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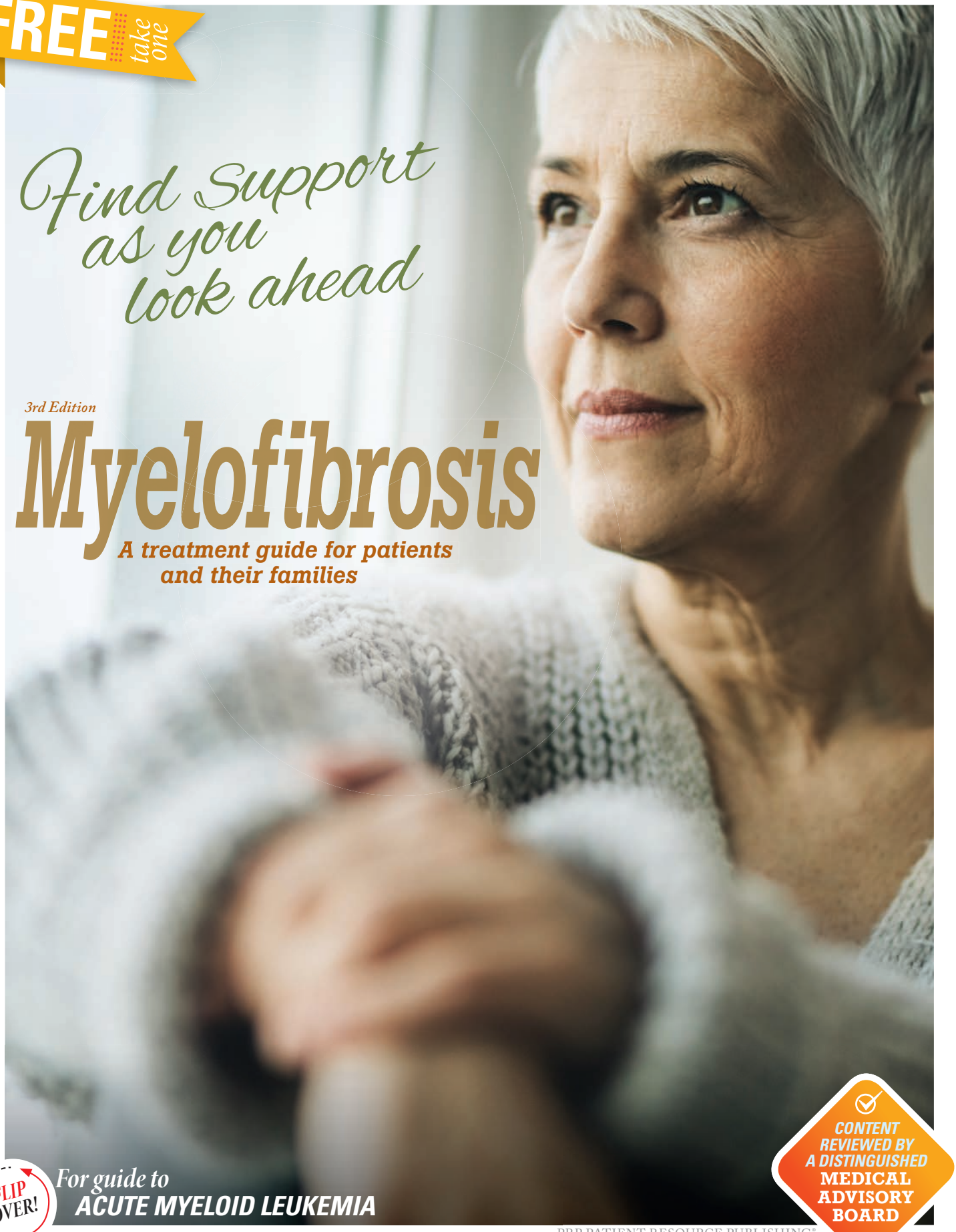
3rd Edition

Myelofibrosis

A treatment guide for patients and their families



FLIP OVER!

For guide to
ACUTE MYELOID LEUKEMIA

CONTENT REVIEWED BY A DISTINGUISHED MEDICAL ADVISORY BOARD

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TRANSFORM 2
M20-178

Myelofibrosis Research Study

Do you or someone you know have Relapsed/Refractory Myelofibrosis?

The TRANSFORM-2 study is a research study evaluating the efficacy and safety of an investigational medication (navitoclax) in combination with ruxolitinib compared to best available therapy. Navitoclax is an investigational drug that is not approved by the FDA or any other global health authority. Safety and efficacy have not been established.

