SRC – PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

January 16, 2025; 1:00 PM – 2:30 PM CST

Voting Members:	**Ex-Officio:**	**SRTR Staff:**
Joseph Hillenburg ('26) (Co-Chair)	Earnest Davis, PhD, MHSA (SRTR staff Co-chair)	Avery Cook. MPH, MSW
Teresa Barnes ('25)	Shannon Dunne, JD (HRSA)	Tonya Eberhard
Calvin Henry ('27)	**Not in attendance:**	Amy Ketterer
Robert Goodman ('26)	Adrianna Alvarez, MS	Sydney Kletter
Matthew Greenberg ('27)		Mona Shater, MA
Morgan Lorenz ('27)		Jon Snyder, PhD, MS
Stephanie Mullett ('25)		**Not in attendance:**
Akshai Patel, PharmD ('27)		Allyson Hart, MD, MS
Not in attendance:		Ryutaro Hirose, MD
Marcus Simon ('26)		Roslyn Mannon, MD, FASN
Teresa Wasserstrom ('26)		

Welcome and opening remarks

Dr. Earnest Davis called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. Dr. Davis noted that there were several new members joining the roster in 2025 and asked that members go around and share who they are, where they are, and what connected them to transplantation. The new members shared first:

- Mr. Matt Greenberg is a 15-year heart transplant recipient living in Miami, Florida, and is followed by Cleveland Clinic Florida; he noted that he works for United Healthcare so has had experience both as a patient and payer.
- Dr. Akshai Patel is a 5-year lung transplant recipient living in central California and is followed by UCSF; he works as a pharmacist and noted that he tried to join the PFAS team several years ago but ultimately had to drop out due to health complications.
- Ms. Morgan Lorenz is a 24-year liver transplant recipient who has recently relocated to Maryland from San Francisco; she works in health policy and reimbursement in the medical device industry and attends graduate school at UCSF for Health Policy.
- Mr. Calvin Henry is a 12-year double lung transplant recipient living in Georgia; he works as a consultant for process improvement and is involved with the Transplant Games, for which he won gold in ballroom dancing.

The existing members shared their backgrounds as well:

- Ms. Teresa Barnes is the daughter of a lung transplant recipient and lives in Missouri; she is heavily involved with a pulmonary fibrosis foundation and is a patient advocate.
- Mr. Bob Goodman is a 11-year heart transplant recipient and lives in New Jersey; he worked as a hospital CEO and on the business side of the health care industry; he is

extremely involved in the transplant space, is a board member for the American Heart Association, and has also won gold medals in the Transplant Games.

- Ms. Stephanie Mullett is the mother of a pediatric liver transplant recipient by her spouse (the recipient's father) 6.5 years ago and lives in Colorado.
- Mr. Joseph Hillenburg is the father of a 13-year pediatric heart transplant recipient and lives in Illinois; he is serving as the new PFAS co-chair.

The SRTR staff and Ms. Shannon Dunne from the Health Resources and Services Administration (HRSA) then briefly described their roles. Dr. Davis shared that he is a 7-year kidney transplant recipient and works as a health care professor and consultant. Dr. Davis concluded the opening remarks by reviewing the agenda for the session and outlining topics of discussion.

SRTR updates: 2025 Task 5 plan

Dr. Davis spoke of the previously executed Task 5 2022 Consensus Conference held by SRTR. He shared that there were a number of corporate sponsors who helped facilitate family and patient travel for about 25% of participants, who were happy to be included in the conference and provided a unique perspective. Dr. Jon Snyder shared that following the conference in 2022, a list of over 100 recommendations of tasks to be completed was compiled, most having to do with the patient-friendly website. He stated that there was a consensus conference planned for 2025 to share the goals and status updates over several days, but that this has been pared down to a 1-hour webinar at the request of HRSA. Ms. Dunne shared that the Organ Procurement and Transplantation Network (OPTN) Modernization Initiative efforts have taken priority and the request is to engage what HRSA sees as the most important stakeholders—the patients and families—and provide a way for them to be updated about the goals. Dr. Snyder shared that the goal is to have the webinar sometime in April 2025, which would coincide with Donate Life Month. Mr. Hillenburg expressed concern as there are other transplant events happening in late April, but noted the need for a master calendar and his work with the American Society of Transplantation (AST) towards compiling a master calendar. Mr. Henry expressed the desire to see the list of recommendations at the next meeting, as well as the current status of each recommendation. Dr. Snyder proposed making that list available prior to the next PFAS meeting, in addition to presenting this during the webinar. Mr. Hillenburg questioned the request of HRSA in regards to limiting the webinar to a 1-hour session, when it was previously scheduled as 16 hours. Ms. Dunne shared that the OPTN Modernization efforts are taking priority and HRSA thought 1 hour was a sufficient time to review what had been completed, but she mentioned the possibility for a longer conference to be scheduled in the future.

2025 article publication

Dr. Davis shared that the paper PFAS members wrote following the 2022 Consensus Conference about patient engagement has been accepted and will be published in the March issue of *Progress in Transplantation*. Dr. Davis explained that with the development of the article, SRTR leadership has recognized that PFAS members can provide more than just the feedback of an important stakeholder group, the patients. He detailed the main themes of the article, which include: identify, prepare, and assign defined roles to a cohort of patients that is representative of the patient populations; establish the patient voice as a measure of success, which requires that direct experiences be shared with each topic or agenda item; and develop questions, discussion topics, and a culture that treats patients as investors in the system rather than transactional customers. Dr. Davis shared that he would distribute the article to PFAS members after it is published, as well as future publication opportunities as they arise.

