

# Touchpoints

the schwartz center  
FOR COMPASSIONATE HEALTHCARE

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## PATIENTS AND FAMILIES TEACH CAREGIVERS ABOUT CONNECTION, UNDERSTANDING AND COMPASSION

*Over the past year, the Schwartz Center has awarded more than \$150,000 in grants to 11 innovative projects, the majority of which use patients and/or family members as educators. When clinicians seek to understand patients as people beyond their illness, the patient-caregiver relationship is enriched and health outcomes are improved. The following stories describe three of these projects—two already in progress and one about to begin—that enable patients and families to teach physicians and trainees important lessons that are not always contained in their medical textbooks.*

### PATIENTS WITH DISABILITIES AS TEACHERS (P-DAT) PROGRAM PROMOTES DISABILITY ETIQUETTE



Medical students Matthew Meeker and Kendra Davis have learned about disability etiquette from Sweety Jain, MD, (standing) and P-DAT patient educators Rebecca Dubin (in blue) and Allison Pfingstl (in pink).

When you meet Rebecca Dubin, please talk to her, not the attendant who has accompanied her to the medical appointment. Don't tower over her wheelchair as you converse: pull up a chair so you're at her eye level. And although she is tiny, weighing only 46 lbs., Dubin is a college-educated, gainfully employed 24-year-old, so don't treat her like a child.

These are some of the tips Dubin, who has a form of muscular dystrophy called spinal muscular atrophy, gives during a three-hour training

for third-year medical students rotating through Pennsylvania's Lehigh Valley Medical Center's departments of Family Medicine, Internal Medicine and Pediatrics. Created and run by family medicine specialist Sweety Jain, MD, Patients with Disabilities as Teachers (P-DAT) educates medical students about the basic etiquette of caring for patients with disabilities. By using patients and their families as instructors, P-DAT also seeks to increase students' comfort level with patients with special health-care needs.

For Dr. Jain, a program like P-DAT is the next logical step in schooling future doctors in the art of compassionate care. "We've finally begun to look at our general patient population in a more holistic way: can they afford their medicine, for example?" said Dr. Jain. "Now we're teaching medical students about the needs of patients with disabilities, who have not had a lot of attention paid to them. The goal of P-DAT is to improve the care of patients with disabilities through education, advocacy and awareness."

The intimate sessions, attended by no more than 10 medical students at a time, begin with the medical students sharing their experiences with people with disabilities. Then patients and their families tell their personal stories—including some of the insensitive treatment they've experienced from caregivers. Participants also get a quick lesson in first person language, a lexicon based on the idea that it is more respectful to mention the person first, then the disability, so as not to define people by their limitations. For example, a blind person becomes a person with blindness. Dr. Jain shows a video called "The Ten Commandments of Communicating with People With Disabilities" and the group talks about how these good manners might play out in healthcare situations.

Jessica Link, a medical student at Drexel School of Medicine, said that her exposure to people with disabilities has been fairly limited and that the P-DAT sessions have increased her confidence. "I realized how much people with disabilities are like you and me, with their hopes and dreams, and how

courageous they are," said Link, who hopes to work as a family physician in a rural area.

"Once you make sure you've accommodated the patient's special needs, it's not that different from taking care of any other patient. There's nothing to be scared about."

Dr. Jain said the Schwartz Center's financial backing has enabled her to both pilot the P-DAT program, and then expand it from its original one-hour format to three hours, compensate the patient and parent presenters and host occasional performances from artists with disabilities. She has also presented the P-DAT program at several state, regional and national medical conferences. "The Schwartz Center has made this program possible," said Dr. Jain. "Its support has enabled me to take it to a whole other level."