Patients must meet the following criteria:

- 18 years of age or older
- Diagnosed with primary myelofibrosis, post-polycythemia vera myelofibrosis, or post-essential thrombocythemia myelofibrosis
- Currently have Intermediate-2 or High-Risk myelofibrosis
- Currently on treatment or have received prior treatment with ruxolitinib
- Have splenomegaly (enlarged spleen)

For more information, ask your doctor about the TRANSFORM-2 Study or visit **www.myelofibrosisresearch.com** and **www.clinicaltrials.gov** (NCT04468984) to see if you qualify.

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3rd Edition

Myelofibrosis

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Knowledge is key for empowered decision making

Learning you have myelofibrosis is often unsettling and unexpected. To better understand this rare blood cancer and make informed treatment decisions, it is important to learn as much as you can. As you do your research, you will find that doctors are learning more about the genetics behind the disease, finding new ways to treat it and developing better ways to address side effects that typically go along with it.

THE BASICS OF MYELOFIBROSIS

Myelofibrosis is one of six myeloproliferative neoplasms (MPNs). These cancers affect the bone marrow in different ways:

- Essential thrombocythemia (ET) — too many platelets
- Polycythemia vera (PV) — too many red blood cells
- Primary myelofibrosis — too many fibroblasts
- Chronic neutrophilic leukemia — too many blood stem cells become a type of white blood cell called neutrophils
- Chronic eosinophilic leukemia — too many of the eosinophil white blood cells in the bone marrow
- Chronic myelogenous leukemia — too many white blood cells are made in the bone marrow

When myelofibrosis develops from ET or PV, it is known as secondary myelofibrosis, which may also be referred to as either post-ET myelofibrosis or post-PV myelofibrosis. When it develops spontaneously, it is known as primary myelofibrosis. Although myelofibrosis is considered a chronic (slow-growing) blood cancer, in some cases it can transform into acute (fast-growing) myeloid leukemia.

Myelofibrosis starts in the bone marrow, which is the soft, spongy center of some bones. It is where blood is created and is made up of blood stem cells, more mature blood-forming cells, fat cells and supporting tissues. Blood stem cells can become one of the following:

- Red blood cells that carry oxygen from the lungs to other parts of the body
- White blood cells that fight off infection and other foreign intruders in the body
- Platelets that help blood to clot and to stop bleeding

This cancer begins when abnormal blood stem cells produce immature cells that grow quickly and take over, crowding out other cells. This affects the development of red blood cells, white blood cells and platelets. They are often misshapen and immature so they cannot perform their normal function. As a result, there are low levels of red blood cells and too many white blood cells (see Figure 1).

When not enough normal blood cells can be made, blood cell production may shift to other organs, such as the spleen or liver, which causes them to enlarge. For example, when the spleen tries to compensate for the lack of blood cells, it enlarges and often presses against other organs.

Myelofibrosis symptoms, progression and treatment can vary widely. Most common symptoms are fatigue, feeling full quickly, weight loss, fever, bone pain, night sweats, itching (especially after bathing), and abdominal discomfort or bloating. In the absence of symptoms, blood tests may indicate abnormal amounts of cells that can prompt the need for further testing.

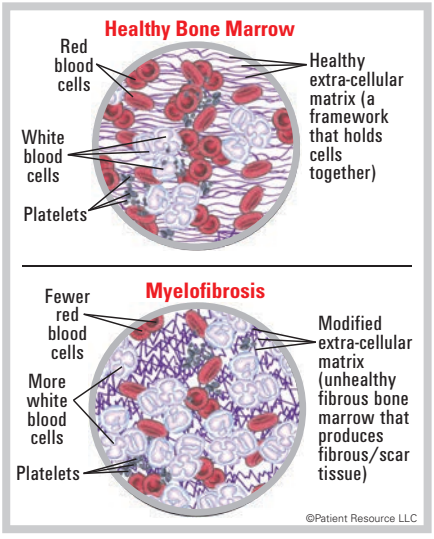
DIAGNOSIS AND GENOMIC TESTING

An initial evaluation typically includes a symptom survey, physical exam, blood tests, a bone marrow biopsy, molecular and genetic testing, and imaging studies to evaluate the size of the liver and spleen.

Identifying any genetic mutations associated with myelofibrosis will be a part of the diagnostic process. Tests will examine a sample of tissue, blood or bone marrow to look for changes in chromosomes while molecular testing checks these samples for certain genes, proteins and other molecules that may have mutations (changes). More than one mutation, called a co-mutation, may be present.

