

## ETHICS ROUNDS

## Was Sarah Murnaghan Treated Justly?

**AUTHORS:** Jennifer deSante, MD, MBE,<sup>a</sup> Arthur Caplan, PhD,<sup>b</sup> Benjamin Hippen, MD, FASN,<sup>c</sup> Giuliano Testa, MD, MBA,<sup>d</sup> and John D. Lantos, MD

<sup>a</sup>Children's Hospital of Philadelphia, Philadelphia, Pennsylvania;

<sup>b</sup>Division of Medical Ethics, NYU Langone Medical Center, New York, New York;

<sup>c</sup>Carolinas Medical Center, Charlotte, North Carolina;

<sup>d</sup>Living Donor Liver Transplantation, Baylor University Medical Center, Dallas, Texas; and <sup>e</sup>Children's Mercy Hospital, Kansas City, Missouri

**KEY WORDS**

child, ethics, cystic fibrosis, lung transplantation, resource allocation, justice

**ABBREVIATIONS**

LAS—Lung Allocation Score

OPTN—Organ Procurement and Transplantation Network

TRO—Temporary Restraining Order

UNOS—United Network for Organ Sharing

Drs deSante and Caplan had the original idea for this paper and helped conceptualize the paper; Drs Hippen and Lantos helped conceptualize the project; Dr Testa helped to analyze the fundamental issues in organ allocation; and all authors contributed to the manuscript and reviewed and approved the final manuscript.

[www.pediatrics.org/cgi/doi/10.1542/peds.2013-4189](http://www.pediatrics.org/cgi/doi/10.1542/peds.2013-4189)

doi:10.1542/peds.2013-4189

Accepted for publication Mar 13, 2014

Address correspondence to John D. Lantos, MD, Children's Mercy Hospital, 2401 Gillham Rd, Kansas City, MO 64108. E-mail: [jlantos@cmh.edu](mailto:jlantos@cmh.edu)

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2014 by the American Academy of Pediatrics

**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to this article to disclose.

**FUNDING:** No external funding.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.

## abstract

Lung transplantation is a potentially life-saving procedure for patients with irreversible lung failure. Five-year survival rates after lung transplantation are >50% for children and young adults. But there are not enough lungs to save everyone who could benefit. In 2005, the United Network for Organ Sharing developed a scoring system to prioritize patients for transplantation. That system considered transplant urgency as well as time on the waiting list and the likelihood that the patient would benefit from the transplant. At the time, there were so few pediatric lung transplants that the data that were used to develop the Lung Allocation Score were inadequate to analyze and prioritize children, so they were left out of the Lung Allocation Score system. In 2013, the family of a 10-year-old challenged this system, claiming that it was unjust to children. In the article, we asked experts in health policy, bioethics, and transplantation to discuss the issues in the Murnaghan case. *Pediatrics* 2014;134:155–162

Lung transplantation is a potentially life-saving procedure for patients with irreversible lung failure. Five-year survival rates after lung transplantation are more than 50% for children and young adults, but there are not enough lungs to save everyone who could benefit. In 2005, the United Network for Organ Sharing (UNOS) developed a scoring system to prioritize patients for transplantation. That system considered both transplant urgency as well as time on the waiting list and the likelihood that the patient would benefit from the transplant. At the time, there were so few pediatric lung transplants that the data that were used to develop the Lung Allocation Score (LAS) were inadequate to analyze and prioritize children, so they were left out of the LAS system. In 2013, the family of a 10-year-old challenged this system, claiming that it was unjust to children. In the article, we asked experts in health policy, bioethics, and transplantation to discuss the issues in the Murnaghan case. Our discussants are Jennifer deSante, MD, a postdoctoral fellow in the Department of Bioethics at the Clinical Research Center of the National Institutes of Health; Arthur Caplan, PhD, the director of the Division of Medical Ethics at the NYU Langone Medical Center; Benjamin Hippen, MD, a transplant nephrologist in private practice at the Carolinas Medical Center; and Giuliano Testa, surgical director of Living Donor Liver Transplantation at Baylor University Medical Center.

## THE CASE

*In the spring of 2013, the case of a 10-year-old girl awaiting a lung transplant became the center of an unprecedented controversy over fairness in the distribution of lungs from cadaver donors.<sup>1</sup>*

*Sarah Murnaghan was born with cystic fibrosis. At the age of 1 she began receiving her care at the Children's Hospital of Philadelphia. In December,*

*2011, her disease had progressed to the point where she was placed on the national transplant waiting list with priority status 1, a status reserved for the patients who most urgently need a transplant. By December 2012, she was on continuous, noninvasive respiratory support at home. In February 2013, she was admitted to Children's Hospital of Philadelphia because of her worsening respiratory status. Despite maximal therapy, her lungs began to fail. During her year-plus time on the waiting list for a lung transplant, no organ deemed suitable by her transplant team had become available.*

