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**AHC Media**

## Should post-transplant quality of life determine patient's eligibility?

Recently ripped from the headlines is the heartbreaking story of a 3-year-old girl in dire need of a kidney transplant. Additionally, she was diagnosed with a rare genetic disease called Wolf-Hirschhorn, which is characterized by a distinctive facial appearance, delayed growth and development, diminished intellectual disability, and epileptic-like seizures.

The parents of the girl say that because she is mentally disabled (among other health issues), she was denied the much needed kidney transplant. They claim the denial came from the United Network for Organ Sharing (UNOS), the private, non-profit organization responsible for managing the nation's organ transplant system under contract with the federal government. They also claim the denial came from an unnamed doctor at The Children's Hospital of Philadelphia (CHOP) in Pennsylvania. The girl's mother said in her online blog that doctors initially told the family that their daughter wasn't eligible for a transplant because of her quality of life (QOL) and her mental condition.

Following the allegations by the family, CHOP released the following statement: "The Children's Hospital of Philadelphia does not disqualify potential transplant candidates on the basis of intellectual abilities. We have transplanted many children with a wide range of disabilities, including physical and intellectual disabilities. We at CHOP are deeply committed to providing the best possible medical care to all children, including those with any

### EXECUTIVE SUMMARY

Reports have surfaced that a 3-year-old girl was denied a kidney transplant in Philadelphia, PA, because of other health issues she faced. The hospital indicated that it does not disqualify potential transplant candidates on the basis of intellectual abilities.

- A difficult decision is the determination of who would likely benefit more from a transplant.
- A study investigated how major pediatric solid organ transplant programs use neurodevelopmental delay (NDD) as a criterion in their listing decisions.
- The patient must be in an overall condition that would support the transplant surgery, as well as the post-transplant regimen of immunosuppressant medications.

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form of disability.”

**Mathew Pauley, JD, MA, MDR**, director of medical bioethics, Kaiser Permanente, Fontana & Ontario Vineyard Medical Centers, Fontana, CA, says, “For me, coming from an ethical perspective, QOL is a personal, subjective assessment that belongs to an individual. Each person has the right to determine what is meant by ‘quality’ and by what criteria their quality can be said to be acceptable to them or not.”

These are most certainly difficult decisions when it must be determined who would likely benefit more from the scarce transplantable organs available.

**Melissa Kurtz, MSN, MA, RN**, bioethics consultant at The Montefiore-Einstein Center for Bioethics, Bronx,

NY, says, “The difficulty in evaluating a person’s post-transplant outcome is that it is very hard to predict a person’s future behavior. Sometimes transplant candidates do better than predicted, and sometimes worse.”

Researchers who conducted a study<sup>1</sup> in *Pediatric Transplantation* set out to investigate how major pediatric solid organ transplant programs use neurodevelopmental delay (NDD) as a criterion in their listing decisions. The researchers developed a survey that was sent to active pediatric solid organ transplant programs across the United States to investigate transplant listing decision-making for NDD children. Respondents to the study were medical/surgical directors and transplant coordinators.

The researchers found that programs inconsistently use NDD in listing decisions. Thirty-nine percent of programs stated that they “rarely” or “never” consider NDD in their decisions, whereas 43% of programs “always” or “usually” do. Sixty-two percent of programs reported that informal processes guide their use of NDD, and no programs describe their process as “formal, explicit, and uniform.”

Of course, the ‘powers that be’ at transplant centers generally want to see transplants succeed. “The role of ethics committees, as well as transplant teams, is to ensure that a candidate’s opportunity for transplant is maximized, while potential harms related to transplant are minimized,” says Kurtz. “In addition, transplant centers are acutely aware of the numbers of individuals in need of transplant and must balance the varying levels of need against one another when deciding how to allocate scarce resources.”

In an earlier study, also in *Pediatric Transplantation*, researchers reviewed the literature on accessibility and outcomes of organ transplantation in mentally handicapped individuals and on the prevalence of organ donation in this population.<sup>2</sup> The study shows that the one- and three-year patient survival rates were 100% and 90%, respectively. The studies reported good compliance with post-transplant medications due to consistent support from family members or caregivers.

The patient must also be in an overall condition that would support the transplant surgery, as well as the post-transplant regimen of immunosuppressant medications. Social factors (such as lack of sufficient social support) are also considered when evaluating a transplant candidate.

Pauley says, “Denial based on current state of health poses no ethical dilemma for me, as long as the process has been fair and deliberative. If my loved one were to be denied, I would need to know that the facts are accurate, and all options have been reviewed.”

An ethics committee might be helpful in facilitating better communication and supporting how informa-

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tion is provided.