FIGURE 1

MYELOFIBROSIS



Approximately half of patients with the disease have a mutation in the *JAK2* gene, which is the most common mutation found in people with myelofibrosis. Most myelofibrosis mutations occur spontaneously and are not inherited from parents. If there are multiple people in the same family with myelofibrosis, you may be referred to a genetic counselor.

Other common mutations found in people with myelofibrosis include the calreticulin (*CALR*) gene and the myeloproliferative leukemia (*MPL*) gene. Other gene mutations that are associated with prognosis include *ASXL1, EZH2, IDH1, IDH2, RAS, SF3B1, SRSF2, TET2* and *U2AF1*. The *BCR-ABL1* gene is often tested to rule out chronic myeloid leukemia (CML).

Your doctor will assign a risk level to your myelofibrosis using a prognostic scoring system that is based on risk factors. High-risk myelofibrosis is more aggressive and may require more intense treatment. ■

MYELOFIBROSIS SUPPORT RESOURCES

- **American Society of Hematology:** www.hematology.org
- **The Angiogenesis Foundation:** www.angio.org/learn/treatments
- **Asian American Donor Program:** www.aadp.org
- **Be The Match:** www.bethematch.org
- **Blood & Marrow Transplant Information Network:** www.bmtinfonet.org
- **Cancer Support Community:** www.cancersupportcommunity.org/myelofibrosis-mf
- **HEADstrong Foundation:** www.headstrong.org
- **The Leukemia & Lymphoma Society:** www.lls.org
- **MPN Education Foundation:** www.mpninfo.org, 480-443-1975
- **MPN Research Foundation:** www.mpnresearchfoundation.org
- **National Organization for Rare Disorders:** rarediseases.org/rare-diseases/primary-myelofibrosis

First diagnosed with essential thrombocythemia (ET) more than 20 years ago, Andrea Spica did not have many treatment options available. When the ET progressed to myelofibrosis, she participated in multiple clinical trials, which offered her several years free of symptoms before undergoing a stem cell transplant. She encourages others to consider clinical trials, keep an open mind and find support.

Clinical trials and support were instrumental in survivor's success

During a routine physical, blood test results showed my platelet count was high. My primary care doctor referred me to a hematologist who diagnosed the cause as essential thrombocythemia (ET). Treatment started with a chemotherapy drug, but I only took it for a couple months because I couldn't handle the side effects. The hematologist switched me to a platelet-reducing drug, and luckily I had no side effects with it. I went on with my life.

After taking this therapy for 10 years, symptoms gradually began to develop. It wasn't until I was on a bike ride vacation with some friends for my 60th birthday that I realized something was wrong. I was very tired and couldn't keep up with them. This was unusual because I was an avid cyclist and could normally ride 150 miles a week. A good friend pulled me aside and asked why I was not keeping up. Her awareness helped me recognize that something more was going on with my health.

I went back to the hematologist, who suspected my condition had progressed beyond ET. He referred me to a well-known cancer center where I had a bone marrow biopsy that confirmed the progression to myelofibrosis. Few treatment options were available at the time, so the doctor suggested a clinical trial, and over time I tried a variety of them. Some worked better than others. I wouldn't be here today if I had not explored clinical trials. They are the only way to advance new treatments and potentially help yourself and others.

Whether I was in a clinical trial or not, I continued searching for other options. I read everything about myelofibrosis I could get my hands on, including medical journals. Through my research, I read about a new *JAK1* and *JAK2* inhibitor drug being tested in a clinical trial that was shown to increase red blood cells. I presented this information to my doctor. He admitted he didn't know much about it, but he discovered I could qualify to get into the trial. I enrolled in it and had several really good years with that therapy. But, over time, it started to fail, which was expected. My red blood cells decreased, and I had to have blood transfusions every three weeks. By this time, I had run out of all options but one: a stem cell transplant.

This was a very difficult decision because the success rate at the time was low (it's much better today). I was concerned I would become ineligible for a transplant as I aged, so I decided to go for it. My sister donated her stem cells.

The process was rough, but I hung in there and the transplant was a success. If you consider this procedure, make sure you find a caretaker willing to help you for three to six months. Also, keeping a good attitude is so important during this time.

Friends and family may struggle with the idea that you have cancer because "you don't look sick." That is why it is important to find a good support group. Talking with others who have myelofibrosis is helpful because they can truly understand what you are going through. I found an in-person meeting through word of mouth. Once I went, I knew I was no longer alone.

