

SRC-PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

June 1, 2022, 11:30 AM – 1:00 PM CDT

Voting Members:

Dale Rogers
Amy Silverstein
Ameen Tabatabai
David Rodriguez
Richard Knight (Co-chair)
Katie McKee

Not in Attendance:

Rolanda Schmidt, PhD

Ex-Officio Members:

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

Guest:

Teresa Barnes
Not in Attendance:
Jennifer Jones
Heather Hunt

SRTR Staff:

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

Welcome and opening remarks

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

- Teresa Barnes, family member of a lung recipient and advocate for lung candidates

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

Update: US transplant metric review (Task 5)

Dr. Hart gave a consensus conference overview. The first day of the conference is a half-day that will focus on the who (stakeholders) and why (need for different metrics). Day two is a full day that will focus on patients and professionals, addressing the what (what information do patients and professionals want and need). Day three is another half day, which will focus on the how (how can this information be obtained).

She moved on to the conference materials, which include a patient informational packet with a list of organization acronyms, a stakeholder list, links to Scientific Registry of Transplant Recipients (SRTR) informational videos, a summary of patient and family focus group findings, common patient questions, and transplant system and metric graphics.

Discussion and feedback: Preconference webinar to prepare patient and family attendees

Dr. Hart said an in-person social event before the conference is not possible but suggested a webinar for patients and families. This webinar could include a high-level overview of SRTR and the

scope of Task 5 (what data should be reported/presented differently, new data collection), the purpose of the consensus conference, etc. Mr. Richard Knight thought the webinar would be a helpful resource before the conference. Mr. Ameen Tabatabai gave a few points: an interactive SRTR website demo ending with a Task 5 overview, a transplant center interactive report review for patient feedback, and a short survey via a link to gather questions and ideas prior to the conference. Ms. Barnes said there should be a visual SRTR overview—what the organization does, why and how it does it, what SRTR offers, and what questions can be answered by the website. Ms. Amy Silverstein agreed visuals would be helpful.

Ms. Silverstein asked how these materials and SRTR data help posttransplant patients, since they already received a transplant. Mr. David Rodriguez said that data were helpful for posttransplant patients relocating to a different area and transplant center. Dr. Hart added it would be helpful to get posttransplant patient feedback on what data could have been helpful. Dr. Jon Snyder said that posttransplant patients are interested in longer-term outcome data, and outcome data about transplant rejection. He said it was important to reconsider what new posttransplant data SRTR could provide. Dr. Ryutaro Hirose added that sometimes posttransplant patients become pretransplant patients again, and data addressing transplant complications, rejection rates, survival outcomes, and quality of life would be beneficial.

Mr. Knight explained that the SRTR website can provide information on all aspects of the transplant journey and for different purposes and audiences, ranging from caregivers to advocacy organizations. Members discussed that data are also essential in advocating for transplant patients. As Dr. Hirose described, data can be used to leverage advocacy groups and advocate for patients and health care at the national, state, and local levels.

Mr. Dale Rogers inquired what percentage of patients partaking in the webinar will be new and experienced, as this affects how the information should be presented. Dr. Hart said ideally it would be a mix, and Mr. Rogers cautioned against new patients getting left behind when it comes to presenting transplant information with a broad audience.

Next, Dr. Cory Schaffhausen went over a few SRTR website highlights for feedback, particularly what elements should be shown to patients for the conference. Prior to, he explained that SRTR's Task 5 and SRTR website redesign projects are going on in parallel, and merging together after the conference. This website reconstruction is looking at different interfaces for patients and professionals. These concepts will be presented to PFAS in about 3 months.

Dr. Schaffhausen said the website has introductory material and guides on how reports are created and how data are used, a list of tools (decision aids, Donation and Transplantation Analytics [DATA]), and infographics. Then, he went over how to search for a transplant center, which consists of using the top header to choose organ type and zip code to search. A summary list of different options within the search radius will appear. Users can change the radius, location, and age group. Summary data available include number of transplants and a few high-level outcomes (how fast patients are getting a transplant and 1-year survival).

Dr. Schaffhausen noted that each transplant center has new interactive reports, including a center's program-specific report (PSR). Individual transplant center pages contain contact information,

sample data, summary tabs for waitlist overview, offer acceptance practices, transplant procedures (who is getting a transplant, center demographic information like age, blood type, body mass index), and transplant outcomes. Other tabs are transplant rates (how quickly patients receive transplant), pretransplant mortality rates (how often patients die waiting), and overall survival from listing (combination of survival while waiting and after transplant). A few of these tabs do not target patient decisions and need revision.

Mr. Knight suggested adding a frequently asked question section, which, when clicked on, would direct users to a specific graphic. Mr. Tabatabai proposed adding a little blurb or a “hover-over” explaining how to use the interactive data. He added that a quicker link to this information in the form of a logo may be better than a hyperlink, and the transplant patient journey graphic may help put into context what data fit into which parts of a transplant journey. Dr. Hart and Ms. Silverstein agreed it was important to highlight what information patients should be aware of that they might be overlooking. Mr. Tabatabai said navigation could be ordered by 1) basic information all patients should know and 2) additional information according to where patients are in the transplant process.

Dr. Schaffhausen reviewed the DATA tool, which encompasses the entire country and how regions compare. Users can view categories such as transplant waiting list, transplant recipients, deceased donor, living donor, and organ types. Within those categories are time trends, plot comparison, survival curves, and maps to compare different color-coded regions. Additional features include viewing new listings, percent listings, transplant rates, blood type, ethnicity, and age. Users can select either regions or the whole country, additional characteristics, and output style. These selections allow users to see different transplant trends, rates, etc.

Ms. Barnes asked if there are information tools to view what centers allow double listing, which centers do not directly compete for organs, or which centers collect data like antibody scores. Regarding specific centers, she asked if there is information on what technology centers have (eg, organ perfusion machines, rehab services pretransplant and posttransplant). Dr. Hart said that information in high demand is not always a part of SRTR data but is and should be acknowledged as important to patients. It also starts a conversation about what data are not collected but should be.

Ms. Silverstein added that it is not SRTR’s job to collect specific kinds of information, however, there are information holes on posttransplant care that should be addressed by other organizations if not SRTR. Dr. Hirose said perhaps the United Network for Organ Sharing (UNOS) should collect more granular data on certain protocols and outcomes. He also said it is important to figure out who should collect what data, and how the data should be disseminated. He added there was a need for SRTR to advise caution to users when interpreting data and jumping to conclusions about centers.

Mr. Knight said it is important to expose and promote these data to patients, so patients can help themselves. He added that at the conference, it will be helpful for more experienced patients to show new patients how data on the SRTR website can answer questions they might have.

Closing business

With no other business being heard, the meeting concluded. The next PFAS meeting is scheduled for September 2022.