“Ethics committees can be a forum to hear a patient/family express concern that the decision to denial fell outside the criteria set,” Pauley says. “Telling someone ‘no,’ especially in a life-and-death situation, requires compassion and time to ensure understanding,” he says.

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## SOURCES/RESOURCE

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- **Mathew David Pauley**, JD, MA, MDR, Director, Medical Bioethics, Kaiser Permanente Fontana & Ontario Vineyard Medical Centers, Fontana, CA. Email: Mathew.D.Pauley@kp.org.
- Chrissy Rivera’s blog, Wolf-Hirschhorn syndrome website. Web: <http://www.wolfhirschhorn.org/2012/01/amelia/brick-walls>. ■

# Study evaluates use of ‘debriefing’ statements

*Subjects felt positive about studies*

A new study looks at an intriguing strategy for improving study subjects’ understanding and knowledge of clinical research. After subjects finished participating in the study, they were given a “debriefing” statement that explained more fully what the study was about and how it would contribute to scientific knowledge.

The study found that debriefed participants were more likely to say they had learned something about the subject and that they felt positive about the educational value of research participation.<sup>1</sup>

“We have a psychology student participant pool,” says **Darcy A. Reich**, PhD, associate professor in the Department of Psychology at Texas Tech University in Lubbock. “For part of their credit in class, they engage in some research project the department is doing.”

The goal was to help psychology students understand the value of research, feel they had contributed to science in a meaningful way, and to empathize with what research subjects experienced. “We’re hoping to

get them interested in the field so they may go on to be researchers,” Reich says. “After everything is finished, the researcher tells participants about what the purpose of the study is, the nature of the findings, and it gives participants a sense of how they might have contributed to the field,” Reich says.

There were seven experiments with 475 university students, she adds. “We debriefed participants and asked them questions,” Reich says.

They found student participants generally were very positive about research, with 98% agreeing that they had contributed to science and 96% agreeing with a statement about how research was for a good cause, Reich says.

The debriefing statements thank subjects for their participation in the study and then discuss more fully what the study was about. They also discuss what researchers hope the findings will show and when results will be made available.

An example of a debriefing statement is as follows: “Thank you for your participation in this research on the effect of proximity and interview techniques on eyewitness memory. Two types of questions were used in this experiment. One was the cognitive interview, and the other was a control interview similar to police questions. The cognitive interview uses four retrieval techniques to bring out the memory of an event. These techniques allow a person to express how they felt at the time of the event, recall the event in different orders, mentally change their perspective about the event, and finally report all information they remember, even if it seems unimportant. It was hypothesized that when testing eyewitness memory, the cognitive interview would elicit more accurate responses when compared to the control interview. It was also hypothesized that even if the participant was farther away from the event, they would still report more accurate information with the cognitive interview.

“It was required for the experimenter to deceive you about the event — that is, the person did not actually win a prize — because it more closely approximates an event in which an eyewitness would be necessary. Eyewitnesses often do not know they are hearing and seeing events that others will want them to remember. When we are trying to remember something, we often act differently.

“Your participation was important in helping researchers learn whether the cognitive interview is better for obtaining more accurate information in eyewitness situations. The findings in this study should help to improve the accuracy of eyewitness interview situations. Improved eyewitness interviewing techniques may aid in solving future crimes in which an eyewitness is present. Also, by participating in this study, you

have firsthand knowledge of what it is like to be in a psychology experiment.

“Final results will be posted on the bulletin board outside of Stewart Hall 213 by the week of Dec. 11. All results are grouped together; therefore, individual results are not available. Your participation will remain confidential.”

The debriefing statement concludes with contact information for any additional questions and with a brief list of references.

“We think the debriefing is very important,” Reich says. “I’m with the IRB at Texas Tech, and we look at the outcomes from cancer treatments and how people respond, and debriefing is really important there too.”

The debriefings for cancer trials help participants realize their contribution is appreciated and the debriefings give them more information about the disease process being studied, she adds.

“For a follow-up study, it would be a great idea to talk with participants about what was most useful in the debriefing,” Reich says.

## REFERENCE

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# Dispatching advocates to inform the public

*Community liaisons explain emergency research*

When investigators seek an exception from informed consent (EFIC) for emergency research, they must show that they have engaged in community consultation and public disclosure, informing the public that they might encounter an experimental intervention while being treated in an emergency setting.

It can be difficult for researchers and review boards to know that the consultation has been truly effective by reaching the population most likely to be affected by the study and giving the public an opportunity to ask questions and make suggestions.

At Virginia Commonwealth University in Richmond, the community engagement staff at the university’s Center for Clinical and Translational Science Research has launched a program to build capacity for engaging the community in these EFIC consultations.

The approach relies on community liaisons who

already are involved in local social services and community advocacy in the Richmond area. They were tapped for their knowledge of how to reach different populations and inform them about studies.