After attending the support group meetings for nearly a year, the leader asked if I would take over the group. I agreed and ran the group for several years. Once I had my transplant, I passed the leadership to another person but I keep up with online meetings. I'm also a member of a bone marrow transplant support group. Today, I'm considered in remission.

Finding support for a rare cancer is especially important. As a result of COVID-19, many support groups are now accessible online across the country. You can find these online meetings through www.mpninfo.org. There is hope, and there is support. ■

Andrea's Advice

- Be an advocate for your own care.
- Keep a good attitude.
- Find people to talk to, and get into a good support group.
- Movement is medicine.
- Do your research.
- If you are considering a transplant, interview the hospitals, doctors and support staff that may be involved. Ensure they have a high success rate for transplants in myelofibrosis patients, not just an overall success rate.
- Don't pick a hospital for a transplant just because it's the closest to you.
- Expect to need multiple treatments over time to manage the disease.
- Don't give up. Myelofibrosis is not a death sentence.

Explore all options before determining your plan

Progress in understanding and treating myelofibrosis in recent years is offering hope to many people diagnosed with this rare form of blood cancer. Research in clinical trials continues to search for new treatments and ways to manage the side effects of the disease and improve patients' quality of life.

Finding a blood cancer specialist with expertise in treating myelofibrosis is highly recommended because many oncologists simply do not have experience with it. A general hematologist/oncologist can give you a referral to a specialist. A second opinion from a specialist is important to confirm the diagnosis and treatment plan. Because myelofibrosis can affect many systems in the body, you will likely work with a multidisciplinary team that will co-manage your treatment.

Myelofibrosis is often treated like a chronic condition that will progress. For the majority of patients, the main goal is to minimize symptoms, which includes improving blood counts and reducing the chance of progression to acute myeloid leukemia. Your doctor will base your treatment on several factors – your symptoms, age and general health – that are combined into a risk score, which is assigned at diagnosis. The more aggressive the disease, the more aggressive the treatment is likely to be.

The Dynamic International Prognostic Scoring System (DIPSS) Plus includes four risk groups, ranging from low to high. It divides risk into four tiers: low risk, intermediate-1 risk, intermediate-2 risk and high risk. In general, patients in the low-risk group, who may or may not have symptoms, may be treated with watchful waiting, a clinical trial or targeted therapy. Patients in the high-risk group may receive a stem cell transplant, targeted therapy or a clinical trial. Multiple prognostic scoring systems exist. Some differentiate between whether patients are asymptomatic or symptomatic. If you are unsure which one your doctor used, ask.

Be aware that it is common for the treatment strategy you begin with to change. Your doctor will continually monitor your condition and make adjustments to your treatment plan for a number of reasons. Sometimes a therapy becomes less effective as time goes on; other times, a new mutation may be discovered and a different therapy may offer more promise. Keep in mind that cancer can be ever-changing, which presents many challenges, so flexibility and patience are important.

Following are descriptions of the most common treatment options. They may be used alone or in combination.

WATCHFUL WAITING

This approach delays active treatment while closely monitoring the course of the cancer and its symptoms. It may be recommended for people with slow-growing disease or those who have very mild or no symptoms. This option, typically for people who are in the lower risk groups, offers the possibility of avoiding the side effects of treatment as long as possible. However, treatment should begin as soon as symptoms appear or test results show the disease is progressing.

STEM CELL TRANSPLANTATION

At this time, the only potential cure for myelofibrosis is a stem cell transplant. Also known as bone marrow transplantation, a stem cell transplant involves an infusion of healthy stem cells into the body, typically after chemotherapy. It is only recommended for intermediate- and high-risk patients.

The most common type used is an allogeneic (pronounced al-oh-jeh-NAY-ik) stem cell transplant, which uses stem cells donated by a family member or an unrelated donor identified through a national or international registry. Other less-matched donor options are under investigation and in clinical trials to provide access for patients who have no available matched donor.

For the donor stem cells to be effective, transplant recipients must first receive a conditioning treatment, consisting of chemotherapy and possibly radiation therapy, to weaken their own stem cells and allow the donor stem cells to replace them and start fighting the cancer. High-dose or myeloablative conditioning treatments are often reserved for transplant candidates in excellent health and with very active and aggressive cancer.

This procedure may be too risky for some older patients who have other health problems, so you are encouraged to discuss this option with a doctor and a transplant center with extensive experience. Some treatment centers offer financial assistance with travel and temporary lodging during treatment. Talk with your health care team at the transplant center and advocacy organizations to learn about the resources available to assist you.

