

SRC-PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

November 22, 2024, 11:00 AM – 12:30 PM CST

Voting Members:

Teresa Barnes
Robert Goodman
Joseph Hillenburg
Stephanie Mullet
Marcus Simon
Teresa Wasserstrom

Ex-Officio Members:

Earnest Davis, PhD (Co-chair)
Shannon Dunne, JD (HRSA)

SRTR Staff

Tonya Eberhard
Allyson Hart, MD, MS
Amy Ketterer
Mona Shater, MA
Jon Snyder, PhD, MS

Welcome and opening remarks

Dr. Earnest Davis called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. He introduced himself as the new SRTR Senior Staff for Patient and Family Affairs, the PFAS co-chair, and a living donor kidney transplant recipient. He reviewed the agenda, and the subcommittee proceeded to the next item.

Membership updates

Dr. Davis said that Ameen Tabatabai resigned his position as PFAS co-chair, which leaves the role open. Ms. Morgan Reid is also stepping down due to other commitments. The new PFAS members start January 2025: Mr. Matthew Greenberg, Ms. Morgan Lorenz, Dr. Akshai Patel, and Mr. Calvin Henry.

SRTR update: 2025 Task 5 consensus conference

Dr. Jon Snyder said that in 2022, SRTR hosted a patient-focused consensus conference for patients and professionals to discuss what types of data and information SRTR could be making available. There were approximately 200 people who attended, with about 25% being patients. The meeting report was published in the *American Journal of Transplantation* (AJT). Dr. Davis also mentioned another patient paper he and others wrote following the consensus conference, "The Power of Patient Engagement: Including Patients in Medical Conferences and Health Care Policy Deliberations," which should be available online in February 2025.

SRTR had been in the planning phase of a follow-up conference scheduled for April 2025, which was to be a 3 half-day, web-hosted conference. The Health Resources and Services Administration (HRSA) informed SRTR on October 15, 2024, that the conference needed to be put on hold due to HRSA's focus on the Organ Procurement and Transplantation Network (OPTN) modernization efforts. The following day, at the SRTR Review Committee (SRC) meeting at HRSA headquarters in Rockville, MD, HRSA said they were open to considering an abbreviated webinar. SRTR was

subsequently notified following the SRC meeting that HRSA would allow for a 1-hour update webinar. PFAS members discussed that it was important to find ways to engage with patients and get patient feedback, and Mr. Joseph Hillenburg said that the American Society of Transplantation (AST) is planning to have a patient and family day at the World Transplant Congress in San Francisco.

Dr. Snyder also mentioned that SRTR has the opportunity give HRSA suggestions on what to build into the scope of SRTR's work every 5 years. He suggested continuing to make suggestions to HRSA to incorporate patient engagement and patient resources into the contract, as HRSA has been willing to take feedback from the SRC and its subcommittees.

Standing meeting scheduling

Dr. Davis asked members if they preferred standard meetings quarterly every 3 months on the third Tuesday or first Monday, as opposed to taking a poll for every meeting. Mr. Robert Goodman, Ms. Teresa Wasserstrom, and Ms. Amy Ketterer agreed on this method. Dr. Davis said a poll will be sent out to determine a time everyone could meet for the quarterly meeting, following the January 2025 meeting.

PFAS visioning

Dr. Davis discussed creating a vision for PFAS through a charter that contains mission, vision, and values statements saying what PFAS is and its roles and duties. Having such a charter would help with bidirectional communication by bringing in voices from other parts of the patient and donor family community within transplantation. It would also help determine what deliverables PFAS wants to accomplish in the future. He invited members to consider what the PFAS vision should entail, and meet prior to January 31, 2025, to bring these ideas to the next SRC meeting. Comments from HRSA and the SRC will be considered when ratifying the PFAS charter.

Members discussed the importance of representation in PFAS, particularly for deceased donor family members. Dr. Allyson Hart said PFAS currently has no members representing deceased donor family members, as the subcommittee is in a transition period right now. She mentioned there is the Living Donor Collective's steering committee to gather input from living donors, and PFAS has tried to strike a balance between diverse representation from the perspective of organ system and donor, recipient, caregiver, and deceased donor family representation. Dr. Davis said they have considered regional, age, and organ diversity in attempting to bring in different backgrounds. Mr. Hillenburg emphasized the importance of feedback from the deceased donor community. Dr. Hart said the current charter does not state that members cannot be added off cycle. Dr. Snyder recommended editing the charter to include that vacancies are filled as they occur while maintaining the open call for nominees at the end of each year.

Dr. Davis said PFAS needs to establish values, and understand who is the customer of its work, such as patients and patient organizations only, or including providers and other groups as well. Once a consumer profile is established, the next step is determining how to reach them and how to collaborate and garner feedback from them.

Mr. Hillenburg said it was important to have a clear definition of "customer." And, to be clear that SRTR's goal is to serve patients directly or indirectly. Dr. Davis said he believed that the customer is

SRTR, and that he is referring to consumers. Whatever PFAS does is done to advance SRTR's ability to engender patient and family values and viewpoints. Dr. Snyder added that SRTR has many customers: HRSA, analytic support to the OPTN in policymaking committees, the applicant board of directors, and other federal agencies. Task 5 focuses on engaging with patients, families, donors, and donor family members. Dr. Snyder said a part of the process was being clear about what SRTR is doing for whom, and trying to meet these needs. Ms. Ketterer said that patients are the target audience.

Dr. Davis said a central part of this discussion was considering what gets put into the rebid of the SRTR contract for HRSA, and how to provide feedback on what is going on with SRTR. He asked members to brainstorm ideas for the charter, considering the purpose around strategies and system activities, and have these ideas prepared for the next meeting. Ms. Ketterer would send out a reminder to keep members on task.

Closing business

Ms. Shannon Dunne thanked the subcommittee on behalf of HRSA. Dr. Davis said PFAS will be looking for another PFAS co-chair. With no other business being heard, the meeting concluded. The next meeting date is to be determined.