**Cornelia Ramsey**, PhD, MSPH, a community research liaison with the center, says the involvement of the liaisons, called community advocates for research (CARs), has extended her institution’s reach in the community. She says VCU’s Clinical and Translational Science Award helps maintain the network of CARs and makes them available as a resource to other investigators going forward.

Ramsey says the idea was developed while developing a community consultation plan for VCU’s participation in the national Rapid Anticonvulsant Medications Prior to Arrival Trial (RAMPART). RAMPART studied whether it was more effective to give seizure patients anti-seizure medication in the field via an IV or an intramuscular injection. Because it would be impracticable to gain informed consent from seizure patients being treated by paramedics, the investigators sought an EFIC, which includes a requirement for community consultation and public disclosure.

At first, Ramsey says, the local group conducted this consultation process through traditional means, including advertising in newspapers, television and radio.

“We connected with those particular community groups that might be in the target population for the study: epilepsy groups, head trauma groups, people who were likely to have a seizure,” she says. “The principal investigator went to those groups, presented the study, and opened it up for questions.”

## Extending the conversation

In listening to those exchanges, Ramsey says she was impressed by the conversation that took place between the investigator and the public.

“It’s really the bi-directional communication that is the intent of community consultation/public disclosure,” she says. “Having that experience made me see that unless we figured out other ways to support that conversation, we would never hear all of their questions.”

Drawing on several models of community engagement in public health, her group developed the concept of the CARs, people active in the communities affected by the study. Some were with epilepsy groups, others worked with community organizations serving populations such as homeless people, and some were associated with churches in the area.

After training the group in research integrity and human subjects protection principles, the CARs were sent out to survey people about their knowledge of

research at VCU and more specifically the RAMPART study. To measure exactly where the message was spreading, the CARs asked those they surveyed for the nearest intersection to their home. Ramsey's group mapped the results, showing which areas were reached by the education efforts.

After gathering this information, the CARs helped develop a plan to take the disclosure further. They called their own community meetings and brought in the study coordinator to explain the study and answer questions. They handed out fliers and posted information on their bulletin boards and in their newsletters.

Ramsey says that because of the CARs' knowledge of their communities, the meetings they held were better attended than the university-initiated ones had been. "It was the community advocates who opened the door a little bit more into the communities, particularly the harder-to-reach communities such as the homeless population," she says. That increased access could be measured in survey responses.

The initial surveys about the RAMPART study, conducted in fall 2009 before the CARs began their own outreach, showed that 8.4% of the respondents had heard about the study, Ramsey says.

A separate but similar EFIC study was launched the following year. This time, the CARs were involved from the outset and helped the investigator create his community consultation/public disclosure plan, using the same strategies they had piloted in the RAMPART study.

A survey conducted in fall 2010 showed that 21.5% of respondents now had heard of RAMPART, and 24% had heard about the second EFIC trial.

## Building capacity

Because of the CTSA funding, Ramsey says VCU can maintain this network of CARs, activating it when needed to help with a study. A second generation of CARs is being recruited and trained, using materials the earlier CARs helped develop.

And the CARs themselves have gained from the experience. After spending so much time brainstorming together about community engagement strategies, Ramsey says the liaisons have begun to work on projects together outside the university. "That's truly building that community's capacity for research," she says.

Ramsey, who also serves on VCU's social-behavioral IRB, says IRBs have an important role to play as they review community consultation and public disclosure plans, to help ensure that the plans include strategies that are likely to reach the intended people in the community.

"It's asking the important questions," she says.

"Who is at high risk for being in this study? How are they represented in our community? Has every effort been made to reach into those communities and have that bi-directional communication? How is that represented in the plan? And how are we taking the information back to the community, once we have study findings?"

While not every institution has access to a CTSA grant, IRBs can direct investigators to institutional resources that can help them craft a more effective plan, Ramsey says.

"Most universities have a service learning component or community outreach; if it's connected with a health system, they have a health system outreach education person," Ramsey says. "There's usually somebody within the university structure who is connecting with the community and could help figure out how to start this." ■

## Seniors lack access to lifesaving organs

Thousands more American senior citizens with kidney disease are good candidates for transplants and could obtain them if physicians would move past outdated medical biases and put them on transplant waiting lists, according to a new study<sup>1</sup> by researchers at Johns Hopkins University, Baltimore, MD.

The Hopkins investigators estimate that between 1999 and 2006, roughly 9,000 adults over age 65 would have been "excellent" transplant candidates and about 40,000 more older adults would have been "good" candidates for new kidneys. None, however, were given the chance.

