

# SRC-PFAS Meeting Minutes

## Patient and Family Affairs Subcommittee Teleconference

December 6, 2022, 11:00 AM – 12:30 PM CST

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**Voting Members:**

Dale Rogers, kidney recipient  
David Rodriguez, kidney and liver recipient  
Rolanda Schmidt, PhD, deceased donor family member  
Katie McKee, living kidney donor  
Christopher Yanakos, living liver donor  
Teresa Barnes, lung recipient family member  
Amy Silverstein, heart recipient  
Stephanie Mullet, pediatric liver family member

**Not in Attendance:**

Richard Knight (Co-chair), kidney recipient  
Ameen Tabatabai, liver recipient

**Ex-Officio Members:**

Allyson Hart, MD, MS (Co-chair)  
Shannon Dunne, JD (HRSA)  
**Not in Attendance:**  
Adriana Martinez (HRSA)

**SRTR Staff**

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

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### Welcome and opening remarks

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. She reviewed the agenda and conflict of interest management, then proceeded with the first item.

### PFAS membership updates

Dr. Hart said Mr. Richard Knight's term will end after December 2022, with Mr. Ameen Tabatabai taking his place as PFAS Co-chair and as a voting member for the Scientific Registry of Transplant Recipients Review Committee (SRC).

### Update on reports from the consensus conference

At the last PFAS meeting, attendees reviewed conference feedback findings, which were distilled into 160 recommendations. Dr. Hart said the next step was to overview and prioritize the recommendations.

Dr. Hart said the consensus conference-related manuscripts were not published yet, with SRTR looking for more dissemination ideas for patients and family members. SRTR was now in stage 3 of implementation, Create and Report, for Task 5. Top priority recommendations from the conference were split into the following levels: 1) data are available, data presentation needs to undergo consideration; 2) data are available but need significant development work to implement; and 3) multiyear projects where SRTR is not involved in the data collection process and needs to partner

with other organizations. The recommendations that follow were under level 1 and/or 2. Dr. Hart also noted that the transplant system map was used to categorize these recommendations.

First, Dr. Hart went over the patient journey line. Recommendations for stop A, Considering Transplant, prioritized providing A.1) personalized predicted waiting times, A.2) survival benefits of transplant versus alternative therapies, and A.4) information on absolute contraindications to transplant (eg, high body mass index). Recommendations for stop B, Seeking a Center, suggested B.1) providing data on which centers are most likely to refer, evaluate, list, and to perform transplant for a patient like me or a loved one. Dr. Ajay Israni remarked that a tool was presented at the consensus conference that informs users which centers perform transplants for patients similar to them.

Recommendations for stop E, Listing, prioritized E.1) providing information about potential for and benefits of listing at multiple centers; E.6) providing data on timing of referral, listing, and the transplant process (eg, time from end-organ failure to referral, time from referral to evaluation, time from evaluation to [active] listing); presenting data with stratification/adjustment for underserved communities; and E.8) providing data on outcomes after listing. Mr. Christopher Yanakos said this topic was of high interest to patients. Ms. Teresa Barnes suggested having a tool that helped with the referral process, or perhaps aiding patients with self-referral. Mr. Dale Rogers asked if SRTR posted where a patient can be listed at multiple centers. Ms. Amy Ketterer said the Communications team was currently working on patient-directed videos correlating to the transplant map that will provide more detailed information to patients.

Recommendations for stop G, Survival on the Waitlist, suggested providing 1) waitlist management tools to help programs manage and understand their waiting list, including data that counter potential risk aversion to list complex patients. Dr. Hart said this point considered what kind of data centers need to understand what offers a patient may consider. Mr. Yanakos was concerned there might be resistance from certain organizations in adopting a tool like this. Dr. Hart thought there was a lot of power in expressing what data patients want and need to see.

Recommendations for stop H, Organ Offer to Patient, proposed providing H.1) predicted survival benefit to accept or decline an offer, H.2) data about the risks/benefits of willingness to accept medically complex donor types, and H.3) estimated time to next offer if declining current offer. Dr. Jon Snyder said many families of deceased donors at the consensus conference were interested in typical use patterns for different types of donors.

