Research nurses provide connection for clinical trial patients, study teams

As clinical trials at Dana-Farber grow in number and complexity, so does the need for constant, seamless communication between caregivers and patients. Through each step of a trial, research nurses are invaluable resources for both groups.

When physicians have patients they feel could benefit from new drugs not yet FDA-approved for human subjects, research nurses are often called upon to explain the risks and benefits of the process. For those patients who do join clinical trials, these specialists become trusted confidants they meet with before every chemotherapy infusion – and often confer with on phone calls in between. Their deep understanding of the science, logistics, and risks of trials informs participants, and their detailed reports to the study team can help lead to changes in how a new drug is delivered.

“The research nurse is the go-to person for management of patients on trials; doctors, clinical research coordinators, and infusion nurses look to them,” says Kristen Johnson, JD, RN, director of Research Nursing. “For the patients, whose time on a trial can last anywhere from a few weeks to several years, this is the person who teaches them when and how to take their medication, what side effects to expect, and who to call when they are not feeling well.”

The research nursing role is particularly important at Dana-Farber, Johnson says, as additional immunotherapy- and cellular-based clinical trials are developed here requiring more intense patient monitoring and inpatient hospitalizations. Clinicians who are central to the process during both planning and delivery are vital.

“Research nurses are important members of the research team, and bring a level of clinical expertise to how we conduct trials,” says Farah Daftary, director of Clinical Trials Operations. “Their knowledge is helpful to bridge gaps between physicians, pharmaceutical companies and other trial sponsors, and patients.”

Johnson oversees approximately 60 research nurses who treat adult patients in phase 1, 2, and 3 trials, and another six focused on pediatric families, and believes success in the field comes from a “deep curiosity” for the science behind patient care. With this in mind, she and colleagues have developed a month-long orientation program slated to start this summer for all new research nurse hires (see sidebar).

Most nurses in this role at DFCI already have a background in traditional oncology nursing. For example, Melissa Hohos, RN, BSN, and Christopher Graham, RN, BSN, were both bone marrow transplant nurses, and now thrive in the role of research nurse.

“We’re in a team environment; by helping the physicians and study leaders make decisions with regard to patient care, you have a real voice in that care,” says Hohos, who works with sarcoma patients. “Due to the complexity of most clinical trials, the team environment is key.”

Hohos and Graham also enjoy providing infusion nurses with new details and changes to trials. “Patients on trials can be here up to 12 hours in a day, and the infusion nurses are with them the most,” says Graham, who focuses on GI patients. “A lot of these drugs don’t even have names yet, so we do a lot of education around what to expect and why we’re using them.”

For Tricia White, 64, a sarcoma patient in her second clinical trial, having Hohos at her side for both has been reassuring. “All my caregivers are wonderful, but what makes Melissa special is how well she understands just what I’m going through,” she says. “Even when I was between trials, she still called at our regular time to check in.”

And when she came to Dana-Farber recently on a non-infusion day, White paid Hohos the ultimate thank you: she stopped by just to say hello – with homemade hot fudge.