"Doctors routinely believe and tell older people they are not good candidates for kidney transplant, but many of them are if they are carefully selected and if factors that really predict outcomes are fully accounted for," says transplant surgeon Dorry L. Segev, MD, PhD, an associate professor of surgery at the Johns Hopkins University School of Medicine and leader of the study published in the *Journal of the American Geriatric Society*. "Many older adults can enjoy excellent transplant outcomes in this day and age," and should "be given consideration for this lifesaving treatment," he says.

Those ages 65 and older make up more than one-half of people with end-stage renal disease in the United States, and appropriately selected patients in this age group will live longer if they get new kidneys as opposed to remaining on dialysis, Segev

says. The trouble is that very few older adults are even put on transplant waiting lists, he adds. In 2007, only 10.4% of dialysis patients between age 65 and 74 were on waiting lists, compared to 33.5% of 18- to 44-year-old dialysis patients and 21.9% of 45- to 64-year-old dialysis patients.

Segev cautions that some older kidney disease patients are indeed poor transplant prospects, because they have other age-related health problems. But he says his team's new findings, in addition to other recent research, show that new organs can greatly improve survival even in this age group.

Segev and his team constructed a statistical model for predicting how well older adults would be expected to do after kidney transplantation by taking into account age, smoking, diabetes and 16 other health-related variables. Using those data to define an "excellent" candidate, the information then was applied to every person 65 and older on dialysis during the seven-year study period. The researchers also determined whether these candidates already were on the waiting list.

"We have this regressive attitude toward transplantation in older adults," Segev says, "one based on historical poor outcomes in older patients, which no longer hold up. Anyone who can benefit from kidney transplantation should at least be given a chance. They should at least be put on the list."

Segev says he knows there is a shortage of kidneys, and some will question whether scarce organs would be put to better use in younger patients. But Segev's study predicts that more than 10% of older patients would get kidneys from living relatives or friends, which would have little impact on the nationwide shortage of deceased donor kidneys. But finding a living donor first requires referral for transplantation.

"By not referring older adults for transplant, we're not just denying them a chance at a kidney from a deceased donor, but we're potentially denying them a kidney from a live donor," he adds.

According to research by Segev and his team published last year in the *Journal of the American Medical Association (JAMA)*<sup>2</sup> live kidney donation is very safe for donor and recipient, and more older adults are donating their kidneys to relatives.

Other research done by Segev has shown that older kidney transplant recipients do well with kidneys from older donors, organs that are otherwise be rejected for use in younger patients.

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## Study: Spirituality may improve quality of life

According to the results of a study<sup>1</sup> in *Psychiatry Research*, spirituality and religiousness might contribute to improved quality of life (QOL) in patients who have been diagnosed with residual schizophrenia.

The study enrolled 103 adults with this particular diagnosis who were outpatients in a psychiatry department. Their mean age was 34 years, the mean age at schizophrenia onset was 23 years, and they had had been diagnosed for a mean of almost 12 years. More than half (62%) were male, 71% were Hindus, and the rest were Sikhs. The mean positive domain score on the Positive and Negative Syndrome Scale (PANSS), which is a medical scale used for measuring symptom severity of patients with schizophrenia, was 9, the negative domain score was 17, the general psychopathology score was 23, and the total PANSS score was 49.

The study points out that previously, research examining the connections between spirituality and QOL has been almost entirely in the context of "chronic and life-threatening" diseases such as cancer, HIV infection, heart disease, and spinal cord injury. That research, too, has found positive associations between "spiritual well-being" and QOL.

For purposes of the study, the researchers assessed patients using the World Health Organization Quality of Life — Spirituality, Religiousness, and Personal Beliefs (WHOQOL-SRPB) Scale. In addition to evaluating the five domains of QOL (physical, psychological, level of independence, social relationships, and environment), this scale includes questions related to spirituality, religiousness, and personal beliefs.

Among the main findings was that the spirituality domain of QOL was significantly related to other QOL domains, including the physical, psychological, and social domains. The results also showed that two facets of the spirituality and religiousness domain of QOL — inner peace and spirituality — significantly contributed to the "variance of all the other domains of QOL." For example, the authors describe inner peace as having "a prominent influence" on other areas of QOL, as well as on general QOL, which "suggests that the most important aspect of the spirituality domain of QOL is inner peace which influences the overall QOL" in people with schizophrenia.

The authors of the study conclude that the study

suggests that the spirituality and religiosity domains of QOL have an important influence on other aspects of QOL of patients with schizophrenia. Because of this, the authors advise clinicians to assess the spirituality status and its meaning to each patient and encourage patients to “turn to religion more frequently if they consider it useful in dealing with their suffering.”