Because this recommendation involved probability of the shortest time period, Mr. Yanakos questioned how such a tool could be incorporated. Ms. Amy Silverstein pointed out that many of these recommendations mainly applied to kidney, and that it would be practical to include other organs as well. Dr. Cory Schaffhausen said the goal of this type of information was partly to make sure patients stay informed, understand the higher risk in turning down an offer, and reduce feelings of uncertainty. Mr. Rogers said it was important for doctors, nephrologists, and primary care providers to know this information too. Dr. Snyder added that the United Network for Organ Sharing (UNOS) was currently piloting a predictive tool for clinicians.

Next was stop I, Deceased Donor Transplant, which had recommendations to provide I.1) transplant rates; with considerations including organ-specific, breakout living donor, and overall transplant

rates, include breakdowns by medical urgency status, applying a consistent start time (eg, dialysis start) and I.2) utilization rates of clinically complex donor organs. Recommendations for stop J, Surgical Recovery, suggested J.1) providing data on length of stay. For stop K, Early Survival After Transplant, recommendations prioritized K.1) providing predicted outcomes for a particular patient at that center if they undergo transplant with particular donor and K.2) providing metrics of tailored outcomes relevant to specific organ types beyond graft failure and death. For stop L after transplant, Long-term Survival, it was recommended to prioritize providing L.1) posttransplant graft/patient survival metrics, adult versus pediatric, longer-term outcomes (eg, 10 years)—more important by patient characteristics than center. Mr. Rogers thought that some of these recommendations could not be achieved due to limiting time factors.

Dr. Hart went on to reviewing the deceased donor line. For stop O, Potential Donor, recommendations prioritized O.1) providing timing data for potential deceased donor families (eg, time from brain death declaration to recovery, total process time, milestones). Recommendations for stop Q, Organ Offered to Center, prioritized Q.1) providing data on acceptance and decline patterns by program, stratified by organ quality, organ type, and candidate characteristics and specific information tailored for pediatric candidates. For stop S, Organ Not Used, it was recommended to provide S.1) organ nonuse rates stratified by organ and abdominal/thoracic. Lastly, recommendations for stop T, (deceased) Donor Family Aftercare, prioritized T.1) information on why donated organs were not used.

Mr. Rogers said implementing these changes would be difficult as they could be interpreted in different ways depending on the stakeholder viewpoints. Dr. Hart said this was because SRTR wants to include what all stakeholders see as important. Dr. Snyder emphasized that this meeting was meant to focus on where SRTR should start first. Dr. Israni said implementation may take time but is achievable. Dr. Schaffhausen pointed out that multiple projects would be going on in tandem as opposed to one at a time.

The living donor line included stop W, Living Donor Recovery, where recommendations prioritized W.2) providing data on near-term complication rates. Dr. Hart moved on to prioritized recommendations under level 3, which included recommendations such as providing A.3) measures of posttransplant quality of life and B.3) data on which centers specialize in certain diagnoses and conditions. Mr. David Rodriguez asked if this displayed paired-exchange donation. Dr. Israni said insurance companies tried to compile data on what centers perform which types of transplants, although this attempt was not as successful as hoped. Mr. Rogers mentioned how many times there was too much competition between centers to gather sufficient information for patients.

Dr. Hart reviewed a few more recommendations on the level 3 list, such as providing E.3) data on how many patients were referred and then listed or not, E.4) rates of referrals versus expected rates of referrals, E.7) data on impact of patient-specific factors on likelihood of listing (eg, medical, economic, linguistic, psychiatric, and psychological factors), P.1) customer experience feedback for potential donor families, and Q.2) granular timing data for organ offer process (eg, when centers are made primary on an offer, how long it takes for center to respond, and timing around late declines). Dr. Hart said SRTR would work with the Organ Procurement and Transplantation Network (OPTN) on level 3 tasks.

Dr. Hart said the next steps were to help prioritize these projects. Members would receive a survey after the meeting to prioritize each task accordingly. While the project scope was challenging, members were enthusiastic about the opportunity to help provide patient-friendly information for the general public.

**Closing business**

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