

SPORE

As a Research Advocate (RA) contributing to Specialized Programs of Research Excellence (SPORE), you will serve as a key participant in the review of grant applications, helping to ensure that research remains patient-centered, relevant, and accessible. Your role is not to be a scientist but to provide an essential perspective that represents the patient and public viewpoint.

\ Duration

- Typically meet monthly, once a year in person
- Long term commitment

Common Frustrations

- Science is high level and can be difficult to understand
- Researchers don't often understand the role of the RA

∨ Who You Are

- Curious & Eager to Learn: You are curious and willing to learn, particularly when it comes to scientific language, research methods, and statistics. You don't need to be an expert but should be comfortable asking questions and seeking clarity.
- Confident & Humble: You are confident yet humble, knowing when to speak up, when to listen, and when to reach out to staff or researchers for more information.
- Open to Debate: You are comfortable with disagreement, as research discussions often involve differing perspectives.
- Patient & Tenacious: You have the patience and tenacity to engage in a lengthy and structured review process.
- Committed & Long-Term Focused: You are committed to long-term engagement, understanding that translational research takes time and that your contributions will evolve over the course of the process.

What You'll Do

- **Engage in Grant Review**: Read and analyze SPORE grant applications, focusing on how the proposed research applies to patients and the broader community.
- Participate in Meetings: Attend regularly scheduled discussions with researchers, statisticians, and other stakeholders to review and assess research proposals.
- Provide Informed Feedback: Contribute to conversations about the research's relevance, patient impact, and translational potential, even in cases where direct patient treatment details are not fully available.
- Navigate Complexity & Uncertainty: Be comfortable with the evolving nature of translational research, where not all answers are immediately clear, and where endpoints often lead to Phase I clinical trials.
- Share Your Point of View: Understand that you are not expected to be a scientist but instead to provide valuable insights from a patient-centered or lay perspective.

- This is a less defined Research Advocate role, requiring flexibility, critical thinking, and a willingness to engage with experts from multiple disciplines, including researchers, statisticians, and other committee members.
- You will work closely with the sponsoring organization, research teams, and staff to ensure that patient perspectives remain at the forefront of research efforts.
- If you are passionate about understanding and influencing groundbreaking research while representing the patient perspective, a role on a SPORE offers a unique and meaningful opportunity.