

# SRC-PFAS Meeting Minutes

## Patient and Family Affairs Subcommittee Teleconference

September 3, 2024, 12:00 PM – 1:30 PM CDT

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**Voting Members:**

Teresa Barnes, lung recipient family member  
Stephanie Mullet, pediatric liver family member  
Marcus Simon, kidney recipient  
Joseph Hillenburg, parent of pediatric heart recipient  
Robert Goodman, heart recipient  
Morgan Reid, kidney recipient

**Not in Attendance:**

Teresa Wasserstrom, family member of lung recipient  
Ameen Tabatabai, liver recipient (Co-chair)  
Earnest Davis, PhD (soon to be Co-chair)

**Ex-Officio Members:**

Allyson Hart, MD, MS (Co-chair)  
Shannon Dunne, JD (HRSA)

**SRTR Staff**

Jon Snyder, PhD, MS  
Amy Ketterer  
Tonya Eberhard  
Mona Shater, MA  
Cory Schaffhausen, PhD

**Not in Attendance:**

Ryutaro Hirose, MD  
Roslyn Mannon, MD

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**Welcome and opening remarks**

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. She reviewed agenda items and briefly discussed the live patient-friendly website. The Health Resources and Services Administration (HRSA) has not approved additional funding to expedite the website's next phase. Dr. Cory Schaffhausen said planning is underway for the final grant year. There will be a focus on migrating content on the srtr.org site to the new preview website, and addressing recommendations from the 2022 consensus conference (eg, predicted waiting time and outcomes calculators). Dr. Hart asked members to provide any website feedback. Mr. Joseph Hillenburg said some provider organizations felt they were not properly ranked. Dr. Hart added that focusing on center performance portrayal in the website redesign is forthcoming.

The subcommittee proceeded to the next item.

**Welcome: Earnest Davis SRTR Senior Staff for Patient and Family Affairs**

Dr. Hart introduced Earnest Davis, PhD, MHSA, as the new PFAS Co-chair (replacing Dr. Hart). Dr. Davis is a kidney recipient, President of the Community Psychology Health Collaborative, and a teaching professor at Xavier University. He was a former member of the Organ Procurement and Transplantation Network's (OPTN's) Executive Board. Dr. Davis was unable to attending this PFAS meeting but will bring a lot of experience to this leadership role. Dr. Jon Snyder added that Dr. Davis is taking Dr. Hart's place since she has accepted the new role of SRTR Deputy Director. SRTR is grateful for his willingness to join PFAS.

## Update: Call for nominations for SRTR Review Committee and subcommittees

Dr. Hart said that in 2023, SRTR began its first call-for-nominations process for the SRTR Review Committee (SRC) and subcommittees to make membership accessible and transparent. She wanted members to be aware that SRTR is looking for additional PFAS members. Currently, no members are rolling off the subcommittee. SRTR aims to expand the number of PFAS members, creating a diverse community with a balanced representation of different organ types. Ms. Teresa Barnes mentioned she knew a few people interested in applying to the other subcommittees. Dr. Hart encouraged members to spread the word about SRTR's call for nominations.

## Discussion and feedback: SRTR 2025 consensus conference

Dr. Hart gave an overview of Task 5, which the 2022 and 2025 consensus conferences fall under. The SRTR contract is structured as a series of tasks to be completed. Task 5 calls for identifying information of interest to critical audiences that need information to assess organ procurement and transplantation, and to develop assessments and metrics that provide information of interest to critical audiences. Dr. Hart highlighted that patients, donors, and family members were at the center of critical audiences for the 2022 consensus conference.

SRTR did a lot of preparatory work leading up to the 2022 consensus conference to ensure patients felt comfortable participating. It spent the first year of the 5-year contract doing stakeholder engagement with different professional and patient audiences, as well as interviews and focus groups to incorporate and accurately represent patient voices. SRTR also did preparatory work with its steering committee and living donor committee. The steering committees and patients advocated for full integration with patients and professionals instead of separating these groups. SRTR gave patient attendees materials on SRTR, the transplant system, etc, so they came to the conference informed and prepared.

Dr. Hart shared a few publications that resulted from the 2022 consensus conference. These included "Stakeholders' perspectives on transplant metrics: the 2022 Scientific Registry of Transplant Recipients' consensus conference" in the *American Journal of Transplantation*<sup>1</sup>; "You don't know what you don't know": A qualitative study of informational needs of patients, family members, and living donors to inform transplant system metrics" in the journal *Clinical Transplantation*<sup>2</sup>; and "Time to discard the term 'discard' " in the *American Journal of Transplantation*.<sup>3</sup> Dr. Hart noted that the manuscript "The Power of patient engagement: Including patients in medical conferences and health care policy deliberations" is currently under review (at a journal).

