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BRIDGE Patient to Investigator Training Module 1
What it Means to be a Patient/Caregiver Research Investigator
Key Terms and Definitions

Clinical Research Coordinator: The person who manages and conducts the day-to-day study activities; following all protocols and regulations.

Data Coordinator: The person responsible for overall data management during the study.

Informed Consent: A document that outlines what people who are thinking about joining a study are agreeing to if they decide to join the study.

Institutional Review Board: A group that follows federal regulations, state laws, and institutional policy to review, monitor, and approve research in order to protect the ethical rights and privacy of the subjects involved.

Patient Advisor: Provides advice, often limited, to researchers. These individuals have a narrow role—researchers approach them to review a specific part of the research—they do not have a voice at all phases of the research study and they are not a member of the research team.

Patient/Caregiver Investigator: Patients or caregivers who are participating members of research teams that are actively involved throughout all steps of the research process.

Principal Investigator: The lead researcher and primary contact for the project. The person responsible for conducting and supervising the research study.

Protocol: A written plan for carrying out a clinical study. A protocol includes what will be done, when, and how.

Regulatory Coordinator: The person who prepares and maintains all Institutional Review Board submissions.

Research Advocate: Promotes, often to other patients and their families, the need to participate—as "subjects" in research.

Statistical Analysis: The technique used to make sense of, and draw some inferences from, data collected.