

Name: Amy Swoboda, BA

Project Role: Stakeholder Co-Investigator

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Personal Statement: Since 2009, I've been an active member of the National Kidney Foundation (NKF) with my husband, a recent kidney transplant recipient. We've organized yearly fundraising walks to help fund research, a field that's dear to me. I've participated as a patient and caregiver advocate at the community and national level. Yet, I still felt dissatisfied with my impact. In 2013, the NKF introduced me to Drs. Browne and Boulware, who were preparing a PCORI proposal to help chronic kidney disease patients obtain transplants. Finally, I felt I could help in a more direct way. Although the proposal was rejected, we forged ahead with the current proposal, an ambitious and carefully constructed proposal intended to evoke a systematic change in how kidney disease patients are identified and managed to help them get the best possible care and ease the progress and burden of their disease. As a former scientist, current RN and caregiver, I have a unique viewpoint on this proposal. It's well thought out and carefully constructed to elicit statistically significant changes. It targets the heart of health care administration with integration of our intervention into the healthcare team and the patient's electronic medical record. I wish such a strategy had been implemented when my husband was first diagnosed with kidney failure. Too many patients lack supportive services needed to carry the burden of their disease. This intervention aims to ensure kidney patients don't slip through the health care cracks. I strongly support the implementation of such an intervention.

Hobbies/Interests: Gardening; Fishing; Knitting/Crocheting; Current research in kidney disease

Why this project is important to me: As a health care provider, advocate, and caregiver, I see people who have been poorly educated on their kidney disease and become ineligible for transplantation. This project will help catch these types of patients early enough to elicit a change in their disease course, health status, and ultimately improve their quality of life.