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1. Snyder JJ, et al. Stakeholders' perspectives on transplant metrics: The 2022 Scientific Registry of Transplant Recipients' consensus conference. *American Journal of Transplantation*. 2023;23(7):875-890.
  2. Hart A, et al. "You don't know what you don't know": A qualitative study of informational needs of patients, family members, and living donors to inform transplant system metrics. *Clinical Transplantation*. 2024;38(1):e15240.
  3. Hart A, et al. Time to discard the term "discard." *American Journal of Transplantation*. 2023;23(5):608-610.

After the 2022 consensus conference, SRTR took feedback from the event and prioritized its recommendations. Dr. Hart said one of the successes of this conference was SRTR's developing questions, topics, and a culture that treated patients as investors in the transplant system rather than transactional customers.

### **Background: 2022 versus 2025 consensus conferences**

The 2025 consensus conference will serve as a follow-up meeting that will report progress SRTR has made since 2022 and get feedback from attendees on the next steps or topics to focus on. Similar to in 2022, the 2025 conference will focus on the patient voice. While the 2022 conference was a hybrid meeting that lasted 3 days, the 2025 conference will be virtual only and last 3 half-days. SRTR aims to have it take place in April 2025. Dr. Hart asked members what should be done to ensure high engagement from patients.

### **Brainstorming and discussion for 2025 consensus conference**

Mr. Hillenburg said to consider having connections to transplant societies and associations to make sure they are welcome. Marketing and Communications Director Ms. Mona Shater said SRTR has built a contact list over the past 6 months and will be using this information once the conference date is finalized. PFAS patient ambassadors will also help to promote the event.

Dr. Snyder added that a list of all recommendations from the 2022 conference that SRTR accomplished will be available at the 2025 conference, and Dr. Schaffhausen is working to categorize these recommendations. Dr. Schaffhausen said these materials may be in a companion document format on a granular level. There are upwards of 100 recommendations that have had some type of progress. Dr. Hart pointed out that this conference will lean heavily on SRTR presentations explaining what has been accomplished. She asked PFAS members how SRTR can maximize the integration of patients and professionals into this setting, while still giving updates.

Mr. Hillenburg said SRTR could use collaborative tools to make an interactive conference, like certain exercises, break-out groups, and word clouds. Dr. Snyder said SRTR will be using the software platform Mentimeter. Ms. Barnes suggested break-out sessions, with each group summarizing their discussion afterwards. Ms. Morgan Reid proposed using the conference to extend the voice of patients to different initiatives happening on the federal level. HRSA, the Centers for Medicare & Medicaid Services (CMS), and the Center for Medicare and Medicaid Innovation (CMMI) could attend to engage directly with the patients, and for patients to see how government agencies work together in the transplant system. Ms. Shannon Dunne from HRSA said HRSA is trying to work more with CMS to focus on patient and family voices. She plans to see if the Organ Transplantation Affinity Group (OTAG) can also be part of the conversation, albeit there are some topics in government agencies that cannot be discussed with the public. Ms. Reid recognized this, but acknowledged patients are often left out of discussion with these agencies and should be included when possible.

Dr. Hart brought up agenda planning, such as including preparatory materials for patients (eg, webinar, informational video), and a progress summary for the recommendations. Dr. Schaffhausen added that SRTR plans to invite speakers from outside initiatives, as there are some 2022 recommendations that map onto an external group's work. For example, there is patient-focused information around CMS's Increasing Organ Transplant Access (IOTA) model.

Mr. Hillenburg added that it is important to positively encourage new patient voices to speak up. Ms. Barnes suggested having patients and/or patient advocates moderating parts of the conference. Mr. Robert Goodman said people may find break-out groups less intimidating, so it is important that these comments are voiced by the group representative; but encouraging others to talk is the best action.

Dr. Hart said the April conference dates are pending HRSA approval. Mr. Hillenburg said that the last week of April has several overlapping conferences, especially the pediatrics. Members provided potential conflicting dates: National Kidney Foundation (NKF) spring clinicals April 10-13, Starzl April 29-30, and Transplant Families April 25.

### **Closing business**

Ms. Dunne thanked the subcommittee on behalf of HRSA. With no other business being heard, the meeting concluded. The next meeting date is to be determined.