

PATRICK MEEHAN  
7TH DISTRICT, PENNSYLVANIA



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**Congress of the United States**  
**House of Representatives**  
Washington, DC 20515-3807

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May 28, 2013

The Honorable Kathleen Sebelius  
Secretary  
Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Dear Madam Secretary:

I am writing to bring to your urgent attention the suffering of a 10-year-old constituent named Sarah Murnaghan and the refusal of the Organ Procurement and Transplantation Network to permit her to receive an adult donor lung.

Sarah suffers from Cystic Fibrosis, and her family and physicians at the Children's Hospital of Philadelphia believe she has only a short time before she succumbs to this disease. She has been placed on the Philadelphia region lung transplant list and would be the first in line for lungs from a donor under 12 years old.

As you are aware, in 1984 Congress passed a law (42 U.S.C. 274) directing the Secretary of Health and Human Services to establish the Organ Procurement and Transplantation Network to coordinate the donation of organs to patients in need. Yet in this case, the OPTN Lung Review Board will not approve Sarah for receipt of an adult lung because she has not reached 12 years of age. Under its rules, adult patients with a less critical current condition would be approved for another adult lung before Sarah. The unfairness of the rules is compounded by the fact that so many more adult lungs are available than lungs from donors under 12 – last year 1,500 adult lungs were donated compared to just 20 from children under 12 years old.

Since as Secretary you are directed by federal law to establish and fund OPTN, and two HHS officials serve as ex officio members of the OPTN Board of Directors, I am requesting that you convene an immediate meeting of the Board or its Executive Committee to address this tragic unfairness and act to give Sarah a chance at life and an adult lung from the next available donor. Sarah's young life literally hangs in the balance.

Sincerely,

Patrick Meehan  
Member of Congress