. I had a Vietnamese family that ended up eating poisonous mushrooms that they were gathering for their restaurant! Lucky for the family, Yelp didn’t exist at that time, the two adults quickly got new livers, and the child didn’t like vegetables. Back in the present, I had to figure out what was going on.

I walked into the room as it was dark and difficult to see. What I saw was this jaundiced man-child, sitting upright in this tiny bed with no shirt on wearing the typical hospital pants. Next to him stood his mother, tall, but with obvious worry and helplessness written all over her face. After introducing myself and my team I asked some basic questions, nothing too incriminating as I didn’t want him to feel uncomfortable in front of his mother. I asked him where did he go, what did he do, did he eat anything “unusual.” The only thing that jumped out was the fact that he had gone to a place that I, and older folk, frequented called Marco Island. This place was known for its calm, laid-back environment for the wealthy, with beautiful beaches... not a “party place” for young spring-



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breakers to get liver failure. Nothing bad could happen on Marco, could it? None of this made any sense. It didn't help that later that morning when speaking to the kid without his mother around, things were not any clearer.

But, at this point it really didn't matter. Who cares *why* his liver failed? We are good at fixing this kind of stuff. And, I mean really, why worry? This is one of my patients that can **actually** talk to me and make sense, as they are usually either muted with a tube stuck down their throat or are so delirious trying to figure out why there are so many rats in their hotel room! More good news...he is on top of the transplant list!! Because his liver failure is **acute** and not chronic, he is almost guaranteed a liver. And this should happen pretty soon as this was donor-cycle season, (the affectionate term frequently used for motorcyclists). He would go through a ten hour operation and then be good as new. Yes, he would have to take costly medications for the



rest of his life that would compromise his immune system and maybe even hurt his kidneys, and yes he couldn't drink as much alcohol in college as his fraternity brothers could, but so what, he'd be alive and have his whole life ahead of him. The dark room wasn't so dark after all and I could go home feeling good.

Seven-thirty the next morning came around and I heard that the kid was still in the cave, waiting on a liver. My team and I rounded on him and still were not able to give him or his parents any more of a satisfying answer to their burning question; "when will he get his transplant?" So frustrating! I did see that his white blood cell count was higher than

the day before and that he now needed oxygen to help him breath. But so what, that's not unusual for someone with a dead liver. I looked at his chest X-ray and it too had changed, with more "white looking stuff" where it should have been "more grey looking." Could he be getting a pneumonia? God, I hope not. That would almost certainly take him off the transplant list and force his parents to make funeral instead of graduation arrangements.

I had no choice but to get an infectious disease specialist involved. The good news was that it was a **trusted** colleague of mine; because there were many that I didn't trust. I needed her to tell me that she didn't think this was a pneumonia and that his transplant was just in need of a donor. But she couldn't. She said, Ali, he has pneumonia and he has to be taken off the transplant list! As the transplantation requires heavy-duty immunosuppressive medications, the infection would surely overwhelm his body and not only lead to his death but a waste of a good donor liver. I could no longer see in that room.

I had to walk into his dark room and ask him where he would like to go because he is no longer on the transplant list as he developed a pneumonia. I wasn't sure if I should also throw in the words "and you are going to die" as his parents stood at his sides. No reaction; probably due to shock.

This kid was only 18 years old, went to spring break and came back with a dead liver? How does that make sense? This kid was built like a house, muscular, good looking and about to graduate from high school with his whole life ahead of him; and I couldn't fix him? That's bullshit, simply bullshit. I've fixed many sicker people, I've gotten drunks back to the bars, gotten junkies back to their dealers, but I couldn't fix this innocent young kid? Makes no sense. Well at least I can get him out of this stupid cave and onto the floors so he could have a bit more privacy? Who are you kidding; that's worthless! I want to help this kid! He deserves to get back to his life, hangout with his friends, go to prom, have his parents watch him walk through his high school graduation ceremony, have him go to college, get married and live the life he was owed. But instead, I had to ask him where he preferred to die. I tell you, it makes no sense.