## REFERENCE

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## New hospice facts and figures

*Report reveals drop in length of service*

The National Hospice and Palliative Care Organization’s (NHPCO) annual report, *Facts and figures: hospice care in America*, shows the number of patients served remains fairly constant at 1.58 million in 2010 (a slight rise from 1.56 million served in 2009). Yet a statistic of concern to hospice and palliative care professionals is the drop in median and average length of service.

The median (50th percentile) length of service in 2010 was 19.7 days, a decrease from 21.1 days in 2009. The average length of service dropped to 67.4 days in 2010 from 69 days in 2009.

“What’s important to recognize here is that half of hospice patients received care for less than 20 days,” says **J. Donald Schumacher**, NHPCO president and CEO. “With drops in both the median and average length of service, there is concern that hospice providers are not reaching the patients and family caregivers who need hospice support in a timely manner.”

Schumacher says that while Medicare’s coverage of hospice has risen in the past decade, it represents appropriate care of dying Americans. What isn’t wanted is for appropriate access of hospice care to drop, particularly with the aging population where more people are dying with complex, multiple illnesses. “There are no better providers more skilled at providing palliative care at the end of life than hospice professionals, and the dying deserve the best care that our society can offer,” he says.

In previous decades, hospices overwhelmingly cared for people with cancer. In 2010, cancer diagnoses dropped to 35.6% from 40.1% in 2009. At 14.3%, heart disease, which is the leading cause of death in the United States, is the leading non-cancer diagnosis

among hospice patients.

In 2010, about 35.3% of patients died or were discharged within seven days of admission (a slight increase compared to 34.3% in 2009). Almost the exact same proportion of patients remained under hospice care for longer than 180 days (11.8% in 2009 and 2010).

“It’s very difficult for patients and families to take full advantage of the range of services hospice offers when they are under care for only a few days. We must be careful about focusing too intently on long-stay patients while turning a blind eye to the large number of patients dying in less than a week,” stated Schumacher.

Two new additions to the new edition of the report include sections looking at hospice care within the Medicare population and within the nursing home. An appendix geared for academics examining the accuracy of NHPCO’s national figures also has been added.

## RESOURCE

• NHPCO Facts and Figures: Pediatric Palliative Care. Free PDF download. Web: <http://bit.ly/wZ1kPe>. ■

## Role of ethics consults for research

In the past decade, a growing number of academic medical centers have begun offering research ethics consultation services in which bioethics experts help scientists address the ethical and societal implications of their laboratory and clinical experiments.

For example, an investigator might want advice on the social and cultural ramifications of conducting genetic research among an indigenous population. But the role of these consults isn’t always well understood. Many researchers believe that institutional review boards (IRBs), which must approve any research involving human subjects, will address these kinds of ethical questions. However, there are some areas of research, such as those involving animal subjects or broad social risk, that fall outside of the regulatory purview of IRBs. The consultation services can help fill this gap, in addition to giving scientists a sounding board for exploring ethical questions early in their research-design process.

A commentary<sup>1</sup> that appears in a recent issue of *Science Translational Medicine* describes how the research consults can serve as a complement to IRBs. The authors outline 11 “triggers” for these types of consultations. **David Magnus**, PhD, director of the

Stanford Center for Biomedical Ethics and the **Thomas A. Raffin**, MD, professor in Medicine and Biomedical Ethics, Stanford (CA) University, is the lead author.

Research ethics consultation services are designed to help scientists address ethical and societal issues that might not be considered in the context of existing regulatory frameworks, such as IRBs. The commentary identifies some types of biomedical research for which the research process can benefit from consultation with ethicists.

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## Palliative care in the ICU

The importance and potential benefits of palliative care to ease suffering and improve quality of life for patients being treated in hospital intensive care units (ICUs) has received increasing recognition but is not without significant challenges, as discussed in a roundtable discussion in a recent issue of the *Journal of Palliative Medicine*.

Palliative care in the ICU requires a team effort. A multidisciplinary group of healthcare experts shared their experiences, views, and advice as participants in the roundtable discussion, Palliative care in the ICU, held in summer 2011 and appearing in a recent issue of *Journal of Palliative Medicine*. (For information about accessing the discussion, see resource, right.) The discussion was led by moderator Judith Nelson, MD, JD, professor of medicine and project director, Improving Palliative Care in the ICU (IPAL-ICU) Project, Mount Sinai School of Medicine, New York City. The participants included: Elie Azoulay, MD, Hôpital Saint-Louis, Université Paris VII, France; J. Randall Curtis, MD, MPH, Harborview Medical Center, University of Washington, Seattle; Anne Mosenthal, MD, University of Medicine and Dentistry of New Jersey — New Jersey Medical School (UMDNJ-NJMS), Newark, NJ; Colleen Mulkerin, MSW, LCSW, Hartford Hospital, CT; Kathleen Puntillo, RN, DNSc, University of California, San Francisco; and Mark Siegel, MD, Yale School of Medicine, Yale — New Haven Hospital, CT.