A non-myeloablative stem cell transplant or mini-transplant may be an option for older, sicker patients. A reduced-intensity conditioning treatment uses milder doses of chemotherapy and radiation therapy for conditioning prior to the transplant. The potential success of this approach depends entirely on the anti-cancer effect of the new immune system transplanted into the patient.

Talk with your doctor about the benefits and risks so you know what to expect with this treatment option. This includes potential short-term or long-term side effects, as well as the amount of help you will need from a caregiver. If a family member or friend cannot help, you may need to consider hiring a temporary caregiver because assistance will be necessary during this time.

The allogeneic stem cell transplantation process has four distinct phases:

1. **Donor identification and evaluation,** which includes tissue typing of related and unrelated donors, selecting the best match and requesting a thorough health evaluation of the donor as well as availability for the transplant time frame.
2. **Conditioning,** which includes chemotherapy and radiation therapy.

REIMBURSEMENT & PATIENT ASSISTANCE RESOURCES

- **myAbbvie Assist:** abbvie.com/patients/patient-assistance, 800-222-6885
- **Bristol-Myers Squibb Access Support:** bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
- **Bristol-Myers Squibb Patient Assistance Foundation:** bmspaf.org, 800-736-0003
- **IncyteCARES for Jakafi:** www.incytecares.com/jakafi, 855-452-5234
- **Inrebic BMS Access Support:** www.bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
- **Vonjo CTI Access:** www.ctiaccess.com, 888-284-3678

3. **Stem cell infusion,** during which the harvested donor stem cells are put into the recipient's body intravenously (through a vein).
4. **Recovery and engraftment,** in which healthy cells begin to grow. There are typically signs of this in the first 30 days, but an enlarged spleen and scar tissue in the bone marrow, common in patients with myelofibrosis, can delay the engraftment process compared to that for other diseases. The patient will be at risk for bleeding and infection while the weakened immune system recovers. This process may take multiple years and will require ongoing use of prophylactic antiviral and antibacterial medications as well as repeat inoculations with childhood vaccines. The number of red cells, white cells and platelets will continue to be monitored until they are back to safe levels. Long-term monitoring and management of Graft-versus-Host Disease (GvHD) will also occur, if applicable. Transplant recipients may require lifelong treatment for GvHD.

CLINICAL TRIALS

Medical research studies may offer access to therapies not yet widely available for myelofibrosis. Ask your doctor whether you should consider a clinical trial at any time during your treatment (see *Clinical Trials,* page 6).

DRUG THERAPY

Targeted therapy drugs are used to slow or stop the progression of disease. These drugs may be given orally as a pill. They travel throughout the body via the bloodstream and primarily affect cancer cells, leaving healthy cells alone.

The drugs approved are kinase inhibitors that block a type of enzyme called a kinase. Tyrosine kinases are a part of many cell functions, including cell signaling, growth and division. These enzymes may be too active or found at high levels in some cancer cells, and blocking them may help keep cancer cells from growing. In myelofibrosis, drugs are approved that target *JAK1, JAK2* and/or *FLT3,* which are enzymes involved with blood cell production. Current therapies treat primary or secondary myelofibrosis that is intermediate, intermediate-2 or high risk.

This treatment does not alter the natural course of the illness, but it is used to decrease spleen size and improve symptoms. Because the currently approved targeted therapies can worsen low blood counts, they must be used with caution and frequent monitoring, if at all.

Chemotherapy travels through the bloodstream and kills rapidly growing cells in the body. It may be given intravenously (IV) into a vein or taken orally as a pill. It is often used in high doses to prepare for a stem cell transplant. In some cases, it is used to treat symptoms of anemia or to reduce high platelet and white blood cell counts.

COMMON DRUG THERAPIES

- fedratinib (Inrebic)
- hydroxyurea
- interferon
- pacritinib (Vonjo)
- ruxolitinib (Jakafi)

As of 10/3/22

Immunotherapy in the form of immunomodulators can be used to slow the growth of cancer by reducing the number of blood cells.

Corticosteroids are drugs used to treat some blood cancers and can help anemia, nausea, vomiting, weight loss, fatigue, night sweats and fevers. They can be used alone or in combination with other types of antiemetic (anti-nausea) therapy.

RADIATION THERAPY

High-energy radiation to destroy cancer cells and shrink tumors may be given to prepare for an allogeneic stem cell transplant, reduce the size of the spleen, decrease bone pain or shrink tumors that have developed outside of the marrow.

