

# SRC-PFAS Meeting Minutes

## Patient and Family Affairs Subcommittee Teleconference

August 30, 2022, 10:00 AM – 11:30 AM CDT

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**Voting Members:**

Richard Knight (Co-chair), kidney recipient  
Dale Rogers, kidney recipient  
Ameen Tabatabai, liver recipient  
David Rodriguez, kidney and liver recipient  
Rolanda Schmidt, PhD, deceased donor family member  
Katie McKee, living kidney donor  
Christopher Yanakos, living liver donor

**Not in Attendance:**

Stephanie Mullet, pediatric liver family member  
Teresa Barnes, lung recipient family member  
Amy Silverstein, heart recipient

**Ex-Officio Members:**

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

**Not in Attendance:**

Adrianna Martinez (HRSA)

**Guests: Not in****Attendance:**

Jennifer Jones  
Heather Hunt

**SRTR Staff**

Ajay Israni, MD, MS  
Jon Snyder, PhD, MS  
Cory Schaffhausen, PhD  
Mona Shater, MS  
Amy Ketterer, SMS  
Tonya Eberhard  
**Not in Attendance:**  
Ryutaro Hirose, MD  
Bert Kasiske, MD

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### Welcome and opening remarks

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. A new member introduced himself:

- Christopher Yanakos: living liver donor; deceased donor family member; Board of Directors, CORE (a western Pennsylvania organ procurement organization [OPO]); member, United Network for Organ Sharing (UNOS) Operations and Safety Committee; member, American Society of Transplant Surgeons (ASTS) Patient Advisory Committee; Board Chair, Surgicorps

Dr. Hart reviewed the agenda and proceeded with the first item.

### Consensus conference debrief

Dr. Hart asked members for feedback on how the conference went. Members thought it went well but that there was room for improvement. Mr. David Rodriguez said there was a need for more patient perspectives, as the conference had more intellectual patients. Mr. Ameen Tabatabai agreed, saying the caregiver, family, and pediatric perspectives were lower than they could have been. Mr. Richard Knight thought some of these issues could have been resolved with more patient engagement input in the final selection of speakers. There were still silos between organizations (eg, transplant, OPOs, dialysis) to overcome to establish better communication, and a tremendous amount of education that must take place for the health care professionals. Mr. Knight had proposed during the conference to do a better job of data sharing, so transplant centers can have access to up-to-date information on patients. He also said people in organizations need to be held accountable if they are not achieving the established metric standards. He emphasized the

importance of education, particularly for patients and health care professionals, on the concept of patient engagement as it is defined from a patient perspective.

Mr. Dale Rogers said from a rural America perspective, the patients who could use it the most do not get much of a voice. He said a lot of information could be gleaned from patients who are really struggling. Mr. Knight suggested, in the future, to have patients lead meetings and be given opportunities to be moderators—a lot can be learned from continued patient and family engagement. Dr. Hart confirmed that patients had been engaged, both in the selection of speakers via their membership on the steering committee and by serving as moderators for the conference breakout groups. Drs. Ajay Israni and Hart reiterated that many professionals were thankful for the patient voice at the conference. Dr. Hart summarized that it was important to keep in mind how to get more patients who are not part of the Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR) committees to participate in future endeavors. Ms. Katie McKee said the conference opened a door to conversation that had not been successfully initiated in the past. Mr. Knight emphasized the appreciation patients had for SRTR in putting in a sincere effort to make the conference possible.

### **People Driven Transplant Metrics: The 2022 SRTR Consensus Conference**

Dr. Hart reviewed conference demographics. The conference was split evenly between virtual and in-person attendance, with most virtual attendees being patients and family members. Of all attendees, 24% were patients, caregivers, donors, family members, and advocates, with 7% having a transplant professional background as well. This group also included living donors and deceased donor family participants. Professionals included transplant providers, surgeons, medical physicians, researchers, OPO professionals, regulators, insurance professionals/payers, and individuals from professional societies, with five former presidents of ASTS attending.

