

FOR IMMEDIATE RELEASE

The Life Raft Group to present poster at National Organization for Rare Disorders Summit

Wayne, NJ October 10, 2017: The Life Raft Group has been accepted to present a poster at the National Organization for Rare Disorders' (NORD) Rare Disease & Orphan Drug Breakthrough Summit on October 16-17, held in Washington, D.C. regarding the launch of GIST/PRIME earlier this year. GIST/PRIME is a new interactive component of the already successful Patient Registry with advanced mobile application technology and cloud storage providing patients a convenient way to input their medical updates and create a portable disease history. These advancements are helpful to both patients and health care professionals.

The poster, entitled "Shouldn't Patient Registries be Attractive to Patients?: Implementing thoughtful technology for richer data" presents the innovative features of GIST/PRIME, a platform wholly designed, built and operated by the patient community to answer the questions of greatest importance to patients. GIST/PRIME gives GIST patients and caregivers a tool to monitor their GIST history and contribute their data, making it easier for them to work with their medical team to improve their medical care with features such as push notification for medical update reminders and a GISTory, which is a comprehensive summary of a patient's GIST medical history. Data entered into GIST/PRIME creates valuable and individualized feedback on a patient's diagnosis, including calculating Risk of Recurrence, and rich real-world data for research.

Founded in 2001, The Life Raft Group Patient Registry has over 15 years of self-reported and clinical data encompassing 35 years of patient history crossing institutional boundaries. Data from the Patient Registry has been published in the Journal of Gastrointestinal Cancer and BMC Cancer with more publications in the pipeline. From the launch of GIST/PRIME, there has been over 4% increase in Patient Registry members and 8% conversion rate over to GIST/PRIME.

About the Life Raft Group

The Life Raft Group is a non-profit with a simple focus: to cure a form of cancer – GIST (gastrointestinal stromal tumors) – and to help those living with it until then. The mission is to ensure the survival of GIST patients through a comprehensive approach connecting individual patients' needs, the worldwide community of GIST advocates and the global health and research environment. This is achieved by focusing on three key areas: Patient Support & Education, Advocacy and Research.

To learn more, visit www.liferaftgroup.org

The Life Raft Group launched GIST/PRIME the newest evolution of the Patient Registry, which is helpful to both patients and health care professionals. GIST/PRIME allows for patients to be immersed in the data collection process with the ability to enter, quality control, and interact with their own data leading to a deeper engagement of patient registry members and richer data over time.

About the National Organization for Rare Disorders (NORD)®

The National Organization for Rare Disorders (NORD)® is the leading independent advocacy organization representing all patients and families affected by rare diseases. NORD is committed to the identification, treatment and cure of the 7,000 rare diseases that affect 30 million Americans, or 1 in every 10 people. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 30 years, NORD has led the way in voicing the

needs of the rare disease community, driving supportive policies and education, advancing medical research, and providing patient and family services for those who need them most. NORD represents more than 260 disease-specific member organizations and their communities and collaborates with many other organizations in specific causes of importance to the rare disease patient community.