Understanding GIST: Gastrointestinal Stromal Tumor, a cancer that affects the digestive system.
ABOUT THIS GUIDE

This guide will:

• Help you understand gastrointestinal stromal tumor (GIST)

• Provide information on its causes and treatment

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WHAT IS GIST?

• GIST is a cancer that starts in the digestive tract and may spread to other parts of the body

• It is a rare cancer
  — Roughly 4500 to 6000 people in the United States are diagnosed with GIST each year

WHO IS AT INCREASED RISK FOR GIST?

Currently, it is not known why some people are at higher risk for GIST. But there are some general trends among people who get GIST:

• It tends to occur in people older than 50
  — However, GIST can occur at any age

• People who have neurofibromatosis seem to be at greater risk

• People who have a family history of GIST syndrome may be at greater risk
  — The syndrome is a rare, inherited form of GIST

• It is slightly more common in men

• It is also slightly more common in African Americans

Terms to Know

digestive tract—The passage that carries food through the entire digestive system. See page 4 for a diagram that shows the organs of the digestive tract.

neurofibromatosis—A genetic disorder that causes tumors to grow on nerves.

GIST syndrome—A rare form of GIST in which an irregular gene is passed from one generation to the next.
HOW DOES GIST START?

• GIST starts in the lining of the digestive tract. It starts in the part of the lining called the stroma
• GIST cancer cells then grow, divide, and multiply when they shouldn’t
• A tumor forms once enough cancer cells are made

HOW DOES GIST SPREAD?

• As the tumor gets larger, some of the cancer cells may get into the blood and spread to other parts of the body
• New tumors may then develop in other organs
  — These new tumors are called metastases
  — This condition is called metastatic GIST
    ◦ For example, cancer from GIST in the stomach can spread to the liver. If this happens, it is still called GIST. It is not called liver cancer. This is because the cancer started in the stomach, not in the liver

Terms to Know

stroma—The tissue that supports an organ.
metastases—Tumors that result from the spread of the first (or primary) tumor to other parts of the body.
WHAT TESTS ARE USED TO DETECT GIST?

Your health care providers may use any or all of the following tests and procedures:

<table>
<thead>
<tr>
<th>TEST</th>
<th>DEFINITION</th>
</tr>
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<tbody>
<tr>
<td>Physical exam</td>
<td>• This is a way to check the body for signs of cancer, like lumps or anything else unusual</td>
</tr>
<tr>
<td>Health history</td>
<td>• Patients are asked if they have any unusual symptoms or about their health history to find out if they are at risk for cancer</td>
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<tr>
<td>Laboratory tests</td>
<td>• These tests check tissue, blood, urine, and/or other substances in the body that may show signs of cancer</td>
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<tr>
<td>X-ray</td>
<td>• Energy waves that make pictures of areas inside the body</td>
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<tr>
<td>CT scan (or CAT scan)</td>
<td>• This is a series of detailed pictures of areas inside the body taken from different angles</td>
</tr>
<tr>
<td>MRI or NMRI</td>
<td>• Uses a magnet, radio waves, and a computer to make a series of detailed pictures of areas inside the body</td>
</tr>
<tr>
<td>PET scan</td>
<td>• A special sugar is injected into the body to help a camera spot cancer cells</td>
</tr>
<tr>
<td>Endoscopy</td>
<td>• A small video camera is inserted into the body using a flexible lighted tube called an endoscope</td>
</tr>
<tr>
<td></td>
<td>– Allows the health care provider to see any lumps</td>
</tr>
<tr>
<td>Biopsy</td>
<td>• A tissue sample is taken and studied by a pathologist to see if the cells carry a receptor called CD117</td>
</tr>
</tbody>
</table>

Terms to Know

endoscope—A lighted tool used to get a deep look inside the body and examine organs.
pathologist—A doctor who identifies diseases by studying cells and tissues under a microscope.
receptor—Part of a cell that binds to a substance in the body and causes an effect in the cell.
WHAT ARE THE TREATMENTS FOR GIST?

Any of the following treatments may be used, either alone or in combination:

**Surgery**
- This is used to remove a tumor or tumors

**Drug therapies**
- These are used to try to prevent the cancer from returning
- These are also used to try to shrink the tumor or stabilize the cancer
- Genetic tests may help predict how the cancer will respond to certain therapies

**Clinical trials**
- Carefully controlled research studies done with patients
- Performed to study treatments or procedures in patients
- Your health care provider can help you decide if a clinical trial is right for you

When making treatment decisions, it may help to discuss what kind of treatment may be best for you. You should talk with your cancer care team, including your doctor and nurse. Also, make sure your primary care physician is aware of your cancer treatment. You can talk with family and friends as well. Do what helps.

You should also talk with your cancer care team at every step of your therapy about:
- Side effects that your treatment may cause
- Ways to avoid or treat side effects
- How the members of your cancer care team think you are responding to your treatment
WHAT SHOULD I ASK MY HEALTH CARE PROVIDERS ABOUT MY CONDITION?

When discussing your condition:
• Have honest conversations with your doctors and nurses
  — They are eager to answer all your questions, no matter how unimportant they may seem
  — Getting answers may help you feel less anxious

Some sample questions:
• Where is my tumor located?
• How likely is this tumor to grow or spread quickly?
• Do you think my tumor has spread beyond the primary site?
• What treatment choices do I have?
• What treatment do you recommend and why?
• How do I know which treatment is right for me?
• What do GIST specialty centers do?
• What risks or side effects are there to the treatments you suggest?
• How will these treatments affect my daily activities?
• Should I follow a special diet?