PFAS member replacement

Dr. Davis detailed that due to increased work and life commitments, two PFAS members have left, leaving a gap in diversity and expertise. Dr. Davis shared that Mr. Ameen Tabatabai had a unique experience of undergoing transplant as a pediatric patient, while Ms. Morgan Reid was involved deeply in transplant policy. Dr. Davis explained that membership has been successful in adding four new members to the roster this year, and have a number of people who applied but were unable to be added due to space. With the departure of the two members, he asked how the group would like to find replacements and proposed two options: choosing members off of an existing list of applications, or being more intentional about choosing new members to help bring back some of the diversity that may have been lost. He detailed the need for a diverse group, and shared that the group is a mix of both transplant recipients and family members, from various regions/states, who are from a wide adult age range, and who have diverse ethnic backgrounds.

Mr. Hillenburg articulated that PFAS has a very diverse group but does not have living donors, or family of deceased donors, represented. Mr. Henry added that although kidney transplants make up the majority of transplants in the US, the current roster does not reflect those data, as there is only one kidney transplant recipient and no kidney recipient family members. Dr. Snyder shared that when the PFAS group initially met, there was a family member of a deceased donor on the subcommittee, which provided valuable insights. Dr. Davis reviewed the list of applicants and stated that none of the current applicants were living donors or family members of deceased donors, so further effort would be required if seeking these members for the subcommittee. Mr. Hillenburg and Dr. Snyder discussed the SRTR Living Donor Collective (LDC) and Living Donor Steering Committee, explaining that SRTR has shown effectiveness in reaching and connecting with this population, and they proposed cross-pollination between the groups to bring the requested diversity to the PFAS group. Ms. Avery Cook shared that she currently works with the LDC and would be willing to approach the group to gauge interest. Dr. Davis asked if there was any dissent toward the option of choosing a new member who would help round out the diversity of the subcommittee; he received agreement and no dissent.

PFAS visioning

Dr. Davis reviewed the need for a statement of purpose and charter for the PFAS. He walked through the different portions of the purpose statement provided by the SRTR Review Committee (SRC) and contract, which is “to provide objective review and advice to the SRTR contract activity as it relates to providing information to patients and families.” He opened the discussion by speaking about determination of PFAS’s mission, vision, and values, and asking members to consider what they hope to impact and their reasons behind joining the subcommittee.

Mr. Goodman shared that after receiving his transplant, he determined that giving back to the community was important and decided to join PFAS because he felt he could have the most impact there. Ms. Barnes shared that she was drawn to PFAS after speaking with Ms. Amy Ketterer at SRTR and wanted to help patients and family members regain some of their power and understanding. Mr. Henry shared that he felt “lost” and “uninformed” when it came to finding a transplant center and information about the transplant system, and that he felt called to provide mentorship regarding dissemination of information provided by SRTR. Mr. Greenberg explained that he has a lot of experience with insurance payers and wanted to learn about the perspectives of physicians and other health professionals regarding the transplant space; he articulated being a voice for patients and helping connect patients and providers. Mr. Hillenburg shared that the SRTR data were provided to him when his son was listed on the transplant list, and spoke of the desire for answers to questions he and other families/transplant patients may have. Dr. Davis proposed several terms as “North star” guidance: awareness, accessibility, mentorship, usability, simplicity, and individualization. Dr. Snyder remarked that there is always more work to be done, and it is encouraging to hear about how information and data can be used and disseminated.

Dr. Davis gave several examples of potential roles and duties for PFAS, including patient-focused articles similar to the recent publication in *Progress in Transplantation* and raising awareness of availability of data and information. Dr. Patel proposed increasing marketing of the SRTR website and ensuring that patients who are undergoing transplant evaluation know about it, rather than them having to find the information on their own. He suggested a packet of information or a flyer with pertinent websites that would be useful to patients and families. Mr. Hillenburg shared that patients are given a lot of information when initiating, including a letter from the OPTN when listed on the transplant list. Ms. Barnes added that this information would be useful before being placed on the transplant list, proposed making this available early on in the process, as well as detailing efforts by specific organizations related to educating patients, and suggested partnering with these groups to increase SRTR website awareness. Mr. Goodman considered that health care as an industry is competitive, and hospitals or transplant centers would not be willing to share information that may lead to a patient receiving transplant elsewhere. He expressed skepticism towards the need for evaluation of differing programs and suggested placing that responsibility on the patient rather than the health care system. He mentioned working with organ procurement organizations (OPOs) to increase knowledge and availability of the SRTR website and information provided. Mr. Hillenburg shared the letter that was provided for him and his family when his son was listed for transplant, circling back to his earlier point of referencing the SRTR website in information provided to the patient. Dr. Davis agreed that this would be beneficial, but he noted that oftentimes patients are provided so much information that they begin to feel overloaded and are unable to parse through the amount of information provided to determine what can be useful.

Closing business

Dr. Davis thanked everyone for their input and explained that he would be reaching out to each member individually to continue these conversations. With no other business being heard, the meeting concluded. The next PFAS meeting is scheduled for April 17, 2025, at 1:00 pm CST.