*With no acceptable donor lungs available, her parents told members of the media that they had only recently learned that Sarah was not eligible to receive adult cadaver lungs. Although Sarah had been listed for both whole lung and lobar transplant since 2011, given her age, she was not given a lung allocation score that would make her competitive in gaining access to adult lungs.*

*UNOS is charged by Congress with rationing cadaver organs, including lungs.<sup>2</sup> Adult lungs are distributed based on a lung allocation score that is based on need, regional location, blood type, and size. UNOS updated its pediatric lung policy in 2010, putting 2 tiers in place for children. Lungs recovered from adolescents (age 12–17) were offered first to adolescent recipients, then to children <12, then to adults. Lungs from children <12 years old were first offered to children <12, then to adolescents, then adults.<sup>3</sup> The basis for this policy was that there were data that predicted the efficacy of adult lungs in adult recipients, but few data on the outcomes of partial lobar lung transplants in children, especially in those <12.<sup>4–7</sup> The known success of adult lung transplantation was given more weight than the unknown efficacy of partial lobe lung transplantation.*

*Sarah's parents, in an attempt to give their daughter the best chance at life, launched a public relations campaign to get her priority access to lungs obtained from the adult cadaver donor list. The publicity from this case prompted a sympathetic response from many members of Congress, who asked Secretary of Health and Human Services Kathleen Sebelius to override the restrictions on adult lungs for patients <12 years old. The Secretary refused to overturn the policy of UNOS.<sup>8</sup> In response, Sarah's family sought the skills of a prominent Philadelphia law firm and filed a lawsuit challenging UNOS policy.<sup>9</sup>*

*With Sarah critically ill, an emergency hearing was held before Federal Judge Michael Baylson. On June 5, 2013, Baylson ordered Secretary Sebelius to allow Sarah to be placed on the adult lung transplant list. This, it was felt, would increase her chances of getting a lung for transplantation.*

*Did Judge Baylson make the right decision to override the UNOS allocation system in this case?*

## Comments by Dr Jennifer DeSante and Professor Arthur Caplan

Until Sarah's case, decisions on who gets cadaver organs for transplantation were based on medically determined and enforced rules.<sup>10</sup> The UNOS system has, for decades, been a model for making tough rationing decisions. Sarah's case challenges the idea that decisions about the distribution of scarce health care resources can be made based on objective criteria and not emotional appeals, media campaigns, or lawsuits.

The UNOS pediatric lung policy was developed based on data from previous lung transplant surgeries, which showed that children <12 would have the best outcomes with organs from donors <12 years old. Furthermore, the medical conditions of children <12

are different enough from adults that it is difficult to calculate an accurate LAS.<sup>11</sup> Cystic fibrosis, a common indication for lung transplantation, presents its own set of challenges for pediatric lung transplant recipients. In 2011 in the United States, there were just 19 lung transplants for children <18.<sup>12</sup> There were >1700 transplants for patients 18 or older.

Lungs for pediatric transplantation are scarce. Of the >400 donors a year <12 years old, <10% of them provide lungs, compared with >35% of the >400 adolescent donors a year. The scarcity in donor lungs is not just because of a lack of donors, but also the constrictions of geography that pertain to lungs. Proximity to the recipient is critical given the short ischemic time of lungs. Therefore nearly 30% of lungs from donors <12 are transplanted into adults. Organ scarcity also reflects the fact that some child lung transplant programs are very conservative as to the cadaver organs they will accept.

None of these facts was brought up in the media debate surrounding Sarah's case. Nor did the congressmen who argued that it would be appropriate to override the UNOS allocation policy seem to be aware of them. Although Pennsylvania Congressman Lou Barletta noted that "with the stroke of a pen [the Secretary] could have granted Sarah a waiver" that would give her a chance to live, he did not mention that Sarah at age 10 might push aside a child of 12 or 13.<sup>13</sup> Nor did he remark that the odds of success for a lung transplant in any recipient were poor, with overall survival at 6 years <50%.<sup>14</sup> Nor did he comment on the additional surgical difficulties of a lobar lung transplant in a patient with severe cystic fibrosis. All of these factors shaped the UNOS pediatric lung allocation policy.

Never before had the UNOS organ allocation policy been successfully chal-

lenged in a single case. Although people had engaged in publicity campaigns to acquire designated cadaver or living organs, never before had the government intervened to negate the medically determined rules for rationing an organ.