Patients in the ICU are often at high risk of dying and might be on life support or require intensive monitoring. There has been a significant shift in the critical care community toward increasing recognition of the

needs of ICU patients and families and the potential for greater use of palliative care to ease their suffering and provide psychological support.

The IPAL-ICU Project of the Center to Advance Palliative Care is supported by the National Institutes of Health and is working to develop recommendations to guide the implementation of palliative care principles and practices in the ICU, focusing on the special issues affecting patients, families, and caregivers in the ICU environment.

“It seems clear that palliative care in the ICU improves the quality of care for both patients and their families. I suspect this will become standard of care in all hospitals in coming years,” says **Charles F. von Gunten**, MD, PhD, editor-in-chief of *Journal of Palliative Medicine*, and provost, Institute for Palliative Medicine at San Diego Hospice.

## RESOURCE

• The roundtable is available for free online at <http://online.liebert-pub.com/doi/full/10.1089/jpm.2011.9599>. ■

## Improving consent in organ donation

Research published in the *British Journal of Anaesthesia* suggests that organ donation rates in the United Kingdom (UK) could be increased if the issues affecting declined consent are improved. At present, only 30% of the UK population is registered on the National Health Service (NHS) Organ Donor Register (ODR).

From 2003 to 2005, the overall consent rate for donation after brain death (DBD) was 59%. This figure remains largely unchanged with a consent rate of 63% for DBD in 2007-2009. The low consent rate for organ donation in the UK is the largest factor limiting actual organ donor.

Organ donation consent is established by views expressed prospectively via membership of the ODR or views expressed to a family member. However, when a patient is deceased and has not previously expressed a wish to their relatives about organ donation, the healthcare professional will discuss donation with the family. Up to 10% of families of potential donors who are on the ODR still refuse assent to donation. At present, it is accepted practice to respect the family's wishes despite the existence of valid legal consent.

The paper, “Consent for organ donation,”<sup>1</sup> published in a special issue regarding organ dona-

tion for the *British Journal of Anaesthesia*, calls for action on the concerns and issues that affect consent.

## Staff care and interaction

The relative's experience and interaction with staff can have a huge impact on the decision to consent or refuse donation. The basic principles of medical practice should always be in place. However, a wider treatment of care for the family itself can have a very positive or negative effect on consent. Provisions of physical support in the form of comfortable accommodation, staff availability throughout the patient's admittance, empathy to the family, and a respectful and dignified treatment are factors that can have a positive impact on donation rates.

## Make sure the family understands

Understanding brain stem death is an important factor in organ donation. Studies have consistently found that an astounding amount of relatives do not fully understand brain death, even after it has been explained by the attending doctors. It is important that brain stem death is explained so that a relative can fully understand that their loved one is dead before donation takes place. Once this understanding has been reached discussion and consent for organ donation then can begin. In the UK, nurses that specialize in organ donation are trained and have the time to make sure families understand this condition. It has been suggested that allowing a family to witness tests or providing imaging or diagrams to explain concepts could help to improve a family's understanding of brain death.

Practical steps for improving consent:

- Promote the need for families to discuss their wishes regarding organ donation.
- Discuss donation at a time separate to that when the family are informed of the death or its inevitability, in an unhurried manner.
- Ensure the family is given specific information and that in particular, concerning DBD, the concept of brain stem death is fully explained.
- Use an approach pre-planned by the coordinator/specialist nurse and healthcare team that considers specific individual circumstances.

## REFERENCE

1. Vincent A, Logan L. Consent for organ donation. *Br J Anaesth* 2012; 108:i80-i87. ■



## Forced abortion for mentally ill?

A Massachusetts appeals court has overturned a ruling by Norfolk probate judge Christina L. Harms who ordered that a 32-year-old mentally ill woman, known as “Mary Moe,” have an abortion against her will even if it meant she had to be coaxed, bribed, or even enticed into a hospital. Additionally, Harms ordered that the Moe be sterilized.

The state appellate court associate justice **Andrew R. Grainger** wrote in the decision, “No party requested this measure, none of the attendant procedural requirements has been met, and the judge appears to have simply produced the requirement out of thin air.”

According to court documents, Moe, who suffers from schizophrenia and bipolar mood disorder, is pregnant and has been pregnant twice before. The first time she had an abortion; the second time she gave birth to a boy who is in the custody of her parents. Between those two pregnancies, she reportedly suffered a psychotic break and has been hospitalized numerous times for mental illness.

According to court records, Moe states that she is “very Catholic,” does not believe in abortion, and would never have an abortion. Her parents, however, have stated that she is not an “active” Catholic. Moe’s parents believe that it is in the best interests of their daughter to terminate her pregnancy.

