Congress of the United States
Washington, DC 20510

September 8, 2014

The Honorable Sylvia Mathews Burwell
Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Burwell:

We write to express our continued concern regarding current policies governing blood, organ, and tissue donation by men who have sex with men (MSM) and to bring your attention to an incident in Iowa that highlights the inherent unfairness and inconsistency in the content and application of these policies.

Recently, the Washington Post reported the tragic story of a gay teenager, Alexander "AJ" Betts, Jr., who took his own life in July 2013 after experiencing months of bullying. Prior to his death, AJ decided he wanted to be an organ donor and his mother, Sheryl Moore, received some comfort from the fact that his heart, liver, lungs, and kidneys helped to save other lives, including that of another teenager. However, the tragedy of Alexander's death was highlighted once again in recent weeks when AJ's mother received notice from a donor network that his eyes had been rejected for donation based on the FDA's five-year deferral of MSM tissue donors. Because Ms. Moore could not confirm that her teenage son had not been sexually active for the past five years, this final anatomical gift was summarily rejected.

As you know, FDA policy currently defers MSM blood donors for life and MSM tissue donors for five years, put in place during a time when there were not accurate screening tests for HIV and other transfusion- and transplantation-transmissible diseases. Federal law, Organ Procurement and Transplantation Network (OPTN) policy, and Public Health Service (PHS) guidelines together govern MSM organ donation; however there is no mandatory MSM deferral because all organ donors, living or dead, are tested for HIV infection. OPTN policy and PHS guidelines require notification to transplant programs receiving organs from a deceased male donor that he may have had sex with another man in the past year (based on behavioral history obtained from someone who knew the donor).

AJ's story is a particularly poignant example of the harms of our policies governing blood, tissue, and organ donation by MSM. As noted in the Washington Post story, AJ's major organs were successfully donated to multiple donors, and consistent with federal law and policy, AJ was tested for HIV before such donations occurred. However, FDA's tissue donation policy nonetheless barred donation of AJ's eyes because his mother was unable to sufficiently answer the behavioral screening questions.

These policies are inconsistent and fail to reflect the advances in HIV detection and the scientific community's understanding of the virus since the policy was first established. Furthermore, these policies continue to perpetuate inaccurate stereotypes, promote discrimination, and discourage individuals from seeking other appropriate health services. We appreciate the efforts of the Department of Health and Human Services to review the blood donation policy, which, as you know, the Advisory Committee on Blood and Tissue Safety and Availability concluded more than four years ago was "suboptimal" and should be changed. It is time that the agency took action, and we encourage such action to also address the deficiencies of the tissue donation policy.

As many of us wrote to Secretary Sebelius a year ago, we are committed to ending the outdated blood donation policy and moving forward with securing the nation's blood supply in a scientifically sound manner. In her response last September, the Secretary indicated that the Department anticipates concluding its internal review for a policy recommendation regarding the blood donation ban "by late 2014," a timeline which you reiterated in your response to questions from your HELP Committee confirmation hearing. We anxiously await that policy change and urge the Department to adopt a risk-based policy for all donors, as supported by the medical community.

AJ's story clearly demonstrates that these outdated policies have real-life consequences, turning away much-needed donations of healthy blood and tissue, even when we face serious shortages. His life ended far too soon, after he faced inexcusable torment simply because of who he was. Yet he made the selfless decision before his death to be an organ donor. Our current policies have failed to respect his dignity as a young, gay man and have wasted the gift of sight that might have helped someone else.

We urge you to develop blood, organ, and tissue donation policies that are consistent, based in current science, and designed to ensure all healthy donors can follow AJ's compassionate example. We also request that you provide us with a written update within 30 days on the following:

(1) The Department's progress in reassessing the policy on blood and tissue donations from MSM;
(2) An estimation of when recommendations for policy changes will be announced publicly and when these changes will take effect; and
(3) What steps are being considered to make the adjustment of the blood and tissue deferral policies possible, such as changes in donor screening protocols or surveillance of donors and recipients?

Thank you for your attention to this important matter and we look forward to a timely response to our request.

Sincerely,

Tammy Baldwin
United States Senator

Tom Harkin
United States Senator

Mike Quigley
Member of Congress

Elizabeth Warren
United States Senator

Christopher A. Coons
United States Senator

Edward J. Markey
United States Senator

Richard Blumenthal
United States Senator

Bernard Sanders
United States Senator

Sheldon Whitehouse
United States Senator

Dianne Feinstein
United States Senator

Patty Murray
United States Senator

Michael F. Bennet
United States Senator

Kirsten Gillibrand
United States Senator

Patrick J. Leahy
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Mazie K. Hirono
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Charles E. Schumer
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James P. McGovern
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Brad Schneider
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Frederica Wilson
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