

the NIH pediatric GIST clinic

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What is Pediatric GIST?

Younger patients with GIST tend to differ from adults

- female gender
- primary location in the stomach
- presence of lymph node metastases
- predominantly epithelioid cell morphology
- no detectable mutations in *KIT* or *PDGFRA* (wildtype)
- **slower growth of tumors, and longer survival**

Why is so little known about younger patients with GIST?

GIST is a rare tumor

Young patients with GIST comprise a much smaller percentage

- the prevalence of pediatric patients is unknown
- possibly less than 200 based on registration with GIST support groups

Treatment regimens of younger patients with GIST has varied markedly, in part due to the lack of a substantial number of patients at any single institution

Is the Term Wildtype/Pediatric GIST Accurate?

The data for this is unknown

Do younger patients have longer survival because they do not have KIT/PDGFR mutations?

Or is it because they are younger?

What are the underlying biological differences?

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Objectives

To bring together healthcare providers who have the most experience in treating patients with GIST, with every child and young adult with GIST

To obtain clinical history, response to prior treatments, histopathologic results, radiographic assessments and genetic/molecular analyses

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Objectives

To create a database of all young patients with GIST from all countries, containing as much information as the patient can provide

www.pediatricgist.cancer.gov

Patients and physicians will have access to their personal folder. The data collected will be updated and summarized every three months.

Currently under construction as a secure website

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Goal

To utilize the combined data from the clinic and the web-based database to design an investigative national treatment protocol with the following components:

- Biological Molecular
- Radiographic Pharmacokinetic

To combine information obtained from the bench, with that from the clinic, to determine the biological differences between older and younger patients with GIST

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The First Clinic

June 19, 2008

At the National Institutes of Health, Bethesda, Maryland.

Registration is currently closed.

The dates of subsequent clinic dates will be announced.

the NIH pediatric GIST team

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Radiologist

Patient Care Coordinator

Clinical Research Dietitian

Pediatric Oncologist

Research Nurse Specialist

Clinical Social Worker

Pediatric Endocrinologist/Geneticist

Pediatric Pathologist

Pediatric Psychosocial Specialist

national pediatric GIST team

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