



Why a Pediatric & SDH-Deficient GIST Consortium?

Historically, most researchers with an interest in Pediatric & SDH-Deficient GIST worked independently, with each seeing very few of these rare disease patients. The National Institutes of Health (NIH) Pediatric and Wild-Type GIST clinic was established in 2008 with the support of advocacy organizations to bring together clinicians and patients to begin to better understand this rare disease. After a successful ten years of this clinic with over 10 peer-reviewed publications describing Pediatric & SDH-deficient GIST, this program is at a crossroads, with no sustainable funding just at a time when no standard of care for this rare disease has been defined.

Because of the need for research for this population, the Life Raft Group created and convened the inaugural Pediatric & SDH-Deficient GIST Research Symposium on July 14-15, 2018. The goal of the symposium was to gather key clinicians/researchers to identify KIT-independent therapies for targeting SDH-Deficient tumors in order to improve patient outcomes.

An outgrowth of the symposium was the formation of the Pediatric & SDH-Deficient GIST Consortium. The aim of the consortium is to extend and sustain the work of the NIH Clinic and other research efforts, with the ultimate goal of finding a cure through global collaboration. As patients' survival and quality of life are dramatically impacted by this disease, it is critically urgent that the leading Pediatric & SDH-Deficient GIST experts collaborate and share data and tissue, with the goal of finding successful targeted therapies that can help keep these patients alive.

Members of The Pediatric & SDH-Deficient GIST Consortium Include Clinical/Research Partners:

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Patient Advocacy Partners Include:

- **Phyllis Gay**, GIST Support International
- **Dr. Victoria Bassett**, GIST Support UK
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- **Norman Scherzer**, The Life Raft Group
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