According to the appellate ruling, the judge ordered that Moe’s parents be appointed as co-guardians and that Moe could be “coaxed, bribed, or even enticed ... by ruse” into a hospital where she would be sedated and an abortion performed.

The appeals court reversed the sterilization order and set aside the abortion order, saying a determination on that matter should go before a different judge “with all possible speed.”

## RESOURCE

- To read the full appeals court decision, go to <http://bit.ly/zf70hX>. ■

## WV first to launch e-Directive Registry

This month, West Virginia is officially known as the first in the nation to implement a statewide electronic registry for advance directives. The cutting-edge technology has been shepherded for two years at the West Virginia Center for End-of-Life Care in Morgantown, WV.

The system allows the advance directives of residents of West Virginia to be available online and accessible to their treating healthcare providers. Advance directives including living wills, medical powers of attorney, do-not-resuscitate orders (DNR), and physicians orders for scope of treatment (POST) are all included in the e-Directive Registry.

The registry is coordinated through the WV Health Information Network, the state's electronic medical records system. The system is compliant with privacy laws and is password-protected.

The project director **Alvin Moss, MD**, says in an online editorial that West Virginia is a leader in embracing the advantages of advance directives.<sup>1</sup> He says surveys the center has conducted over the years consistently reveal 75% of West Virginians say they don't want to be kept alive on machines at the end of life and that they would prefer to die comfortably in their home, which are wishes expressed in their advance directives.

### REFERENCE

1. Higgins S. State first to launch electronic advance directive registry. West Virginia Public Broadcasting 2012; Web: <http://bit.ly/yR90RK>. ■

## CHA applauds Obama mandate

Under the new contraception mandate policy from the Obama administration, women will have free preventive care including contraceptive services regardless of where they work. But if a woman's employer is a charity or hospital that has an objection as part of its policy, then her insurance company will be required to offer her contraception coverage.

This mandate that accommodates faith-based employers who object to paying for health insurance that covers contraceptive services was welcomed by the president

and CEO of the Catholic Health Association (CHA) **Sister Carol Keehan**. "The unity of Catholic organizations in addressing this concern was a sign of its importance," Keehan said in a written statement.

The Obama administration published final rules in the Federal Register that would exempt churches, other houses of worship, and similar organizations from covering contraception on the basis of their religious objections and establish a one-year transition period for religious organizations while the policy is being implemented.

An Obama administration official said the decision achieves two goals: It allows women to receive available and affordable care, and religious institutions don't have to pay for it.

Keehan said in her statement, "We are pleased and grateful that the religious liberty and conscience protection needs of so many ministries that serve our country were appreciated enough that an early resolution of this issue was accomplished."

### RESOURCES

- Catholic Hospital Association of the United States – Statement from Sister Carol Keehan. Web: <http://bit.ly/zv3r5U>.
- Fed Reg. 45 CFR Part 147 <http://bit.ly/y9QGRj>. ■

## Promising research news: Stem cell use as vision aid

Encouraging results occurred with the first tests in humans with vision problems and the use of stem cells. Most research with stem cells has been performed on lab animals, but in this research, two legally blind women were involved in the study. Both appeared to gain some vision after receiving an experimental treatment using embryonic stem cells.

The study began last summer at the University of California, Los Angeles (UCLA). Both patients were injected in one eye with cells derived from embryonic stem cells. One patient had the "dry" form of age-related macular degeneration, which is the most common cause of blindness. The other had a rare disorder known as Stargardt disease that also causes serious vision loss.

After four months, both patients showed improvement in reading progressively smaller letters on an eye chart. The patient who suffers from Stargardt disease went from seeing no letters at all on a vision chart to being able to read five of the largest letters.

Researchers caution the work is still preliminary. Scientists at UCLA and Advanced Cell Technology, in Santa Monica, CA, which funded the work, said they

were pleased that there have been no signs of rejection or abnormal growth months after the procedure.

## RESOURCE

Embryonic stem cell trials for macular degeneration: a preliminary report. Web: <http://bit.ly/yhNES6>. ■

## The new face of assisted suicide

Lawrence Egbert, MD, 84, a retired anesthesiologist from Baltimore, MD, is said to be next in line as the face of assisted suicide, after the death of Jack Kervorkian last year. According to online reports, Egbert has helped about 300 people commit suicide and has been present for 100 suicides in the last 15 years.

Egbert differs from his predecessor Jack Kevorkian, MD, by providing guidance and support to individuals wishing to end their life, where Kevorkian was known as more of a “radical” because he took an active role in some suicides.