There is no denying the need to ration organs for transplantation. The question is not whether there should be rationing of scarce, life-saving resources, but how the scarce resources should be rationed. And as Sarah's case shows, there are actually 3 critical questions about the ethics of rationing in health care: Who do we want making rationing decisions and on what basis? Do we want our health care resources distributed by federal judges, members of Congress, or those who can mount media campaigns? If these are not the proper allocators, then who is? Rationing in health care should not be the job of the government, lobbying parents, attorneys, or public relations firms. They lack the required medical knowledge to decide who can benefit from access to scarce resources or the ability to create rules based on data and outcomes. Rationing is best left in the hands of those who can bring expertise to bear to determine need and the critical factors that shape successful transplant outcomes.

Sarah's parents had every right to advocate for their child, including involving the media and taking legal action. Sarah's doctors were correct in supporting every realistic option for Sarah's care. Physicians have a fiduciary responsibility to their patients, which requires them to act in the best interest of every individual patient, even at the cost of denying resources to others.

When a physician is at a patient's bedside, the physician is advocating for what is best for that patient, regardless of outside factors and limitations. But in transplantation, as in many

areas of health care, rationing decisions must be made. For almost 3 decades, Americans have allowed UNOS to make these decisions. In the Murnaghan case, Judge Baylson claimed that the UNOS pediatric lung allocation policy was "arbitrary," capricious, and based on inadequate evidence. If the UNOS lung policy had been arbitrary or capricious or discriminatory, then it surely would be appropriate to pursue a legal appeal on behalf of Sarah. But, ironically, the UNOS policy was driven by the absence of adequate information concerning the efficacy of lobar lung transplants that would justify giving children higher priority for adult lungs. What the judge saw as arbitrary, UNOS experts saw as a policy reflective of the inadequate evidence concerning transplants for children versus adequate evidence supporting the efficacy of adult lung transplants.

The intervention by the court in response to media and political lobbying should not be a precedent for who should decide or on what basis rationing ought to proceed. The evidence-based UNOS system has done a good job of allocating scarce organs without favor or politics for decades. Sarah Murnaghan's parents (and lawyers), in deciding to fight for Sarah's chance at life, threaten to topple one of the few transparent rationing schemes that has secured public support. It may now be replaced by a system that privileges those who can command publicity and legal firepower.

Rationing scarce resources fairly is difficult. Evidence-based rules and expert opinion can be overwhelmed by the plight of a particular patient. Rationing protocols need the law to protect against invidious discrimination. There may even be a case to give special consideration for children simply because they are persons with unfinished lives.<sup>15</sup> But rationing, to be fair, also needs to be sufficiently transparent

and grounded in evidence-based rules able to withstand the emotional tsunami that a dramatic case can create.

### Comments by Dr Benjamin E. Hippen

Judge Baylson did the right thing. It is unfortunate that he had to.

In an editorial about this case, Halpern claims that Judge Baylson's decision "...exalted (Sarah Murnaghan) and another child above a national policy."<sup>16</sup> I disagree. To see why, it is necessary to examine exactly what Judge Baylson did and did not do.

What he did was issue a 10-day temporary restraining order (TRO) against the Department of Health and Human Services and their policy for organ allocation. This was done so that Murnaghan would not suffer mortal harm while the parties were compelled to assemble and state their cases for adjudication on the merits. In issuing this order, Judge Baylson determined that (1) the disputed policy was "arbitrary and capricious," (2) that Murnaghan had a high likelihood of prevailing on the merits of her case, and (3) that Murnaghan had the prospect of serious harm in the absence of temporary relief.

This decision did not show favoritism to Sarah Murnaghan. Instead, it questioned the fairness and the scientific validity of the policy of the Department of Health and Human Services for organ allocation. It allowed her to have the same chance, not a better chance, as everyone else in the country to receive an organ. That was the right thing to do.

Fortunately for her, Murnaghan was transplanted in the 10-day window offered by the TRO. Thereafter, the UNOS/Organ Procurement and Transplantation Network (OPTN) Executive Committee adopted an exception (with a sunset provision in June 2014) to their own lung allocation policy, Policy 3.7, which permits lung transplant candidates <12 to apply for individual case

review for inclusion in the LAS for the purpose of allocation. The exception to Policy 3.7 provides for the opportunity, after individual peer review and approval by a UNOS/OPTN subcommittee, for candidates <12 to be granted equal (not "exalted") consideration alongside candidates >12 for organs from adolescent and adult donors. "Consideration" is not a euphemism, and the exception to Policy 3.7 is not a *carte blanche*. Approving or not approving a <12-year-old candidate for inclusion in the LAS based on specific clinical concerns, such as whether an individual <12 candidate's thoracic morphology is suitably similar to a >12 candidate for the purpose of receiving lungs from an adult donor, or whether a particular individual <12 candidate is not a candidate for lung transplantation by virtue of having a particular underlying diagnosis or combination of comorbidities that make success unlikely, is explicitly the purview of a national committee of expert clinicians who are not directly involved in any individual case. In other words, UNOS adopted Judge Baylson's approach.

