

Congress of the United States
Washington, DC 20510

June 3, 2013

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

Dear Secretary Sebelius,

We appreciate your continued engagement regarding the circumstances surrounding 10-year-old Sarah Murnaghan. Attorneys for Sarah have sent you a detailed legal opinion outlining our point which is that you have the ability and the authority to intervene to allow for Sarah and other children under the age of 12 to become eligible for adult organs.

This is permissible for two reasons. First, you have the ability to set aside the under-12 policy on an emergency basis according to Section 121.4(d) of the organ donation regulations:

Policies or practices that are subject of critical comments remain in effect during the Secretary's review, unless the Secretary directs otherwise based on possible risk to the health of patients or public safety.

Second, we believe the regulations allow for you to direct OPTN (Organ Procurement and Transplantation Network) to conduct an experimental variance under Section 121.8(g). In Dr. John Roberts's response to your request for additional information regarding organ donation policy, he indicated that medical literature suggests that such pediatric lung transplants have comparable outcomes but small sample sizes. An experimental variance in Sarah's case could help better inform the medical community's understanding of how these transplants work in pediatric settings.

We do not have much time to wait. We respectfully request a meeting as soon as possible to discuss your response to this urgent matter. Thank you for your consideration.

Sincerely,



Pat Toomey
U.S. Senator



Patrick Meehan
Member of Congress