

**Name:** Dori Schatell, MS

**Project Role:** Stakeholder Research Partner

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**Personal Statement:** I am the Executive Director of the non-profit Medical Education Institute (MEI) which serves the mission of helping people with chronic disease learn to manage and improve their health, focusing on chronic kidney disease. We develop evidence-based kidney patient education materials that start with hope, are written at the 6th grade ( or lower) reading level, designed using adult learning principles, and grounded in self-determination theory to encourage patients' intrinsic motivation to engage in their own healthcare. Our goal is to create expert patients who self-manage at the highest possible level. We advocate for person and family-centered care and help renal professionals to better understand patient perspectives, as well. In 1989, fresh out of grad school for an MS in Child & Family Studies (focusing on family systems) from the University of WI-Madison, I went to work for Edith Oberley, who founded Medical Media Associates and MEI, and was fascinated by chronic kidney disease and the enormous disparity between the handful of patients who lived actively and productively for decades after diagnosis—and the majority who succumbed to depression and death within just a few years. My career has been dedicated to helping patients live as well and as fully as possible.

**Hobbies/Interests:** Travel; mosaic art; antiques & vintage; permaculture gardening backyard chickens; Cosplay (Civil War, SteamPunk, Faerie)

**Why this project is important to me:** Every day since 1997, I've been in contact with, at first, hundreds, and now thousands of people at varying stages of chronic kidney disease and their loved ones. Over the years, the input from 15,000+ people has made it very clear that there are tremendous gaps in most U.S. healthcare with regard to kidney disease. CKD too often goes unsuspected, untreated, unstopped. Even when it is identified in time to intervene, patients tend not to be approached as PEOPLE who are scared, angry, depressed—the messages they receive are often strictly clinical and can't even be heard through the powerful denial. I believe that the greatest hope for a better way is in a comprehensive system, like Geisinger, with an advanced EHR system and the ability to track people over time and connect them to resources that can help them. This project is an opportunity to test a thoughtful, sensitive, patient-centered model, and it is tremendously exciting to be a part of it and to have an opportunity to build on and test our My Life, My Dialysis Choice decision aid.