**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.