SRC – PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

April 17, 2025; 1:00 PM – 2:30 PM CDT

Voting Members:
Joseph Hillenburg ('26) (Co-chair)
Teresa Barnes ('25)
Teresa (Wasserstrom) Forney ('26)
Robert Goodman ('26)
Alin Gragossian, DO, MPH ('26)
Matthew Greenberg ('27)
Calvin Henry ('27)
Morgan Lorenz ('27)
Stephanie Mullett ('25)
Akshai Patel, RPh ('27)
Marcus Simon ('26)

Not in Attendance:
Aissatou Sidime-Blanton, CFP, CLU

Ex-Officio:
Earnest Davis, PhD, MHSA (SRTR staff co-chair)
Shannon Dunne, JD (HRSA)

HRSA:
Arjun Naik

SRTR Staff:
Avery Cook, MSW, MPH
Tonya Eberhard
Allyson Hart, MD, MS
Amy Ketterer
Sydney Kletter Sharma
Mona Shater, MA
Jon Snyder, PhD, MS

Welcome and opening remarks

Dr. Earnest Davis called the Patient and Family Affairs Subcommittee (PFAS) of the Scientific Registry of Transplant Recipients (SRTR) Review Committee (SRC) meeting to order. Dr. Davis began by providing an update on a patient who received a pig kidney xenotransplant. He shared that the patient successfully underwent the procedure but had since reported complications that led to the removal of the organ. Dr. Davis explained that he would like to send a get-well-soon card from PFAS, for which no dissent was reported. Dr. Davis noted that since the first-quarter meeting, two members had been added to the PFAS roster: Dr. Alin Gragossian and Ms. Aissatou Sidime-Blanton. Dr. Gragossian introduced herself as a heart transplant recipient and intensive care unit (ICU) physician currently employed by an organ procurement organization (OPO), who would be serving on PFAS through 2026. Dr. Davis introduced Ms. Sidime-Blanton, who was unable to attend, as a living donor and finance professional who would serve on PFAS for the remainder of 2025. Mr. Joseph Hillenburg shared that Dr. Gragossian has a substantial online presence—she operates a blog called *A Change of Heart* and a podcast.

SRTR updates

Dr. Jon Snyder provided an update on the follow-up to the 2022 Task 5 consensus conference, a meeting that focused on patient-friendly SRTR tools and websites; the upcoming 2025 follow-up will now be a condensed 1-hour webinar. He shared that although this follow-up was originally envisioned as a full conference, due to changes within the Health Resources and Services Administration's (HRSA's) Modernization Initiative priorities, the event was reframed to summarize key advancements like the integration of patient-centered website tools and updates aimed at enhancing accessibility for both patients and professionals. Dr. Snyder emphasized ongoing efforts to incorporate patient feedback into SRTR's work, notably through resources such as the new *Patient Pulse* section of the SRTR newsletter, spotlighting patient stories and education.

PFAS updates

Dr. Davis, Dr. Snyder, and Dr. Allyson Hart discussed authorship opportunities, such as a recently published article in *Progress in Transplantation,* which advocated for stronger patient representation in national transplant deliberations. Dr. Davis encouraged members to contribute content to upcoming newsletters and informed them of open opportunities on the Organ Procurement and Transplantation Network (OPTN) Board of Directors, with reassurances that serving on OPTN committees would not conflict with PFAS duties.

Discussion and feedback

Dr. Davis focused most of the meeting on refining the vision and future activities of PFAS. He presented a synthesis of feedback collected through one-on-one conversations with PFAS members following the previous meeting. This feedback was used to develop proposed metrics for evaluating the committee's success. These include monitoring the number of hits on patient-centered tools on the SRTR website, gauging the volume of calls to the SRTR help line (including possibly using a customer relationship management tool), and conducting user surveys to assess tool usability and effectiveness. The group discussed broader measures of impact, such as increased transplant rates resulting from better patient education and empowerment. Additional suggestions included tracking the number of unique transplant centers from which website users accessed tools and the volume of attendees for patient education webinars. Mr. Hillenburg and Ms. Teresa Forney pointed out that measuring raw numbers might not capture true engagement or value. They advocated for more qualitative metrics that reflect how effectively the committee's efforts are reaching and empowering patients. This led to a broader conversation about how to best define and measure meaningful success.

Planned activities to achieve these goals were outlined and discussed. Among these were the continued vetting of new and existing SRTR products and website features by serving as a test group and offering enhancements that would benefit patient/donor/advocate audiences. The group agreed that teaching patients how to navigate the SRTR website to foster independence should be a core priority. This includes developing targeted webinars for diverse audiences: patients, advocates, nurses, dialysis staff, primary care providers, and peer mentors. Additional proposed activities mentioned included creating and regularly contributing to the *Patient Pulse* section of the SRTR newsletter; embedding PFAS members in patient and caregiver communities, both online and in person, to raise awareness of SRTR resources; and recording short testimonial videos from transplant recipients, donors, and families that demonstrate the real-world utility of SRTR tools. There was strong support for PFAS members to represent SRTR at external medical or patient conferences, such as the American Thoracic Society or pediatric transplant meetings, to directly engage with providers and caregivers. These ideas highlighted a desire to extend PFAS' influence beyond a consultative role and move toward more proactive community-facing engagement.

Special attention was given to addressing long-term transplant survivorship and unmet informational needs beyond the point of transplant surgery. Ms. Morgan Lorenz raised a key point about transplant recipients navigating posttransplant life challenges, such as relocating to new regions, seeking pregnancy, or managing insurance. She emphasized the value of tailored data and resources to support these life stages and advocated for SRTR to build out tools that better support patients well beyond their transplant date. In support of this, Dr. Davis referenced the concept of “positive deviance” in suggesting that the group could help identify and analyze the characteristics of patients with exceptional long-term outcomes to derive insights and best practices. Doing so would not only benefit transplant recipients but also help identify where data gaps exist in the system. This would likely require new approaches to collecting and analyzing data, as well as better integration of patient experiences into SRTR’s evaluation framework. Ms. Teresa Barnes proposed partnerships with disease-specific organizations (e.g., the Pulmonary Fibrosis Foundation) that serve patients who may eventually need transplants, and she advocated for transplant education early in the disease journey.

The meeting concluded with the presentation of a draft visioning document that consolidates PFAS’ mission, roles, and future direction. This draft included clarified objectives, definitions of member responsibilities, communication strategies, and the identification of key activities and corresponding metrics. Dr. Davis requested that members review the document in detail following the meeting and provide feedback before its formal adoption. He shared that the ultimate goal is to codify PFAS’ structure and goals in a living document that guides future work and can evolve with changing needs. There was broad consensus that PFAS has matured into a strategic partner for SRTR and HRSA and is well-positioned to shape patient-centered transplant initiatives. Committee members expressed strong enthusiasm to continue amplifying the patient voice, enhancing accessibility of SRTR tools, and expanding community engagement. The committee’s ongoing commitment to patient empowerment, thoughtful data advocacy, and outreach was emphasized as essential to supporting both transplant candidates and transplant recipients at every stage of their journeys.

Closing business

With no other business being heard, Dr. Davis concluded the meeting by thanking everyone for their input. Mr. Goodman echoed the sentiment that the meeting was very productive, and Dr. Snyder expressed his excitement for the future and where PFAS is headed. The next meeting will take place on July 24, 2025, 2:00-3:30 pm CDT.