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fact sheet

Medical Updates on Myelofibrosis

Researchers have made important improvements in the treatment of myelofibrosis over the past several years. This fact sheet explains the disease, treatment options, and quality of life issues to help patients and their loved ones cope with a diagnosis.

Overview of myelofibrosis

Myelofibrosis is a type of chronic leukemia which causes blood cells to grow uncontrollably, creating scar tissue in a person's bone marrow. The scar tissue slows the production of blood cells, causing patients to develop anemia. The disease can lead to an enlarged spleen and liver. Other symptoms may include bone aches and pain, night sweats, low-grade fevers, itching, weight loss, fatigue, and shortness of breath.

The origins and risk factors for myelofibrosis are unknown. The condition is rare, affecting 3,000 to 4,000 people in the U.S. each year. Several academic institutions across the U.S. have established centers of excellence to help patients diagnosed with the disease.

Review of current therapies

The primary treatment approach for myelofibrosis is focused on managing symptoms, such as anemia, an enlarged spleen and liver, as well as addressing quality of life issues.

Current therapies involve radiation, oral chemotherapy, and medications including prednisone to boost red blood cell production. Blood transfusions and a bone marrow transplant may also be considered.

To address serious itching associated with the disease, antihistamines or UV light can provide relief. Some patients have also benefited from antidepressants that have anti-itching effects, such as paroxetine (Paxil) or sertraline (Zoloft).

Several years ago, researchers made a major breakthrough by identifying a gene called JAK2, which is mutated in half of all myelofibrosis patients. JAK2 inhibitors improve a patient's symptoms, relieving night sweats, weight loss, itching, and other difficult issues that patients experience. But the drugs have not been overly effective in treating anemia. However, medications and blood transfusions can help increase red blood cell count. Because frequent blood transfusions over a lifetime may lead to iron overload, it is important to talk with your doctor to discuss the best treatment approach for you.

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Role of clinical trials

There has been a tremendous amount of research to better understand myelofibrosis and identify new strategies to help patients live longer. Recently, the U.S. Food and Drug Administration approved the first drug to treat myelofibrosis, called ruxolitinib (Jakafi). Jakafi works as a JAK2 inhibitor. Clinical trials are under way to test if similar drugs can produce comparable results in patients. Drugs that might improve scarring in bone marrow are also being studied, as well as combination therapies. If you have questions about clinical trials, talk with your doctor or health care provider.

Seeking regular follow-up care

By measuring the impact of the disease, doctors are able to assess if therapies are meeting the expected goals in alleviating anemia, improving the patient's quality of life, and delaying the growth of the cancer.

Follow-up care will require regular blood tests to analyze blood counts and bone marrow biopsies to track changes in bone marrow scarring. Speak with your health care provider to find out when and how often you will need to undergo these tests.

Monitoring treatment progress is an important aspect of your health care and a team approach to communication is critical to ensure the best patient outcomes.

Cancer*Care* Can Help

If you or a loved one has been diagnosed with myelofibrosis, contact Cancer*Care*. We are a national nonprofit organization that provides free, professional support services for anyone affected by cancer. Our services include individual counseling, support groups, education, financial help, and referrals to other resources. To learn more, call us at **800-813-HOPE (4673)** or visit **www.cancercare.org**.

Questions to Ask Your Doctor

Here are some questions you may want to ask your doctor or nurse to help you understand your treatment and follow-up:

- What is my recommended treatment?
- How often will I receive treatment?
- What are the possible side effects?
- Am I eligible for a clinical trial?
- How often should I seek follow-up care?
- Am I eligible for a bone marrow transplant?
- Where can I get more information about JAK2 inhibitors and treatment options?
- Is there anything else that I should know?

This fact sheet was made possible by a grant from Incyte Corporation.

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