Dr. Hart said preconference preparation for patients and family members consisted of acronym and stakeholder lists, links to SRTR and Task 5 videos, a summary of patient-family focus group findings, the transplant system subway map, and the metrics framework. Data collected from the conference (eg, flipcharts, worksheets, moderator and virtual chat notes) are currently being distilled into a format for publication. Dr. Hart said information important to patients and families was not necessarily monolithic. Some topics included who can and cannot access transplant, who is referred and evaluated and not just who is listed, which candidates like me are listed and undergo transplant, and the ability to compare centers. There was interest in more data on patient-reported outcomes besides 1-year graft failure. Living donors were interested in long-term outcomes on an individual basis—not all donors averaged together. Deceased donor families wanted to know what happened to their loved one's organs, how many lives were saved, and other families' donating experiences. Families were strongly opposed to using the term "discard." Dr. Hart reiterated that all of the information will be distilled to determine what can be worked on, and which organizations to start collaborating with.

Regarding outcomes and manuscripts from the consensus conference, Dr. Hart asked members about strategies for disseminating findings to the public. Mr. Yanakos suggested sending printed materials that include a website link or QR code to transplant centers and OPOs that could be distributed to patients. Mr. Tabatabai suggested having transplant centers include a link to SRTR in their patient resource website pages. SRTR could also use web analytics to track who visited the

SRTR website, and where people are being directed from. Mr. Knight proposed establishing a relationship with dialysis organizations (eg, Visonex, Fresenius, DaVita) by offering centers the opportunity to share their information and insights. Mr. Rogers said not to forget about rural Americans, many of whom do not have internet. Dr. Hart suggested brainstorming with Mr. Rogers in the future on how to reach this demographic group.

### **SRTR website redesign update**

Dr. Cory Schaffhausen went over mock-up concepts for the new srtr.org homepage. He clarified that the website has not been rebuilt yet. Four 90-minute Zoom sessions for patient feedback on the new concepts already took place. The first concept displayed a pop-up window on the homepage as an optional tour. The tour can highlight key buttons and locations, a transplant center search link, and a help button. Dr. Schaffhausen noted a library of explainer videos and a frequently asked questions (FAQs) user guide and glossary may be added. He said he received feedback on modifying labels and making font and images bigger.

Dr. Schaffhausen reviewed the webpage that displayed the option of going to the patient landing page or professional landing page. Feedback included changing the “transplant patients” label to patients, families, and donors for inclusivity. The professional side may center more on statistics and technical displays to inform practices and policies at a center. Similar to professionals, patients will be able to access data, but it will be for helping inform patient decisions. The rest of the page gives an overview of menu options, both patient focused (transplant journey, find a center, guides, FAQs) and professional focused (reports, initiatives). Farther down the page is an interactive organ transplant journey map that contains explanations for each step, and links to view data for easy access. He added that the faces on the website will rotate by day and visit for more diversity.

Dr. Schaffhausen transitioned to the page for patients, families, and donors. Different online service providers are currently being explored for accessibility features (giving the user ability to change font size, contrast, color palettes). The interactive transplant journey map is oriented vertically for easier visibility on a mobile device. The map allows the user to “fade out” certain sections so it is easier to focus on other parts. Feedback suggested separating the living donor and deceased donor portions for easier distinction. Below the map is a section exploring the possibility of including content from partner organizations (eg, UNOS), which could increase engagement, although there is no firm plan in place. Dr. Schaffhausen said UNOS has mentioned it would like to work with SRTR to align their two websites.

Dr. Israni suggested placing the SRTR contact number at the top of the page for prominence. Dr. Hart remarked that usability testing will be done as the website is built out and more of the granular feedback can be addressed later. Dr. Schaffhausen added that the page was intentionally given a minimalistic look as that was preferable. Next, he showed a separate tab that explored the idea of using icons and graphic illustrations. Feedback suggested it might be easier to identify with an icon, although there were positive preferences for specific images too. In addition, there were requests to represent pediatrics or families, meaning it may be easier to customize an image that is created.

Dr. Schaffhausen went over the current mock-up for the professional side. These materials may be used to monitor a transplant center or an OPO, and to compare with other similar centers and OPOs in a region to determine if a center is trending in a certain direction. There are links to centers and

OPO directories, and links to tools professionals may share with patients. Data requests are also available here, and to patients as well via a link on the patient landing page.

**Closing business**

Dr. Israni said SRTR is in the process of getting a renewal for an Agency for Healthcare Research and Quality (AHRQ) R01 grant. Once an exact starting date is known, the ideas AHRQ is willing to fund related to the SRTR website will be presented to the subcommittee. Much of it will focus on creating a tool in Spanish for patients to find centers.

With no other business being heard, the meeting concluded. The next meeting date is to be determined.