

SRC – PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

July 24, 2025; 2:00 – 3:30 PM CDT

Voting Members:

Joseph Hillenburg ('26) (Co-chair)
Teresa Barnes ('25)
Teresa (Wasserstrom) Forney ('26)
Robert Goodman ('26)
Matthew Greenberg ('27)
Calvin Henry ('27)
Morgan Lorenz ('27)
Stephanie Mullett ('25)
Aissatou Sidime-Blanton, CFP, CLU ('25)
Marcus Simon ('26)

Ex-Officio:

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

Not in Attendance:

Adriana Alvarez, MS (HRSA)
Brianna Doby, MPH (HRSA)
Emily Graham (HRSA)
Allison Hutchings (HRSA)
Sarah Laskey, PhD (HRSA)

SRTR Staff:

Avery Cook, MSW, MPH
Tonya Eberhard
Allyson Hart, MD, MS
Amy Ketterer
Grace Lyden, PhD
Cory Schaffhausen, PhD
Mona Shater, MA
Jon Snyder, PhD, MS

Not in Attendance:

Alin Gragossian, DO, MPH ('26)
Akshai Patel, RPh ('27)

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 welcomed all attendees, and a brief roll call was taken to ensure quorum. Dr. Davis emphasized the importance of maintaining active participation, especially given the key agenda items involving updates on SRTR initiatives, discussion of PFAS nominations, and finalization of the PFAS charter. Attendees were reminded of the committee's role in amplifying the patient and family perspective in transplant outcomes reporting and decision-making.

SRTR updates

Dr. Jon Snyder provided an in-depth update on SRTR's ongoing Task 5 initiative, originally introduced in 2020 to enhance patient and caregiver engagement. He reviewed the history of the consensus conference held in 2022, where over 100 recommendations were made to improve patient-centered information delivery. Current progress focuses on three major tools, which are nearing launch: (1) the Long-Term Outcomes application, extending transplant survival data reporting to 15 years with interactive patient-specific tailoring; (2) the Personalized Waiting Time Calculator for kidney transplants, which provides individualized timelines with comparison features across transplant centers; and (3) the Multiorgan Explorer, a tool designed to assist patients requiring complex multiorgan transplants by offering detailed data on center experience and outcomes. Dr. Grace Lyden, a biostatistician and co-chair of the Analytical Methods Subcommittee (AMS) of the SRC, supplemented these updates with a detailed walk-through of the Personalized Waiting Time Calculator. She highlighted its functionality in comparing transplant centers

and clarifying factors that influence waiting times, such as blood type, body mass index (BMI), and geographic region. Dr. Snyder emphasized the importance of these tools in advancing transparency and patient autonomy. Dr. Davis shared that SRTR is working to schedule a webinar at which updates on the Task 5 consensus conference from 2022 would be provided, and Ms. Shannon Dunne from the Health Resources and Services Administration (HRSA) confirmed that the webinar would likely take place in early September.

Dr. Lyden presented a topic to PFAS members for their opinions regarding the tier rating system on SRTR's website. She shared a case study involving pediatric heart transplant data inconsistencies, which sparked debate about whether tier ratings should be posted when recent data indicate zero transplants. Ms. Stephanie Mullett and Ms. Morgan Lorenz both expressed concern about potential confusion for patients and caregivers; they emphasized that this precious time may be better spent working with a transplant center that could actually meet a patient's needs. A call was taken to make a vote on removing tier ratings in cases where no transplants were performed in the most recent year, which was motioned by Ms. Aissatou Sidime-Blanton, seconded by Mr. Calvin Henry, and passed unanimously with no abstentions or oppositions.

PFAS updates

Dr. Davis provided an overview of the PFAS nominations process and noted that several applications had been received for both member and co-chair roles, including candidates representing diverse transplant experiences (eg, living donor, deceased donor family member, kidney recipient, dual-organ recipient). Mr. Marcus Simon volunteered to serve as the PFAS representative on the nominations committee. Attendees expressed optimism about the strong applicant pool and discussed the value of maintaining a balanced representation of patient, donor, and caregiver voices. In addition, Dr. Davis presented a list of upcoming transplant-related conferences, such as the Association for Multicultural Affairs in Transplantation (AMAT) conference, the American Society of Nephrology's (ASN's) Kidney Week, and SRTR's Task 5 webinar in September 2025, encouraging members to attend or promote these events within their networks to strengthen patient advocacy and awareness.

PFAS charter discussion

The committee engaged in an extended dialogue on finalizing the PFAS charter, which will serve as the guiding framework for roles, responsibilities, and long-term objectives. Dr. Davis highlighted the purpose of the charter: supporting SRTR and HRSA in providing objective patient-centered reviews, while also broadening outreach to improve awareness of SRTR tools. The discussion centered on three proposed workgroups: (1) Authorship – tasked with writing educational articles and contributions to SRTR newsletters on patient-centered topics; (2) PFAS Advocates – members trained to represent PFAS at patient-facing events, conferences, and community forums, ensuring consistency in messaging; and (3) Awareness – focused on expanding outreach to organizations beyond transplant-specific groups, such as insurance companies and broader patient advocacy organizations.

Emphasis during a significant portion of the discussion was on the importance of a structured PFAS orientation for new members. The proposed orientation will include an overview of SRTR history, PFAS contributions, and hands-on familiarization with SRTR patient tools. Members also suggested segmenting resources by audience (patients, donors, caregivers) to increase accessibility. Mr. Henry advocated for maintaining a historical record of PFAS contributions and discussions to ensure continuity and

institutional memory. The committee agreed to incorporate this tracking system moving forward, as there is not currently a process in place.

Dr. Davis detailed that the governance section of the charter affirmed that PFAS decisions will be made by majority vote, with HRSA retaining veto authority when necessary. Resource allocation was discussed, with recognition that additional initiatives (such as patient-facing outreach campaigns) may require HRSA approval for funding. A motion to adopt the PFAS charter as revised was presented by Ms. Teresa Barnes and seconded by Ms. Teresa Forney. The motion passed unanimously.

Closing business

With no other business being heard, Dr. Davis concluded the meeting by thanking everyone for their input. Ms. Dunne expressed appreciation for the PFAS members' insights and noted the alignment of PFAS priorities with HRSA's broader goals. The next meeting is scheduled for October 23, 2025, at 2:00-3:30 pm Central Time.