SURGERY

This treatment is primarily used to remove the spleen (a procedure called a splenectomy) if it becomes very large, is causing anemia or is lowering platelet counts. ■

DONORS CAN SAVE LIVES

At any given moment, thousands of people need lifesaving blood stem cell transplants but have no available donor. Organizations such as Be The Match (operated by the National Marrow Donor Program) have created registries of millions of potential donors. Minority donors are especially needed. Learn more at www.bethematch.org

Ongoing Care: Regular follow-ups are necessary

Part of treating myelofibrosis will be ongoing monitoring of your treatment, symptoms and health status. Regular follow-up appointments help ensure your treatment is working and that the disease has not become resistant to the medications. You will be responsible for letting your medical team know about any symptoms that develop between appointments.

Myelofibrosis typically affects blood counts, such as too many or too few red blood cells, white blood cells and platelets. The following treatments may be used to manage blood counts.

Androgens are a type of hormone therapy that promotes the development of male hormones. They may be given to improve anemia.

Blood transfusions are given for severe anemia. Blood donated by another person may be given intravenously (IV) to a patient through a vein in the arm.

Erythropoietin is a growth factor designed to stimulate bone marrow stem cells to make red blood cells, which may improve anemia. Your doctor will check your erythropoietin level before recommending this therapy.

Granulocyte colony stimulating factors and **granulocyte macrophage stimulating factors** are drugs that may be administered to help the body make white blood cells other than lymphocytes. White blood cells are often damaged by treatment, which can increase the risk of infection.

Phlebotomy is the removal of blood from the body through a vein in the arm. This is sometimes used to remove extra red blood cells.

Platelet transfusions may be given for a very low platelet count. Platelets donated by another person may be given intravenously to a patient through a vein in the arm. ■

Research studies advance myelofibrosis treatment options

Advances made in the treatment of myelofibrosis have come from research studies known as clinical trials. These highly regulated studies offer access to state-of-the-art cancer treatments that are not otherwise available. They are used to search for new and better ways to prevent, diagnose, treat and cure cancer, particularly rare types like myelofibrosis. They are also conducted to help prevent and relieve the symptoms and side effects of cancer.

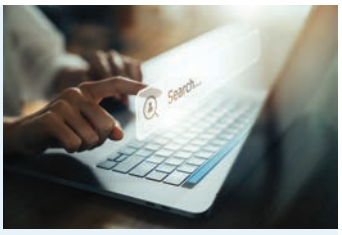
As with any cancer treatment, the therapies used in clinical trials present potential risks as well as extra time commitments. Ask your doctor about possible side effects and the schedule to accommodate the tests and appointments that are required.

A clinical trial may offer multiple benefits, including the following:

1. In some cases, a clinical trial may be your best first treatment option, especially if your diagnosis has few or no approved therapies.
2. More specialists will be involved in your care. You will be monitored by the medical team managing your trial as well as by your regular oncologist.
3. It could offer an alternative if your cancer has become resistant to your current treatment.
4. The treatment being tested may offer fewer side effects than your current treatment, improving your quality of life.
5. By participating, you will be a partner in cancer research, helping improve treatments for future patients. The need is great for more clinical trial participants to volunteer; minority patients are particularly needed. ■

How to search online for a clinical trial

The first place to ask about clinical trial information should be your doctor and health care team. You can also search online on your own. Use the list of clinical trial sites below and ask your doctor for additional recommendations.



Start by entering your diagnosis. To further customize your search, enter applicable criteria, such as age and previous treatments, on the Results screen.

Refine your search even more by adding a particular treatment type or genetic mutation. You can also add a National Clinical Trial identifier, which is a unique eight-digit code preceded by "NCT" that is assigned to each trial.

Enter your home address if you prefer a clinical trial close to home. Add additional locations if you're willing and able to travel for treatment.

Check the recruitment status of each trial. The status will indicate whether the trial is actively seeking patients, not yet recruiting or otherwise inactive. The status will change, so check for updates.

Take any potential trials you are interested in to your doctor to learn more and discuss whether they may be a good fit for you.

