

PATRICK MEEHAN
7TH DISTRICT, PENNSYLVANIA



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MARITIME TRANSPORTATION

June 3, 2013

Secretary Kathleen Sebelius
U.S. Department of Health and Human Services
Hubert Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Dear Secretary Sebelius,

Thank you for directing Dr. John Roberts, President of the Organ Procurement and Transplantation Network (OPTN) Board of Directors to consider age classification and the qualification of pediatric patients under 12 years of age as transplant candidates from older donors. I am grateful that you shared his response with me and your follow-up letter dated May 31, 2013 asking Dr. Roberts to initiate a process to review the OPTN lung allocation process as soon as possible.

As a former U.S. Attorney, it had been part of my responsibility to interpret and defend federal statutes and regulations. After considerable review of the facts of the case of 10 year old Sarah Murnaghan, the legal authorities governing organ procurement and transplantation, the policies of OPTN and related entities and the powers vested in you and the OPTN Board, I am of the opinion there is a basis for a resolution. I believe Sarah may be appropriately considered for adult or adolescent lungs without upsetting precedent or violating the consistency of allocation policy.

I have solicited the views of certain medical and legal practitioners in the transplant area which have helped shape the following observations. I hope that you share the conclusions above and that you will utilize the authority inherent in your position to allow Sarah to be fairly placed among the multiple candidates seeking new lungs.

OPTN is tasked under statute with assisting in the nationwide distribution of organs "equitably" among transplant patients. The inequity in the treatment of Sarah relates to her classification by age. While the Lung Allocation Score (LAS) for adults and adolescents is based on medical evidence, Dr. Roberts' letter confirms that the applicability of LAS criterion for younger children is "unknown" largely due to the very few number of pre-adolescent patients. Sarah is disadvantaged because of her arbitrary assignment to a class. Because the classification is arbitrary it is discriminatory and therefore an injustice to Sarah.

Age-related criteria is a predictor of her survivability after transplant. The highly skilled transplant team at Children's Hospital of Philadelphia has confidence in her survivability as

evidenced by their own appeals to OPTN, which were denied. As Dr. Roberts explains, the specific emphasis in developing LAS scores is to base organ allocation on a balanced “net-benefit” concept. Under the two critical criteria - need and survivability - Sarah’s circumstances, if balanced, would likely make her a top candidate for available lungs. Her age is not a disqualifying factor as there is recognition of the ability to conform an adult lung to Sarah’s chest cavity.

I am grateful for your direction to Dr. Roberts and the OPTN Board to reconsider policy as it relates to a pre-adolescent like Sarah. It affirms what I have heard from various experts, that there are legitimate questions raised. I share your determination this review be done in a transparent and timely, though systematic way. The great concern is that any policy reviews will take time that Sarah does not have.

I have reviewed a legal analysis which concludes that you are empowered to direct OPTN, or another appropriate entity, to disregard Sarah’s age as a disqualifying factor and to rectify this discriminatory inequity. I urge you to do so. In the alternative, there is a sound basis for the OPTN Board to issue a variance for Sarah to the current policy that would explore ways to improve organ allocation while you await a final decision on changes that will be proposed. I believe that analysis has been shared with you and it conforms to research and advice I have sought.

I encourage you to use these powers with the appreciation that doing so will not upset policy consistency. An inherently discriminatory policy, even one so narrow in scope, cannot be allowed to stand during the period in which a deliberative process is undertaken to correct it. In light of the few numbers of similarly situated patients as Sarah, it will not cause a flurry of subsequent similar petitions. Moreover, while it is sometimes suggested that Sarah should not be placed into the line in a manner that displaces another candidate, I argue that such reasoning is faulty. Sarah is not asking to be placed ahead of another, but rather she is petitioning for the ability to compete for equitable treatment based on sound medical judgment and that she be accorded her appropriate place in line. Her need and survivability are the critical factors. She is nearly 11 years old. If she was 12 this wouldn’t be an issue. This is a sensitive and emotionally charged issue, to be sure, but these appeals are grounded in reason and in law.

I hope that, in the future, this sad matter can lead more people to understand how they can become organ donors. I stand ready to work with you in Congress to explore ways to increase awareness. I simply hope that Sarah will be there standing beside us as a living example of the difference an organ donation can make. I ask you to act expeditiously.

Sincerely,

A handwritten signature in blue ink, appearing to read "Patrick Meehan", with a long horizontal flourish extending to the right.

Patrick Meehan
Member of Congress