

SRC – PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

January 16, 2026; 2:00 PM – 3:30 PM CT

Voting Members:

Sejal Patel, MD ('28) (Co-chair)
Kathleen Anderson ('28)
Sean Eiles ('28)
Joseph Hillenburg ('26)
Robert Goodman ('26)
Matthew Greenberg ('27)
Akshai Patel, RPh ('27)
Marcus Simon ('26)

Ex-Officio:

Earnest Davis, PhD, MHSA (SRTR
Staff Co-chair)
Adriana Alvarez, MS (HRSA)
Sarah Laskey, PhD (HRSA)
Annie Tor (HRSA)

SRTR Staff:

Avery Cook, MSW, MPH
Amy Ketterer
Sydney Sharma
Mona Shater, MA

Not in attendance:

Teresa Forney ('26)
Alin Gragossian, DO, MPH ('26)
Calvin Henry ('27)
Morgan Lorenz ('27)
Aissatou Sidime-Blanton, CFP, CLU ('28)

Not in attendance:

Brianna Doby, MPH (HRSA)
Shannon Dunne, JD (HRSA)
Emily Graham (HRSA)
Allison Hutchings (HRSA)

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. Quorum was met, although Dr. Davis noted that there were no votes to be taken during the meeting. He expressed his excitement about the new members joining the subcommittee and reviewed the conflict-of-interest management guidelines, with Ms. Avery Cook confirming that all members have submitted their conflict-of-interest forms. Dr. Davis reviewed the agenda for the meeting.

Dr. Davis and Mr. Marcus Simon reviewed the work of the nominations committee, with Mr. Simon serving as chair of the PFAS nominations committee. Dr. Davis shared the process for applications to be submitted and reviewed, culminating in an SRC vote to approve members. Dr. Davis detailed that 13 applications were received and reviewed, with three members and one co-chair being selected to serve on the subcommittee, based primarily on the needs of the PFAS for 2026 and beyond. Dr. Davis introduced the new members—Ms. Kathleen Anderson, Mr. Sean Eiles, Dr. Sejal Patel, and Ms. Aissatou Sidime-Blanton—then provided a brief background on each and shared what brought them to the subcommittee, including their connection to the transplant space and their pertinent personal or professional background.

SRTR contract update

Dr. Davis reviewed updates on the SRTR contract and shared that Sapient has been added by the Health Resources Services Administration (HRSA) to assist with some IT transition. Dr. Davis and Ms. Mona Shater shared that the current contract extension is in place until March 20, 2026, with potential to extend the contract another 6 months, but that no agreement had been reached between HRSA and SRTR at this time. He explained that the PFAS meetings beyond March 20, 2026, had been scheduled but could potentially be canceled if the contract does not get extended further.

Feedback from Task 5 webinar

Dr. Davis recapped that the Task 5 webinar took place on September 3, 2025. This was a follow-up to the 2022 Consensus Conference, which was held in suburban Minneapolis and focused on initiatives like increasing awareness of SRTR's work. Many recommendations were identified, and the Task 5 webinar served to provide an update on the status of those recommendations being addressed. Dr. Davis noted that there were 42 registrants for the webinar with patient or family ties to SRTR. They accounted for 12% of the attendees and, more specifically, were recipients (22), caregivers (12), living donors (6), and other (2). Most webinar attendees (78%) were representatives from transplant centers, including coordinators, physicians and nurses, and organ procurement organization (OPO) professionals. Dr. Davis segued into a discussion about the representation of patients during the webinar and discussed brainstorming efforts to increase patient and family awareness of SRTR's work; he highlighted the desire to increase awareness prior to transplant and the work to be done to accomplish those goals.

Dr. Davis emphasized that there were no patients who were currently on the waiting list represented at the webinar and asked the group to suggest initiatives to target that population. Mr. Eiles, a new member who was a donor to his adopted daughter, reviewed his family's introduction to the transplant process and awareness of SRTR and their work. He shared that his family worked closely with their transplant center and transplant administrators, but that there seems to be a disconnect between the information being received by transplant centers and their staff and dissemination to patients. He suggested highlighting earlier awareness and working with transplant centers to share the work SRTR does prior to patients' receiving a transplant. Mr. Robert Goodman emphasized that the information would need to be shared by transplant centers rather than OPOs, as they have the most patient contact and can point patients in SRTR's direction. Dr. Davis said that a few of the tools developed by SRTR include information on how to choose the best transplant center for each patient's needs and suggested targeting patients earlier in the transplant process to help introduce these tools to provide further support. Dr. Sejal Patel suggested outreach through social media and newsletters to increase awareness, as well as attendance at support groups as suggested by transplant centers. Ms. Shater highlighted the upcoming unification of the patient-friendly preview site and SRTR's home page and shared that specific experiences were being created to target patients, caregivers, and donors, but Dr. Davis pointed out that these resources would still require awareness of SRTR's work to navigate to the website. Dr. Davis and Mr. Goodman suggested targeting physicians who work with patients prior to them being referred to transplant centers, such as nephrologists. Mr. Simon suggested working with advocacy groups and social workers that work closely with physicians and patients starting the transplant process and seeking to increase awareness of SRTR's work earlier in the transplant process. Ms. Sarah Laskey, a HRSA representative,

shared that HRSA agrees with the importance of increasing visibility to patients early on in the transplant process to the resources available.

[Dr. Sejal Patel shared in the chat that she would be signing off during this discussion.]

PFAS council/workgroup updates

Dr. Davis reviewed the three workgroups that the subcommittee members had elected to split into for increased work on authorship, advocacy, and awareness. Dr. Davis explained that the awareness workgroup would convene and work to increase awareness through upstream measures. He shared the aims of each workgroup and that Ms. Cook would be reaching out to schedule meeting times to discuss strategies and initiatives.

Previous work with HCDS

Dr. Davis reviewed the work done in collaboration with the SRC Human-Centered Design Subcommittee (HCDS) and the small-group sessions done to review and suggest changes to projects within the patient-friendly website. Six projects have been reviewed and with input provided—the most recent being tier icons to gauge transplant center metrics, moving from a five-bar visual system to a speedometer visual.

Transplant community calendar

Dr. Davis highlighted upcoming transplant activities within the next 3 months, including conferences across the country. He said that there was no expectation of attendance at these meetings but that he wanted to share this information in case any members wanted to attend a meeting being held locally. He reviewed that, at this time, HRSA is unable to financially support conference attendance, but conference organizers may have opportunities for patient and family scholarships. He noted that several conferences are targeted toward professionals, so they may be higher level than patients and family are used to. He also shared the list of upcoming Organ Procurement and Transplantation Network (OPTN) regional meetings, which are being held virtually, and encouraged attendance to learn of local changes in transplant policy and processes.

Closing business

With no other business being heard, Dr. Davis concluded the meeting by thanking everyone for their input. He said that he and Ms. Cook would be reaching out in the next week to schedule workgroup meetings. The next PFAS meeting is scheduled for Friday, April 17, 2026, at 2:00 PM CT, but may be adjusted or canceled depending on the SRTR contract.