The Murnaghan's lawyer, Steven Harvey, argued that Murnaghan (and Javier Acosta) should have their cases assessed on a common metric of medical urgency, a metric the LAS is designed to measure, without consideration of age alone as an advantage or disadvantage for allocation purposes. He argued, "Murnaghan...asked only that they be given access to adult lungs based on the medical urgency of [her] condition...they sought no special preference."<sup>17</sup> And, Murnaghan did not receive special preference: she was allocated organs by virtue of her high LAS, a score that is calculated in an identical way for every other recipient. This is no more unfair than a scenario in which another >12-year-old candidate was rapidly evaluated and listed

with a high LAS at a given institution, thereby "bypassing" other candidates. It is true that Murnaghan was able to list as Status I as well as being included in the LAS, but this did not offer her any additional advantage relative to other candidates. Status I listing is available only to candidates <12,<sup>18</sup> and organs are offered to Status I candidates only if the organ offer is turned down for all eligible candidates >12. Therefore, candidates >12 are not disadvantaged by candidates with dual listing.

Judge Baylson enforced a temporary course of action that, in retrospect, was ratified (and thereby mooted) by the policy exception adopted by the UNOS/OPTN Executive Committee 4 days later. For their troubles, Baylson and Harvey have been pilloried. The UNOS/OPTN Ethics Committee released a high-handed, condescending statement averring, "Politicians and judges who intervene in a complex allocation algorithm may be well-intentioned but fail to consider all the moral variables that must be balanced at the macro level rather than through an individual candidate's experience."<sup>19</sup>

Aside from the point that the Murnaghan family was explicitly not seeking an exception based on "an individual candidate's experience," but instead the opportunity for candidates <12 as a class not to be excluded from LAS, the allusion to complexity and the need for macro-level balancing begs the question: Did the policy exception approved by the UNOS/OPTN Executive Committee meet the Ethics Committee's protean standards of respect for "complexity" and "macro-level" balancing, or not?

Consider the counterfactual: But for the brief filed on Murnaghan's behalf and the order issued by Baylson, it is extremely unlikely that the Executive Committee would have considered, much less approved, the exception to Policy 3.7. Did the Executive Committee reconsider the policy on the merits, or

instead was the exception approved merely as an expedient stopgap to avoid the expense, attendant bad publicity, and uncertain consequences of litigation? Critics of Judge Baylson and Attorney Harvey remain silent on these points.

John Roberts, the then-president of UNOS/OPTN, thought approval of the policy exception was not merely realpolitik. He told Bloomberg News, “My sense is that that particular age may be difficult to justify from a scientific point of view. The exception will allow us to re-examine the lung allocation policy considering the most recent data.”<sup>20</sup>

What would lead someone to think the existing data were insufficient to use age as a cutoff for inclusion in the LAS? Ironically, it is the same reason that Halpern<sup>16</sup> cites as the reason that candidates <12 were not included in studies validating the LAS: there have historically been very few children <12 listed for lung transplantation. Halpern<sup>16</sup> argues that “Applying [the LAS] model to children might therefore cause inequitable prioritization....” Maybe so, but here Halpern<sup>16</sup> conflates the absence of evidence as evidence of absence as regards the applicability of LAS to selected candidates <12, when the appropriate attitude to this question is one of equipoise.

Furthermore, there were a total of only 49 registered candidates ages 6 to 11 listed for lung transplantation from September 2010 to March 2013, compared with 7323 candidates aged >18 over the same period (Fig 1). The comparatively small number of candidates <12 compared with the larger number of candidates >12 (the category that sets the relative risk = 1.0) means that the confidence intervals (for a 95% confidence level) on any relative risk calculation for the 0 to 5 and 6 to 11 subgroups will be broad, as they are in Fig 2. To demonstrate “sig-

	REGs Ever Active	REGs with at Least 1 Offer		REGs with 3+ Offers or Acceptance		REGs with an Acceptance	
	N	N	%	N	%	N	%
<b>Age</b>							
0 - 5	54	29	53.7	27	50.0	26	48.1
6-11	49	34	69.4	29	59.2	18	36.7
12-17	115	100	87.0	88	76.5	62	53.9
18+	7,323	6,826	93.2	6,262	85.5	4,396	60.0