CLINICAL TRIAL RESOURCES

- **AbbVie Clinical Trials:** abbvieclinicaltrials.com
- **Be the Match | Jason Carter Clinical Trials Program:** www.ctsearchsupport.org, 888-814-8610
- **Cancer Support Community:** www.cancersupportcommunity.org/find-clinical-trial, 888-793-9355
- **Center for Information & Study on Clinical Research Participation:** www.searchclinicaltrials.org
- **ClinicalTrials.gov:** www.clinicaltrials.gov
- **Lazarex Cancer Foundation:** www.lazarex.org, 877-866-9523
- **The Leukemia & Lymphoma Society:** www.lls.org/treatment/types-of-treatment/clinical-trials/finding-a-clinical-trial
- **National Cancer Institute:** www.cancer.gov/clinicaltrials
- **NCI Cancer Information Service:** 800-422-6237
- **WCG CenterWatch:** www.centerwatch.com, 866-219-3440

Myths vs. Facts

You may be hesitant to consider a clinical trial, especially if you are unfamiliar with them. Understanding what they are – and what they are not – will help you feel more informed. Following are some common myths about clinical trials and the facts that dispel them.

MYTH: ***Drug therapies used in cancer clinical trials are unapproved and, therefore, unsafe.***
FACT: Trials are designed with strict safety measures in place that were established and are enforced by the U.S. Food and Drug Administration (FDA). While many trials are focused on the development of new treatments, the majority of cancer clinical trials include treatments that are already approved, sometimes alone and sometimes in combination with new therapies.

MYTH: ***I can't participate if I don't live near a city with a large cancer center.***
FACT: Clinical trials take place in nationally known cancer centers in major cities, but also in university medical centers, regional hospitals and even oncologists' offices. And, certain portions of some trials can be conducted virtually, which may reduce travel for some appointments or the need to sign the Informed Consent form in person.

MYTH: ***Once I start the trial, I can't change my mind.***
FACT: Participation is always voluntary, even after the trial has started. You can withdraw at any time and for any reason.

MYTH: ***I can only join a trial if I have no other treatment options.***
FACT: This is a common misconception, but many trials today are open to patients at every stage. Depending on the diagnosis, a clinical trial may be considered as a first-line treatment.

MYTH: ***Health insurance policies never cover experimental therapies.***
FACT: Some parts of a clinical trial, such as routine patient care costs, are usually covered. To be sure you understand the parts of the clinical trial that your health insurance will cover, review your policy and contact your insurance company. Also, ask the clinical trial coordinator whether the costs not covered by your health insurance plan will be covered by the trial sponsor or whether they will be your responsibility. ■

R E S E A R C H S T U D Y

The ENVELOP Study

A Clinical Research Study for Myeloproliferative Neoplasms and Chronic Myelomonocytic Leukemia

We are conducting a research study to evaluate the safety and effectiveness of an investigational medication called navitoclax in adults with the following types of blood and bone marrow conditions: Polycythemia Vera (PV), Essential thrombocythemia (ET), Myelofibrosis (MF), and Chronic Myelomonocytic Leukemia (CMML).

Patients must meet the following criteria:

- 18 years of age or older
- Documented diagnosis of primary or secondary Myelofibrosis (MF), Essential Thrombocythemia (ET) or Polycythemia Vera (PV) or Chronic Myelomonocytic Leukemia (CMML)
- Have declined or not had success with at least one standard treatment
- Additional study entrance criteria will apply

ENVELOP

Scan Here to Learn More

Navitoclax, an investigational agent, is under clinical development and is not approved by regulatory health authorities. Its safety and effectiveness are under evaluation.

Partner with your medical team for effective symptom management

The symptoms and side effects of myelofibrosis are unique to each person, making a personalized approach to managing them essential. As a result, you will work closely with a multidisciplinary health care team that will help you manage the disease so you can maintain a good quality of life.

Your team will draw on a broad range of services known as palliative care or supportive care. Palliative care is often confused with hospice care, but palliative care services may be used at any time during the cancer care continuum, while hospice focuses on end-of-life care.

Supportive care addresses the physical, emotional, practical, spiritual, financial and family-related challenges of people diagnosed with cancer and their loved ones.

POTENTIALLY SEVERE SIDE EFFECTS

Though serious side effects are rare, they can occur with certain types of treatment. Ask your doctor whether you are at risk from the therapies in your treatment plan, how to identify the symptoms and when to seek emergency care. Report symptoms immediately if they occur so they can be treated promptly. Some potentially severe side effects include the following:

