# Do you have myelofibrosis or essential thrombocythemia?

Learn more about the MOST study (Myelofibrosis and Essential Thrombocythemia Observational Study).





### What Is an Observational Study?

An observational study collects information about you and your medical care. The focus of this type of study is on usual (routine) medical care. This is the care or treatment routinely given by a doctor for a certain condition or illness.

#### To learn more about observational studies and clinical studies in general, refer to

- https://clinicaltrials.gov/ct2/about-studies/learn#ObservationalStudies
- https://www.fda.gov/downloads/forconsumers/byaudience /minorityhealth/ucm465711.pdf
- https://www.fda.gov/ForPatients/ClinicalTrials/ucm407821.htm

## What Is the MOST Study About?

The purpose of this study is to learn more about myelofibrosis (my-eh-low-fi-BRO-sis) (MF) and essential thrombocythemia (throm-boe-sie-THEE-mee-uh) (ET). Among other things, the study will examine

- O How the disease and your treatments change over time
- O How the disease and your usual care affect your daily life
- What other medical issues, if any, occur during the course of the disease

Incyte, a company that develops drugs for MF and ET, is the study sponsor.

## How Do I Know if I Qualify for the MOST Study?

#### INCLUSION CRITERIA

Every study has guidelines to help determine if a person is eligible to take part or not. Inclusion criteria are all the things that must be true for you to join a study. For this study, some of these include



- Have been diagnosed with low-risk MF by your doctor, OR

If you have **ET**, you must also



#### **EXCLUSION CRITERIA**

Exclusion criteria are all the things that would prevent you from joining a study. For this study, some of these include



You are participating in another clinical study by Incyte (this study's sponsor) and have not completed the 30-day end-of-study visit

Your doctor or a study doctor has determined that it would not be in your best interest to participate because of your medical condition

#### To find out if you can be in the MOST study, call this number: 1-844-466-7867, then select option 1. You may have to answer some pre-screening questions.

Talk to your doctor if you are interested in participating in the MOST study. To find a study center near you, call 1-844-466-7867, then select option 1.

You can also visit clinicaltrials.gov and enter NCT02953704 to learn more.



Have been diagnosed with intermediate-risk MF solely because of your age





## What Else Would I Need to Do if I Want to Join the MOST Study?

A study doctor will decide if you qualify based on the information you provide and your existing lab test results. If you qualify to join, you will need to read and sign an informed consent document.

## How Long Will I Be in the MOST Study?

Your treating doctor will keep track of your disease and treatment for a period of at least 36 months (3 years).

## What Will Be Expected of Me During the **MOST Study?**

You will continue with your usual care and continue with any medicines you are now taking. Any office visits and lab tests will be according to the normal routine practices of your treating doctor(s) or study doctor(s). There is no study drug involved in this study. There will be no added visits or appointments as a result of you being in the study.

At your enrollment visit, you will be asked to participate in 3 optional sub-studies. You do **NOT** have to participate in a sub-study to be in the MOST study. If you choose to participate in the sub-studies, you will be asked to provide samples of saliva, blood, or bone marrow. The schedule for sample collection will be as follows:

- Saliva—provide saliva just one time, at enrollment visit only
- Blood—give blood every 6 months
- O Bone marrow—have a bone marrow biopsy every 12 months

# What Costs May Be Covered During the MOST Study?

The study team may help you check with your health plan and your doctor about any costs related to the study. Your routine medical care will be billed to you or your insurer in the ordinary manner. You will not be paid for being in the study.

#### You should learn before joining this study

- Which part of the research-related care will be free • Which costs your insurer will pay; which costs you will have to pay O If you will be reimbursed for travel costs up to a certain amount per visit

## Are There Benefits and Risks to Being in an **Observational Study?**

Your current doctor is the best person to help you understand the possible benefits and risks of joining a study.

#### Below are 2 websites that can help you start a conversation

- https://www.nhlbi.nih.gov/studies/clinicaltrials/benefitsrisks
- https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics



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## Is There a MOST Study Center Near Me?

Review the map to find the study center nearest to you. To get the address and phone number of a study center, call the number below. You can also visit **clinicaltrials.gov** and enter **NCT02953704** to learn more.

#### To learn more about the MOST study, call

# 1-844-466-7867, then select option 1.

You can also visit clinicaltrials.gov and enter NCT02953704 to learn more.

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