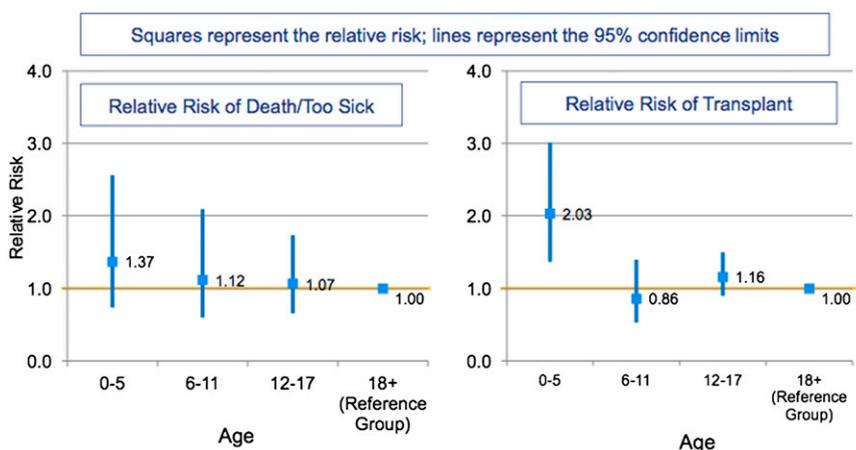
**FIGURE 1**

Number of lung registrations with offers or acceptance by age, September 12, 2010 to March 11, 2013. Included lung registrations with or without any other organ(s). Age was determined based on maximum of age at listing or age at start of period. From the OPTN/UNOS Steering Committee Meeting, June 10, 2013. [http://optn.transplant.hrsa.gov/ContentDocuments/OPTN\\_Exec\\_Comm\\_mtng\\_materials\\_06-10-13.pdf](http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Exec_Comm_mtng_materials_06-10-13.pdf)

nificant” harm, the relative risk of death and relative risk of not receiving a transplant would have to be of sufficient magnitude to overcome these broad confidence intervals, which is a nearly insurmountable standard of proof.

In short, Roberts is correct that age cutoffs are difficult to justify from a scientific point of view. The policy exception approved by the UNOS/OPTN Executive Committee does not delegate allocation decisions, much less the practice of medicine, to judges or to the legal representatives of telegenic

transplant candidates. Instead, it delegates them to a committee of qualified medical and surgical peers to consider candidates on a case-by-case basis, taking all clinical factors (and not just age) into account, while concomitantly generating prospective data on a question on which there is clinical equipoise. Had this policy exception been extant policy at the outset, it is likely that no suit would have been brought, and no TRO would have been necessary. That it was justifiably necessary ought to be occasion for circumspection, and not approbation, on the part of transplant



**FIGURE 2**

Unadjusted relative risk of death/too sick and transplant by age group for lung alone candidates ever waiting during September 12, 2010 to March 11, 2013. Age was determined based on maximum of age at listing or age at start of period. From the OPTN/UNOS Steering Committee Meeting, June 10, 2013. [http://optn.transplant.hrsa.gov/ContentDocuments/OPTN\\_Exec\\_Comm\\_mtng\\_materials\\_06-10-13.pdf](http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Exec_Comm_mtng_materials_06-10-13.pdf)

policy professionals. Here, the fault is not in our stars, but in ourselves.<sup>21</sup>

### Comments by Dr Giuliano Testa

The case of Sarah Murnaghan is dramatic and unfortunately not unusual. The child has a chronic pulmonary condition that can be treated only with a transplant. She has to wait for a long time for the therapy that ultimately may prolong her life.

According to data from the Scientific Registry Transplant Recipients, there were 1305 patients awaiting a lung transplant in the United States in 2011. Of these, 36.5% had been waiting for >1 year. The mortality rate while on the lung waiting list was 15.7% in 2011 and many patients were taken off the list because, while waiting, they became too sick to survive a lung transplant.

Things were even worse for pediatric patients. For those between 0 and 11 years, the group Sarah Murnaghan was in, there were 43 active patients in 2011. Only 19 (44%) of these received a transplant and 13 (30%) died while on the waiting list.<sup>22</sup> Clearly, there are not enough lungs to transplant the patients in need.

In the condition of scarce resources, the medical community established precise rules with the aim of allocating the few organs available to the patients most in need. These rules were established as a mandate of the federal government through the report of a Federal Task Force on Organ Transplantation instituted in 1984 for proposing policies for organ procurement and distribution.<sup>23</sup> It states that the community should have dispositional authority over donated organs, that professionals should be viewed as trustees and stewards of donated organs, and that the public should be heavily involved in the formation of policies of allocation and distribution. UNOS is the agency in charge of drafting rules and regulations of organ allocation. They do this through a democratic

process that involves the distribution to all transplant centers of a proposal, an open forum to comment on the proposal, a general vote, and ultimately the codification of the proposal into a policy.

The lung allocation policy is as follows: pediatric patients <18 years of age are divided into 2 groups, <12 and >12 years of age. Patients <12 years of age are ranked by priority, based on respiratory failure and pulmonary hypertension, by geography (because ischemia time dictates success after transplantation), by blood type, and by waiting time on the list. Lungs from donors ages 0 to 11 years are first offered to a recipient of the same age group then to the others; recipients of identical blood type are given precedence to recipients with compatible blood type. Any transplant center can appeal to a regional review board, made up of transplant physicians of the same region, and the review board may or may not grant the exception.<sup>24</sup>

The Murnaghan family appealed to a judge to overrule UNOS regulations. They asked that Sarah be considered for lungs from adult donors with the aim of having access to a larger pool of donors. The judge granted the parents' request. Sarah Murnaghan was transplanted with organs originally destined to an older recipient. The first transplant failed and Murnaghan was retransplanted shortly thereafter, this time with a successful outcome.