In April 2011, Egbert was acquitted in an assisted suicide case in Arizona and avoided conviction. He faced criminal charges in Georgia in connection with allegedly assisting in the suicide of a Georgia man with advanced and debilitating jaw cancer, until Georgia’s highest court recently concluded that the state law restricting assisted suicides violated free speech rights. This ruling ended the long-running criminal case against Egbert. ■

## Informed consent book is recommended reading

The medical web site Medscape recently polled its readers and queried experts to compile a recommended reading list for medical professionals. On the list was author Rebecca Skloot’s account of the life of a poor African-American tobacco farmer, Henrietta Lacks, who was admitted to a hospital in 1951 and diagnosed with cervical cancer.

Unbeknownst to Lacks or her family, some cell samples were taken without her consent because informed consent had not yet become the standard of care. The book, that also won the National Academy of Sciences’ 2011 Best Book Award, investigates the racial and ethical issues surrounding informed consent.

Scientists used the cells for medical research worldwide. The cells, known as HeLa, were even sent into

space to detect DNA damage caused by space radiation. The HeLa cells continued to live and reproduce in culture long after Lacks’ death.

The family learned about the cells when a researcher approached them in hopes of studying them. The resulting misunderstanding, compounded by their lack of healthcare and other factors, led to them closing themselves off from research and media inquiries.

The book, *The Immortal Life of Henrietta Lacks*, spent 47 weeks on *The New York Times* bestseller list. It documents the Lacks family’s struggle and how the HeLa cells became one of the most important tools in medicine. They were vital for developing the polio vaccine, cloning, gene mapping, in vitro fertilization, and more. Henrietta’s cells have been bought and sold by the billions, yet she remains virtually unknown, and her family in Baltimore can’t afford health insurance.

Skloot, speaking recently at Northwestern

*Continued on p. 36*

## CME INSTRUCTIONS

To earn credit for this activity, please follow these instructions.

1. Read and study the activity, using the provided references for further research.
2. Log on to [www.cmecity.com](http://www.cmecity.com) to take a post-test; tests can be taken after each issue or collectively at the end of the semester. First-time users will have to register on the site using the 8-digit subscriber number printed on their mailing label, invoice or renewal notice.
3. Pass the online tests with a score of 100%; you will be allowed to answer the questions as many times as needed to achieve a score of 100%.
4. After successfully completing the last test of the semester, your browser will be automatically directed to the activity evaluation form, which you will submit online.
5. Once the completed evaluation is received, a credit letter will be e-mailed to you instantly.

## CME OBJECTIVES

Upon completion of this educational activity, participants should be able to:

- Discuss new developments in regulation and health care system approaches to bioethical issues applicable to specific health care systems.
- Explain the implications for new developments in bioethics as it relates to all aspects of patient care and health care delivery in institutional settings.
- Discuss the effect of bioethics on patients, their families, physicians, and society.

## COMING IN FUTURE MONTHS

- How ethical is complementary medicine?
- Death with dignity discussion
- Confidentiality and electronic health records
- Religion-based palliative care

University, Evanston, IL, said she was surprised at the book's impact. She never imagined that it would be read in schools across the country, research institutions, and the halls where they make the laws.

## RESOURCES

- For more information on The Immortal Life of Henrietta Lacks, visit <http://rebeccaskloot.com/the-immortal-life>.
- The Henrietta Lacks Foundation strives to provide financial assistance to needy individuals who have made important contributions to scientific research without their knowledge or consent. Web: <http://henrietalacksfoundation.org>. ■

## CME QUESTIONS

1. According to the journal *Pediatric Transplant*, what factors are considered when evaluating a transplant candidate?
  - A. The patient must also be in an overall condition that would support the transplant surgery.
  - B. The patient should be able to adjust to the post-transplant regimen of immunosuppressant medications.
  - C. The patient should have sufficient social support.
  - D. All of the above
2. True or False: According to research by Dorry L. Segev, older kidney transplant recipients do well with kidneys from older donors, organs that are otherwise be rejected for use in younger patients.
  - A. True
  - B. False
3. According to J. Donald Schumacher of the National Hospice and Palliative Care Organization, what is the suspected reason for the drop in median and average length of service in palliative care?
  - A. A large percentage of patients died or were discharged within seven days of admission.
  - B. Hospice providers are not reaching the patients and family caregivers who need hospice support in a timely manner.
  - C. Half of hospice patients received care for less than 20 days.
  - D. None of the above
4. According the research published in the *British Journal of Anaesthesia*, in what way can family consent in organ donation be improved?
  - A. Promote the need for families to discuss their wishes regarding organ donation.
  - B. Ensure the family is given specific information and that in particular, concerning DBD, the concept of brain stem death is fully explained.
  - C. Use an approach pre-planned by the coordinator/specialist nurse and healthcare team that considers specific individual circumstances.
  - D. All of the above

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