

Why a Pediatric & SDH-Deficient GIST Consortium?

Pediatric and SDH-deficient GIST patients live with a rare form of Gastrointestinal Stromal Tumors (GIST). Although rare, they represent a mighty force with a strong, global support network. These patients face a disease that has limited treatment options. Historically, clinicians and researchers worked independently and saw very few patients, who were at one time labeled wildtype. Few effective therapies exist despite the research efforts of the NIH Succinate Dehydrogenase (SDH) and Ultra Rare GIST Clinic or the UK-based PAWS-GIST Clinic.

Because of the need to advance research and for clinicians and research teams to collaborate, The Life Raft Group spearheaded the launch and creation of the Pediatric & SDH-Deficient GIST Consortium at the Biden Cancer Summit in 2018. The aim of the Consortium is to extend and sustain the work of the NIH and UK Clinics 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 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.

For more information on our collaborative efforts in SDH research, visit this link:

<https://liferaftgroup.org/pediatric-sdh-deficient-gist-consortium/>

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