The ethical principles that drive the allocation system are justice and utility. Justice dictates that treatments be allocated equally and fairly; that is, patients in similar clinical conditions should be treated in a similar manner and have access to similar treatments. Utility is of paramount importance because, in a situation of dire scarcity, treatments should be allocated to those patients most likely to benefit from them.

The fairness of the system should be judged based on the degree to which it

balances concerns about justice with concerns about utility.

From the perspective of the surgeon who transplanted Murnaghan, these ethical principles were less important than the principle of beneficence. His aim was to do good to the sick child who had entrusted him with her care. Other doctors, with other patients who needed lung transplants, would have similar claims to act on their patients' behalf. Other patients who could have received those lungs and had the same right to treatment of Sarah Murnaghan, did not get a transplant.

The tension is between the needs of the patient seen in his or her individuality and the commitment of the surgeon to his or her patients on one side and the need of all other patients in the same conditions and their right to receive treatment.

Organ allocation policies have the role of striking a balance between these needs and resolve the existing tension. They were created with the goal of allocating organs justly. In a situation of dire scarcity, just allocation mechanisms will inevitably seem unfair to some.

The judge who ruled in favor of Murnaghan thought he did justice to a child with a terminal disease. But by his overruling of the carefully designed UNOS policies, he did an injustice to other patients who, according to existing policies, had a right to the organs that were given to Sarah. Although we rejoice about the return to health of a young child, we cannot say that justice was done in this case. Judge Baylson should not have overturned UNOS policy.

### OUTCOME OF THE CASE

On June 12, 2013, Sarah was transplanted with a set of partial lungs from an adult cadaveric donor. She immediately developed primary graft dysfunction and that evening was placed on veno-arterial extracorporeal membrane oxygenation and

relisted. She received a second lobar transplant from an adult donor 3 days later. These lungs were infected with pneumonia at the time of the donor's death, but the infected tissue was removed before transplantation.<sup>25</sup> Sarah continued to have many challenges, including a respiratory infection, a tracheostomy, and surgery on her diaphragm, before she was discharged from the hospital on a ventilator on August 27. She is, apparently, still doing well at home.

### Comments of John D. Lantos

Organ allocation is one of a few situations in American medicine today in which there is a dire scarcity of resources. Need far outstrips supply. This has been the

case with organ replacement technology since the earliest days of renal dialysis when a group, nicknamed the "God Squad," decided who should have access to the very few dialysis machines in Seattle.<sup>26</sup> Calabresi and Bobbitt<sup>27</sup> defined "tragic choices" as those situations in which explicit allocation decisions must be made about who shall die. They define a number of different ways in which such allocation decisions may be made: market mechanisms, queues, lotteries, accountable political processes, and the like. But their conclusion is that none of these is ideal, all have recognizable problems, and that when the problems of one allocation system become too unbearable, we shift to another that seems fairer, only to eventually tire of the

new one for foreseeable reasons. The LAS replaced a system in which organs were allocated based only on the amount of time that a patient was on the waiting list. It was, essentially, a queue. The LAS attempted to improve the fairness of that system by considering illness severity and prognosis. For a while, that seemed fairer. The Murnaghan case highlights the ways in which the LAS might treat children unfairly. It should lead to a careful reassessment of the mechanisms by which lungs for transplantation are allocated. It is not fair to allocate lungs based on age, race, or gender. It is fair to allocate lungs based on prognosis. Age does not appear to be associated with prognosis.<sup>28</sup> Thus, children should have the same chances of getting a lung transplant as adults.

