



the NIH pediatric GIST clinic

The Pediatric GIST Clinic at the NIH

We are pleased to announce the inaugural pediatric GIST clinic at the National Institutes of Health. The study of rare diseases is difficult. However, our belief is that a gathering of patients and healthcare providers will generate a wealth of information to discover the underlying mechanisms behind pediatric GIST, as the first step towards a cure.

Am I eligible?

You (or your child) are eligible to attend the clinic if you have been diagnosed with GIST.

How will I benefit by participating?

You will be seen by some of the national leaders in the field of GIST. This includes geneticists, medical oncologists, pediatric oncologists and pediatric surgeons. In addition, we have assembled a team of healthcare providers to help manage some of the problems associated with GIST. This includes physicians who specialize in pain management, dieticians and psychosocial experts. Pathologists and radiologists will also participate. We would like to stress that our goal is not to take over your care from your oncologist. However, the number of experts from different fields who are thinking about the specifics of your care may allow us to make recommendations to your oncologist and surgeon with the goal of improving your health. Additionally, you will have the chance to interact with other patients and families, whom you may know already through the internet.

Will this clinic benefit others?

The contribution that your visit to this clinic will make to the care of others cannot be emphasized enough. Our philosophy is that the opportunity to evaluate every patient with pediatric GIST will help the community understand the mechanisms that underlie this disorder. We will have the opportunity to amass details of your history, response to prior treatments, radiographic assessments and molecular studies. The data for a single patient does not provide much insight. However, when combined with that of all other patients, the information will generate many leads to help us better understand the genetic and clinical elements of pediatric GIST.

What is the goal of the clinic?

The combined data that we obtain from these clinics may allow to us to design a treatment protocol in the near future. This protocol will have a biological component (to see which biochemical pathways are activated in the tumor), a molecular component (to determine which genes are disrupted), a radiologic component (to assess different imaging modalities) and a pharmacokinetic component (to see if drug levels in your body are appropriate). We will learn what is important to you, and then determine how best to implement that in the study. Your oncologist will remain in charge of your care. Our role will be to help provide any parts of your care that may not currently be available at your hospital.

When is the clinic?

The first clinic will occur on June 19, 2008. Those traveling from outside the DC area may wish to arrive on the 18th. Dates for subsequent clinics will be announced.

Who will pay for this visit?

The pediatric GIST clinic is sponsored by the National Cancer Institute and the National Institute of Child Health & Human Development. Most expenses will be paid by the NCI and NICHD. Please read below for more details, especially for patients age 21 and older.

The Pediatric GIST website and registration.

A secure website is currently under construction. Registration will occur by e-mail until this site is complete.

How do I register?

Please send an e-mail to kimsuyou@mail.nih.gov. State your intention to attend on June 19, 2008. A return e-mail will be sent to you the following day with further instructions. Registration for the initial clinic will be limited to the first 12 patients who respond.

I would like to attend, but I am busy that day.

We will be happy to schedule you for a subsequent clinic, once we have determined future dates. However, it would still help us greatly if you could forward your medical information to us before the first clinic. Please send an e-mail message to kimsuyou@mail.nih.gov. State your wish to attend future clinics. Please state if you are willing to forward your medical information at this time. A return e-mail will be sent to you the following day with further instructions.

I cannot travel to the NIH, but I would like to provide my information for the database.

The information that you provide is equally valuable and will benefit us, and the pediatric GIST population, greatly. The goal is to obtain data from every patient with pediatric GIST. To enter your information, please send an e-mail message to kimsuyou@mail.nih.gov. State that you cannot attend the clinic, however, you would like to provide your medical information for the database. A return e-mail will be sent to you the following day with further instructions.

Transportation

For patients under age 21, airfare for the patient and one parent is provided. For patients age 21 and over, airfare is provided for the patient only. Exceptions for travel support for an additional person can be requested and if approved, travel expenses will be provided. Travel expenses are authorized for patients residing outside a 50 mile radius of the NIH campus in Bethesda, Maryland. For patients who reside less than 50 miles from the NIH, neither travel expenses nor food vouchers are provided. For patients who reside outside the United States, airfare will be provided from the closest point of entry within the United States. Free round trip shuttle service is available from the three local DC airports.

Lodging and meals

Patients under the age of 25 and one parent are eligible to stay free at the Children's Inn. If room is not available at the Children's Inn, then the patient and parent will be housed at a local hotel at no charge. For patients age 25 and over, the patient will receive a reimbursement of \$75 per day for food and lodging at a local hotel. For patients under the age of 21, a \$10 food voucher will be provided to the patient and a \$10 food voucher will be provided to the parent daily. For patients age 21 to 24, a \$10 food voucher will be provided daily to the patient.

We hope that you will join us in the effort to discover more about GIST by participating in the pediatric GIST clinic or by contributing to the pediatric GIST database.