

SRC-PFAS Meeting Minutes

Patient and Family Affairs Subcommittee Teleconference

December 7, 2023, 10:00 AM – 11:30 AM CST

Voting Members:

Ameen Tabatabai, liver recipient (Co-chair)
Dale Rogers, kidney recipient
David Rodriguez, kidney and liver recipient
Rolanda Schmidt, PhD, deceased donor family member
Katie McKee, living kidney donor
Teresa Barnes, lung recipient family member
Stephanie Mullet, pediatric liver family member

Not in Attendance:

Christopher Yanakos, living liver donor

Ex-Officio Members:

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

SRTR Staff

Ajay Israni, MD, MS
Jon Snyder, PhD, MS
Amy Ketterer, SMS
Tonya Eberhard
Mona Shater, MA
Cory Schaffhausen, PhD

Not in Attendance

Ryutaro Hirose, MD

Welcome and opening remarks

Dr. Allyson Hart called the Patient and Family Affairs Subcommittee (PFAS) meeting to order. Dr. Hart told members that the new nominating process for PFAS was completed, and she went over the PFAS member transitions in 2024. Ms. Amy Silverstein, who passed away from lung cancer, would have been rotating off the subcommittee. Other members leaving include Mr. Dale Rogers, Mr. David Rodriguez, Dr. Rolanda Schmidt, and Ms. Katie McKee. Dr. Hart said Mr. Christopher Yanakos is also rotating off PFAS due to unforeseen circumstances. New 2024 members include kidney recipient Mr. Marcus Simon; Mr. Joseph Hillenburg, a parent of a pediatric heart recipient; heart recipient Mr. Robert Goodman; Teresa Wasserstrom, a family member of a lung candidate; and kidney recipient Ms. Morgan Reed.

Mr. Ameen Tabatabai spoke about evolving PFAS. Future efforts include expanding representation across organs, age groups, genders, and geographical areas. There is also the plan to increase member numbers into the teens to include diverse voices.

Discussion: Getting the word out about SRTR

Dr. Hart said the remainder of the meeting would focus on brainstorming how to disseminate SRTR information to patients. Ms. Mona Shater, the Marketing and Communications Director for SRTR, went over current efforts SRTR has in place to circulate materials to its stakeholders. Information dissemination methods include internal distribution lists of organ procurement organizations (OPOs) and transplant centers for sending out press releases and announcements, contacts with the United Network for Organ Sharing (UNOS) and news outlets that help spread news and updates, the

SRTR newsletter with nearly 3,000 subscribers (35% open and 10% click-through rates), and SRTR website banners on a 15- and 30-day rotation for relevant announcements. The SRTR website receives 15,000 to 17,000 hits per month.

Also, Ms. Shater said SRTR uses the social media platforms X (formerly known as Twitter), LinkedIn, and YouTube. YouTube houses SRTR live/recorded webinars and educational tutorials, with a shift to majorly educational tutorials/content in the past 3 years, and less focus on live webinars. Three new educational videos have been released recently. LinkedIn includes a mix of announcements, human interest stories, and the latest news. With engagement decreasing on X, SRTR is evaluating other platforms for spreading SRTR content. SRTR also has a 1-800 number and email address for questions or comments. Ms. Shater said that many questions from the frequently-asked-questions (FAQs) sections on the website are taken from questions asked by patients and professionals via email or phone.

SRTR also exhibits a booth at conferences every year, including the Transplant Management Forum (TMF), the American Transplant Congress (ATC), the Association of Organ Procurement Organizations (AOPO), and the Transplant Quality Institute (TQI). Conference presence is very important, as it is a way to engage with other organizations, answer data questions, discuss current SRTR projects, and increase newsletter sign-ups.

Now, SRTR is shifting to a patient focus with the patient-friendly website. Ms. Shater noted SRTR is working with other organizations to avoid duplicative content and provide links to other entities if they have more helpful information.

The subcommittee discussed how to best circulate SRTR information to patient populations. Mr. Rogers emphasized the need to redirect energy to the pretransplant demographic by reaching out to nephrologists, primary care physicians, and dialysis units. Mr. Tabatabai agreed, and suggested focusing on organizations that represent pretransplant conditions. Ms. Teresa Barnes proposed speaking directly to the patients of these organizations on what SRTR has to offer, such as via a Zoom online event.

Mr. Rogers said information travels fast by word of mouth in patient groups, and addressing just one area to get the attention of new patients would help immensely in spreading the word. Mr. Rodriguez said transplant support groups were important to consider. Mr. Tabatabai added it would be helpful to focus on events like the Transplant Games, and additional walks and runs that represent diseases that end up being precursors for transplants. Mr. Rogers said one the best ways to reach new patients was by speaking at weekly or monthly Facebook online events hosted by smaller transplant organizations and support groups. Ms. Shater requested the names of specific entities via email that SRTR could reach out to. Mr. Rogers suggested contacting the American Association of Kidney Patients (AAKP) and the National Kidney Foundation (NKF) asking for more information on smaller patient organizations.

The PFAS meeting attendees discussed media campaign strategies to get information directly to patients instead of going to medical professionals first. Ideas included sending existing SRTR brochures to patient spaces such as dialysis units, and having digital brochures to distribute to patient organizations over social media. Ms. Shater added that the new patient-friendly website will

include a media-kit space where people can download content and share, which can be given to new patient organization connections to share as well. She also said that electronic and print versions of information can be promoted across SRTR social media platforms prior to the launch of the new website. PFAS would be notified so members could help distribute the materials.

Mr. Tabatabai had the idea of using SRTR content to build tiered courses or a journey of learning for patients, professionals, and transplant centers on LinkedIn. Users could take these courses to be certified in SRTR information specific to their role in transplantation. Mr. Tabatabai and Ms. Barnes agreed with the idea of doing a pilot of live Zoom calls discussing certain transplant topics to benefit patients. Ms. Barnes also suggested distributing a prerecorded Zoom video on LinkedIn that gives an overview of SRTR and encourages patient organizations to reach out to schedule an online event with SRTR. Mr. Rogers urged SRTR to have the new incoming subcommittee members apply their perspective of when they were brand new patients to transplant topics.

Dr. Hart shifted the conversation to SRTR social media engagement. Ms. Shater explained SRTR looked into potentially using Facebook as a platform, but it did not seem like it was the right information distribution channel for SRTR content. Mr. Rodriguez said this was a good way to reach patient groups; however, Ms. Stephanie Mullet said that cost-wise, Facebook was not the most feasible option. Mr. Rogers said it might be beneficial to have a staff member assigned to managing SRTR's social media presence. He stressed that because social media has such a dominant presence today, it was important to be on all social media platforms. Ms. Barnes added that SRTR could use story-oriented campaigns on social media, where patients who have gotten or are going to receive a transplant talk about how SRTR tools helped them make decisions right for them.

Dr. Hart thanked members for their input and encouraged continuous feedback in the future. Ms. Barnes, Mr. Rodriguez, Mr. Rogers, and Mr. Tabatabai volunteered to help with SRTR co-presenting on patient-related research findings or website topics in the future. Dr. Hart said she would set up a call with Ms. Shater to discuss how to implement the strategic planning ideas.

Closing business

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