Also, be sure to write down questions of your own.
• For example, you may want to find out more about things you can do to better manage your treatment
WHAT’S NEXT?

Follow-up tests
Your health care provider will decide which tests you should have and how often they should be done, based on the original stage of your cancer and your response to treatment.
• X-rays, CT scans of the abdomen and chest, and other imaging studies may be taken to check your progress and see if the cancer has returned
• Your health care provider will also check for new tumors or spreading of the cancer. Blood tests to check organ function may also be requested

Keep track of your treatment
Your body is unique. Health care providers can determine certain facts about tumors. They can use different types of treatments to help fight the cancer. But no one can say for sure how your body will respond to cancer or its treatment.
• At each visit, talk to your health care provider about how you are responding to treatment
• Note any side effects you may have
• Tell your health care provider about any drugs, treatments, or herbal supplements you are taking
GASTROINTESTINAL STROMAL TUMOR

WHAT’S NEXT? (CONT’D)

Lifestyle
Making changes in your lifestyle can help your recovery. These may help:

• Stop smoking
  — If you smoke, quitting now will improve your overall health
  — The return of your sense of smell from quitting may also help you enjoy a healthier diet during treatment and recovery

• Drink less alcohol
  — Have no more than 1 to 2 drinks per day

• Eat a well-balanced diet and maintain a healthy weight
  — Eat more fruits, vegetables, whole grains, and high-fiber foods
  — Eat less fatty meats
  — Discuss your diet with your health care provider

• Exercise when you are ready
  — Consult with your doctor or nurse regarding any exercise limitations you may have

• Give your body the rest it needs to recover from treatment
  — Cancer treatment can add to the fatigue caused by the disease itself

• Make an extra effort to talk with loved ones
  — Talk about how you are doing. Talk about your feelings
    ▪ This will help people understand what you are going through. It will give them a chance to help you
  — Talk about treatment choices. If you can, work together to make treatment decisions
    ▪ When you can, attend doctors’ appointments together so you have the same information

• If you have children, talk with them about your condition
  — Take their feelings seriously
    ▪ Children have many different reactions when they learn a parent is ill
    ▪ Tell them that it’s okay to have lots of different feelings and that you have them as well

  — Try to offer a balanced outlook
    ▪ It’s usually best to give a realistic but hopeful summary of the situation. Try to focus on the efforts that are directed toward recovery

  — Prepare your children for the effects of treatment
    ▪ Cancer and cancer treatment can often change the way a person looks
    ▪ It’s best to prepare children in advance so they know what is happening

• Consider going to a meeting of a local support group
  — Cancer diagnosis and treatment, for most, represent major challenges that affect patients and their loved ones
  — Support groups can reduce anxiety associated with isolation

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CANCER RESOURCES

The American Cancer Society (ACS)
800-227-2345
www.cancer.org
• News about cancer studies
• Facts about treatments
• Stories about cancer survivors
• Helpful advice about GIST
• Links to support groups

National Comprehensive Cancer Network (NCCN)
215-690-0300
www.nccn.com
• Cancer information for patients, caregivers, and their families
• Treatment summaries and guidance for patients
• Information on obtaining financial assistance
• Tips for living with cancer

The National Cancer Institute (NCI)
800-422-6237
www.cancer.gov
• Facts about cancer, treatments, and clinical trials
• How to pay for cancer treatment
• Information on choosing hospice and home care
• Finding support groups

Cancer.Net
888-651-3038
www.cancer.net
• Information about cancer studies
• Advice on coping with cancer
• Latest news about cancer from cancer experts
• Treatment facts and side effects management
• Information available in Spanish
PATIENT SUPPORT RESOURCES

Life Raft Group
973-837-9092
www.liferaftgroup.org
• Disease information and treatment options for patients with GIST
• Financial and logistical support
• News about research and clinical trials
• Monthly GIST-related Webcasts and blogs

GIST Support International (GSI)
215-340-9374
www.gistsupport.org
• Support for GIST patients and their families and friends
• Information on current GIST research through Webcasts and publications
• Contact with GIST patients, caregivers, and health care providers by e-mail

GIST Cancer Research Fund (GCRF)
845-634-6060
www.gistinfo.org
• Patient stories and online resources
• Helpful advice on living with GIST
• News about research and clinical trials
• Guide to side effects management

Cancer Hope Network
800-552-4366
www.cancerhopenetwork.org
• Live online help
• Support services for people living with cancer
• Matches patients one on one with cancer survivors

Cancer Information and Counseling Line (CICL) 800-525-3777
• A service of the AMC Cancer Fund
• The toll-free help line provides information and short-term counseling to patients and their families
• Counselors are available Monday through Friday, 8:30 AM to 4:30 PM Mountain Time, to provide emotional support and resource referrals

The Wellness Community (TWC)
888-793-WELL (9355)
www.thewellnesscommunity.org
• Community-based support groups for people living with cancer, guided by trained professionals
• Information for patients and caregivers
• 24/7 online support

CancerCare®
800-813-HOPE (4673)
www.cancercare.org
• Helpful cancer advice and counseling
• Facts about cancer
• Free financial services