## REFERENCES

- Levs J, Welch C, Asher Z, Bixler J. Dying girl's plight sparks fight over organ transplants. CNN Cable News Network. May 29, 2013. Available at: <http://edition.cnn.com/2013/05/29/health/pennsylvania-girl-lungs>. Accessed December 11, 2013
- OPTN: Organ Procurement and Transplantation Network. Available at: <http://optn.transplant.hrsa.gov/policiesAndBylaws/nota.asp>. Accessed December 11, 2013
- Organ Procurement and Transplantation Network (OPTN) Policies. Policy 10: Allocation of Lungs. Available at: [http://optn.transplant.hrsa.gov/ContentDocuments/OPTN\\_Policies\\_PC\\_08-2013.pdf#nameddest=Policy10](http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Policies_PC_08-2013.pdf#nameddest=Policy10). Accessed December 11, 2013
- Keating DT, Marasco SF, Negri J, et al. Long-term outcomes of cadaveric lobar lung transplantation: helping to maximize resources. *J Heart Lung Transplant*. 2010;29(4):439–444
- Benden C, Inci I, Weder W, Boehler A. Size-reduced lung transplantation in children—an option worth to consider! *Pediatr Transplant*. 2010;14(4):529–533
- Marasco SF, Than S, Keating D, et al; Cadaveric Lobar Lung Transplantation. Cadaveric lobar lung transplantation: technical aspects. *Ann Thorac Surg*. 2012;93(6):1836–1842
- Mohite PN, Popov AF, Yacoub MH, Simon AR. Living related donor lobar lung transplantation recipients surviving well over a decade: still an option in times of advanced donor management. *J Cardiothorac Surg*. 2013; 8:37.
- Norman B. Kathleen Sebelius at center of storm over child's lung transplant. Available at: [www.politico.com/story/2013/06/kathleen-sebelius-childs-lung-transplant-92237.html#ixzz2nBmX8sVb](http://www.politico.com/story/2013/06/kathleen-sebelius-childs-lung-transplant-92237.html#ixzz2nBmX8sVb). Accessed December 11, 2013
- Baylson MM. United States District Court. Eastern District of Pennsylvania. Janet and Francis Murnaghan v. United States Department of Health and Human Services. Rep. no. Civil Action 13-3083. June 2013. Available at: [www.paed.uscourts.gov/documents/opinions/13D0484P.pdf](http://www.paed.uscourts.gov/documents/opinions/13D0484P.pdf). Accessed December 11, 2013
- United Network of Organ Sharing. Questions and answers for transplant candidates about lung allocation policy. 2010. Available at: [www.unos.org/docs/Lung\\_Patient.pdf](http://www.unos.org/docs/Lung_Patient.pdf). Accessed April 21, 2014
- Ladin K, Hanto DW. Rationing lung transplants—procedural fairness in allocation and appeals. *N Engl J Med*. 2013;369(7): 599–601
- Department of Health and Human Services. 2011 Annual Data Report. Scientific Registry of Transplant Recipients. Available at: [http://srtr.transplant.hrsa.gov/annual\\_reports/2011/default.aspx](http://srtr.transplant.hrsa.gov/annual_reports/2011/default.aspx). Accessed September 4, 2013
- Hoffman B. Rep. Barletta: Sebelius could easily have interceded in sick girl's case. Newsmax. June 6, 2013. Available at: [www.newsmax.com/US/barletta-sebelius-sick-girl/2013/06/06/id/508548](http://www.newsmax.com/US/barletta-sebelius-sick-girl/2013/06/06/id/508548). Accessed September 4, 2013
- National Heart, Lung, and Blood Institute. What are the risks of lung transplant? May 1, 2011. Available at: [www.nhlbi.nih.gov/health/health-topics/topics/lungtxp/risks.html](http://www.nhlbi.nih.gov/health/health-topics/topics/lungtxp/risks.html). Accessed September 4, 2013
- Reese PP, Caplan AL. Better off living—the ethics of the new UNOS proposal for allocating kidneys for transplantation. *Clin J Am Soc Nephrol*. 2011;6(9):2310–2312
- Halpern SD. Turning wrong into right: the 2013 lung allocation controversy. *Ann Intern Med*. 2013;159(5):358–359
- Harvey SG. The 2013 lung allocation controversy. *Ann Intern Med*. 2013;159:794
- UNOS/OPTN. Policy 10: allocation of lungs, Tables 10-4 and 10-5. Available at: [http://optn.transplant.hrsa.gov/ContentDocuments/OPTN\\_Policies.pdf](http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Policies.pdf). Accessed February 10, 2014
- UNOS/OPTN. Executive committee meeting June 10, 2013: agenda and materials. Available at: [http://optn.transplant.hrsa.gov/ContentDocuments/OPTN\\_Exec\\_Comm\\_mtnng\\_materials\\_06-10-13.pdf](http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Exec_Comm_mtnng_materials_06-10-13.pdf). Accessed December 1, 2013

