

Meeting Summary and Takeaways

January 16, 2015

Our meeting with HRSA was a very promising first step for our engagement with them. Several of our Coalition meeting attendees had decades of experience working at federal agencies (including Labor, Homeland Security, and the Center for Medicare and Medicaid Services). While all Coalition meeting attendees were excited by the meeting and thought it went well, the attendees with the most federal experience were the most enthusiastic about how we demonstrated strong community engagement in a friendly, collaborative, yet firm way.

HRSA was open to policies to promote living donation and expressed that both the grant policies and the Annual Performance reports were under reconsideration. Bob Walsh, the Director of the Division of Transplantation, emphasized that he had not been involved with the previous decision to exclude living donation from HRSA grantmaking. He also said that he had no opposition in principle to including living donation metrics on the 2016 Annual Performance Report.

The general scarcity of HRSA funding was emphasized. Jim Bowman, the Medical Director of the Division of Transplantation, said he believed living donation was more profitable for transplant centers. Thus, transplant centers could be more relied on to invest in promoting living donation, and HRSA's money could be spent elsewhere. Chris McLaughlin, Chief of the Operations and Analysis Branch in the Division of Transplantation, expressed concern with metrics to increase living donation given the personal nature of the donation decision. HRSA expressed strong support for transplant education efforts, particularly of the public and patients on dialysis.

We asked for a public meeting, which Walsh plans to explore in the weeks ahead. As we anticipated, HRSA counter-proposed with having the Advisory Committee on Transplantation consider this. We were against this proposal because (1) ACOT did not meet at all in 2014; (2) several ACOT recommendations have not been acted on; and (3) a couple ACOT members expressed to us that ACOT would be an inappropriate venue. Our best prediction is that we will ultimately be able to set a non-public stakeholder meeting for some time before May 2015.

We plan on sending a set of materials responding to HRSA concerns to Walsh on February 9th, 2014. It is crucial to demonstrate sustained support and engagement with the issue, so we will continue with our plans for outreach to new coalition members, Congress, and the media. We will also continue demonstrating support through social media and by individual letters of support.