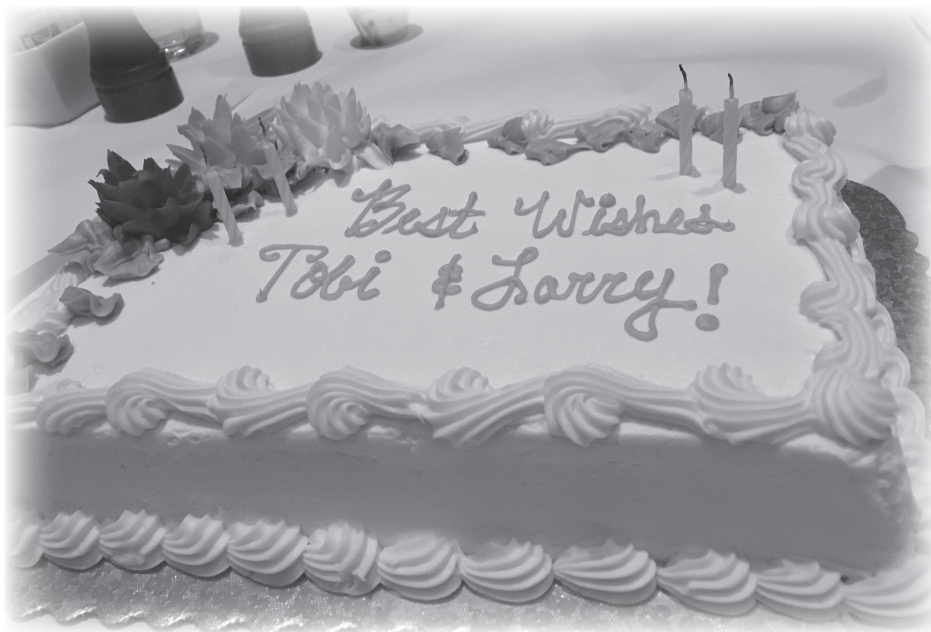
What's even worse is that if this happened only several years later he would have remained on the transplant list. I mean for God's sake, we transplant everybody nowadays. For real, we've transplanted a mummy! This lady had some sort of rare syndrome that essentially left her mummified; the Egyptians would have been impressed! And we transplanted her?? She obviously died after wasting over 6 months of ICU resources, but the kid from years ago is dead without even giving him a chance with a new liver. Makes no sense. I have so many similar stories of people that were simply awful transplant candidates, but got transplanted. At one time I thought that the transplant team was just trying to get their numbers up, transplanting anyone and everyone who looked yellow and could lie down! It was getting so bad that I decided there is no way I'm donating **my organs** if this is how they were being misused.

When I asked him if he'd like to leave the ICU and go to a "regular floor" knowing he was going to die, he told me that he preferred to go home and be with his family and friends instead. I assured him that we would help him fulfill that wish as I engaged all those involved in the logistics of the process of getting him discharged to home. Then I went home.

When I walked in the next morning and saw that room 17 was dark with an empty, well-made bed, I was prematurely happy, he must have gone home. I asked "when did the kid with liver failure go home?" The reply I got was worse than I could have imagined: "He never made it home." He died in the room that I left him in. I couldn't even grant him the simple wish of going home to be with his friends. It makes no sense.

I'm a tough cookie and it takes a bit to make me sad, depressed or frankly emotional. I feel that I'm truly wired and built to do the work that I do; fight death until death becomes the better option. But to tell an innocent, young person that they are going to die is simply awful, that's why I could never take care of sick kids. To this day I still get chills **EVERY** time I speak of this tragedy. This experience along with caring for the critically ill and dealing with personal challenges (life) has helped me develop what I call "emotional maturity" as I've learned to appreciate and promote the good in everyday living. I **always** make sure I have a good day. I accept nothing less and try and spread this same philosophy to all. Life can **always** be worse, so don't get down on things....just take a ride with me in my ICU and I'll show you what's really bad. But coping with the death of innocent kids is exhausting, draining, and simply awful. If only we could have sped up time for this kid....he would have had a liver and life. It's a terrible reminder that life is just not fair; fair is only a place where pigs are judged.

Life can always be worse, so don't get down on things....just take a ride with me in my ICU and I'll show you what's really bad.



... and they had their cake and ate it, too!

It was a special dinner in Cleveland, honoring the almost 19 years of administrative support Tobi and Larry Mattes (center) have provided for BENO. Many of you have worked with them at the annual conference, received newsletters and brochures they worked on and have been notified by them that it was time to renew your membership. They have been available for whatever the Board and members needed, learning to work with the website and troubleshooting wherever necessary. They are the organization's "official" record keepers. Current President, Cassandra Hirsh, Treasurer Margot Eves, several past presidents and current Board Members assembled to say "thank you" and to wish the Matteses well in their retirement.

WELCOME

New BENO Members



Esther Bernhofer, PhD

Cleveland Clinic
Cleveland

Sarah VerLee, PhD

Nationwide Children's Hospital
Columbus

Judy Doyle, BA, BS

Abeona Therapeutics
Cleveland

Greg Otterson, MD

Ohio State University
Columbus

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- Participation in an Ethics Consultation course

For these and other reasons that help us further our common values and mission, please join or renew your membership in the Bioethics Network of Ohio by going to www.BENOethics.org. Questions? Email ljmarket@ma-marketing.net

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