20. Edney A. Dying girl needing lung forces change in US policy. Bloomberg News, June 11, 2013. Available at: [www.bloomberg.com/news/2013-06-10/u-s-organ-donor-committee-votes-to-ease-under-12-lung-policy.html](http://www.bloomberg.com/news/2013-06-10/u-s-organ-donor-committee-votes-to-ease-under-12-lung-policy.html). Accessed December 1, 2013
21. Shakespeare W. *The Life and Death of Julius Caesar: Act 1, Scene II*. Available at: [http://shakespeare.mit.edu/julius\\_caesar/full.html](http://shakespeare.mit.edu/julius_caesar/full.html). Accessed April 21, 2014
22. Scientific Registry Transplant Recipients. Available at: [www.srtr.org](http://www.srtr.org). Accessed December 11, 2013
23. National Organ Transplant Act: Public Law 98-507. October 19, 1984. Available at: [www.gpo.gov/fdsys/pkg/STATUTE-98/pdf/STATUTE-98-Pg2339.pdf](http://www.gpo.gov/fdsys/pkg/STATUTE-98/pdf/STATUTE-98-Pg2339.pdf). Accessed April 21, 2014
24. HRSA UNOS. Policy management/policies. Available at: [http://optn.transplant.hrsa.gov/PoliciesandBylaws2/policies/pdfs/policy\\_9.pdf](http://optn.transplant.hrsa.gov/PoliciesandBylaws2/policies/pdfs/policy_9.pdf). Accessed April 21, 2014
25. Loviglio J. Sarah Murnaghan now has pneumonia in one lung. NBC News. July 8, 2013. Available at: [www.nbcnews.com/health/sarah-murnaghan-now-has-pneumonia-one-lung-6C10570533](http://www.nbcnews.com/health/sarah-murnaghan-now-has-pneumonia-one-lung-6C10570533). Accessed December 11, 2013
26. Alexander S. They decide who lives, who dies. *Life Magazine*. 1962;53:102–125. Available at: <http://ihatedialysis.com/forum/index.php?topic=23860.0>. Accessed November 29, 2013
27. Calabresi G, Bobbitt P. *Tragic Choices*. New York: W.W. Norton; 1978
28. Snyder JJ, Salkowski N, Skeans M, et al. The equitable allocation of deceased donor lungs for transplant in children in the United States. *Am J Transplant*. 2014;14(1): 178–183

**COLLEGE EDUCATIONS PAY OFF:** *As a student, I am constantly reminded of the high cost associated with obtaining a medical degree. I am not alone. For several years, the cost and value of college and professional degrees have been the topic of intense debate. The rising costs of a college education often deter many prospective students unsure whether a college education is really worth the investment. While the concern over cost is well-founded, a new study completed by the Pew Research Center should put some minds at ease.*

*As reported by National Public Radio (Around the Nation: February 11, 2014), the Center used nationally representative data from both a survey of young adults and the Current Population Survey (a monthly U.S. Census Bureau study of multiple generations) in order to assess attitudes regarding higher education and the financial impact of earning a college degree. Study findings indicated that those with a college degree now make about \$17,500 dollars per year in income more than those who do not have a college degree. This increase in income is a part of a widening wage gap particularly between those with the lowest and highest levels of education. Unskilled jobs or those not requiring a college education pay poorly. And, while educational debt can cause mental burdens in addition to financial concerns, 83% of bachelor's degree holders believed their degrees to be a worthwhile investment. So, when the thought of the dollars associated with an education keeps students and their families up at night, it is important to remember the future financial and intellectual payoff.*

*Noted by Leah H. Carr, BS, MS-IV*

## Was Sarah Murnaghan Treated Justly?

Jennifer deSante, Arthur Caplan, Benjamin Hippen, Giulano Testa and John D. Lantos

*Pediatrics* 2014;134;155

DOI: 10.1542/peds.2013-4189 originally published online June 2, 2014;

### Updated Information & Services

including high resolution figures, can be found at:  
<http://pediatrics.aappublications.org/content/134/1/155>

### References

This article cites 7 articles, 1 of which you can access for free at:  
<http://pediatrics.aappublications.org/content/134/1/155#BIBL>

### Subspecialty Collections

This article, along with others on similar topics, appears in the following collection(s):  
**Ethics/Bioethics**  
[http://www.aappublications.org/cgi/collection/ethics:bioethics\\_sub](http://www.aappublications.org/cgi/collection/ethics:bioethics_sub)  
**Surgery**  
[http://www.aappublications.org/cgi/collection/surgery\\_sub](http://www.aappublications.org/cgi/collection/surgery_sub)  
**Transplantation**  
[http://www.aappublications.org/cgi/collection/transplantation\\_sub](http://www.aappublications.org/cgi/collection/transplantation_sub)

### Permissions & Licensing

Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:  
<http://www.aappublications.org/site/misc/Permissions.xhtml>

### Reprints

Information about ordering reprints can be found online:  
<http://www.aappublications.org/site/misc/reprints.xhtml>

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



# PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## **Was Sarah Murnaghan Treated Justly?**

Jennifer deSante, Arthur Caplan, Benjamin Hippen, Giulano Testa and John D. Lantos

*Pediatrics* 2014;134;155

DOI: 10.1542/peds.2013-4189 originally published online June 2, 2014;

The online version of this article, along with updated information and services, is located on the World Wide Web at:

<http://pediatrics.aappublications.org/content/134/1/155>

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2014 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