- **Bleeding problems** (hemorrhages) and **bruising** may occur. Inform your health care team about any history of bleeding problems, and contact them immediately if you experience any of these symptoms: blood in your stools or black, tar-like stools; pink or brown urine; unexpected bleeding or severe bleeding you cannot control; vomit that looks like coffee grounds; coughing up blood or blood clots; increased bruising, dizziness, weakness or confusion; changes in speech; or a long-lasting headache.
- **Infection** can occur as a result of a low white blood cell count (neutropenia) or other factors. Contact your doctor immediately – do not wait until the next day – if you have any of these symptoms: oral temperature over 100.4 °F, chills or sweating; body aches, chills and fatigue with or without fever; coughing, shortness of breath or painful breathing; abdominal pain; sore throat; mouth sores; painful, swollen or reddened skin; pus or drainage from an open cut or sore; pain or burning during urination; pain or sores around the anus; or vaginal discharge or itching. If you cannot reach your doctor, go to the emergency room.
- **Tumor lysis syndrome** (TLS) may occur after treatment of a fast-growing cancer, especially certain blood cancers. As tumor cells die, they break apart and release their contents into the blood. This causes a change in certain chemicals in the blood, which may cause damage to organs. There may also be worsening of your kidney function or an increase in the level of potassium in the blood. TLS can potentially cause damage to the kidneys, heart, liver or other organs. Symptoms may include vomiting, diarrhea, muscle cramps or twitches, neuropathy and decreased urination.

SOME COMMON SIDE EFFECTS

Supportive care often focuses on managing physical symptoms such as fatigue, weight loss, bone and joint pain, fever, rash, night sweats, gout, headaches, Graft-versus-Host Disease (GvHD), diarrhea, mouth sores, nausea and vomiting, and abdominal pain due to an enlarged liver or spleen.

Additional care will be needed for managing blood cell count levels, which are affected by treatment and the disease. Following are blood cell count issues that may develop:

- Anemia (too few red blood cells)
- Extra medullary hematopoiesis (production of blood cells in the spleen or liver)
- Leukocytosis (too many white blood cells)
- Thrombocytosis (too many platelets) or thrombocytopenia (low platelet counts)
- Thrombosis and thrombohemorrhagic complications (blood clotting or bleeding complications)

MANAGING ANEMIA AND FATIGUE

Myelofibrosis interferes with the development of healthy blood cells and frequently causes anemia. When someone is anemic, they do not have enough red blood cells to carry oxygen throughout the body. This results in symptoms of fatigue, shortness of breath, feeling cold and looking pale.

Regardless of the cause of anemia, your supportive care team will help you manage it. Therapies used include androgens, blood transfusions, corticosteroids, erythropoiesis stimulating agents and immunomodulators (see *Ongoing Care*, page 5). In some cases, your doctor may recommend supplements to replace low levels of iron, folate or vitamin B12.

Other therapies for anemia are being researched in clinical trials. Ask your doctor whether you may be a candidate for one.

In the meantime, there are some actions you can take to ease the fatigue caused by the anemia. Tell your doctor if you are feeling weak and tired; get enough sleep; take a walk; eat a well-balanced diet; and perform activities that bring you joy. ■

CAREGIVER & SUPPORT RESOURCES

- **American Psychosocial Oncology Society Helpline:** 866-276-7443
- **CanCare:** www.cancare.org
- **CANCER101:** www.cancer101.org
- **Cancer*Care*:** www.cancercare.org
- **Cancer Connection:** www.cancer-connection.org
- **Cancer Hope Network:** www.cancerhopenetwork.org
- **Cancer Support Community (MPN):** www.cancersupportcommunity.org/myeloproliferative-neoplasms
- **Cancer Support Community Helpline:** 888-793-9355
- **Cancer Survivors Network:** csn.cancer.org
- **Caregiver Action Network:** www.caregiveraction.org
- **CaringBridge:** www.caringbridge.org
- **Center to Advance Palliative Care:** www.capc.org
- **Chemo Angels:** www.chemoangels.com
- **Cleaning for a Reason:** www.cleaningforareason.org
- **Connect Thru Cancer:** www.connectthrucancer.org
- **Family Caregiver Alliance:** www.caregiver.org
- **Friend for Life Cancer Support Network:** www.friend4life.org
- **The Gathering Place:** www.touchedbycancer.org
- **Imerman Angels:** www.imermanangels.org
- **Livestrong Foundation:** www.livestrong.org
- **LivingWell Cancer Resource Center:** www.livingwellcrc.org
- **Lotsa Helping Hands:** www.lotsahelpinghands.com
- **National LGBT Cancer Project:** www.lgbtcancer.org
- **Patient Empowerment Network:** www.powerfulpatients.org
- **SHARE Caregiver Circle:** www.sharecancersupport.org/caregivers-support
- **Triage Cancer:** www.triagecancer.org
- **Well Spouse Association:** www.wellspouse.org
- **weSPARK Cancer Support Center:** www.wespark.org

PATIENT
RESOURCE

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