

Step-by-step guide:

MPN PROGRESSION Registry® user registration process

Step 1

Visit the MPN Research Foundation website

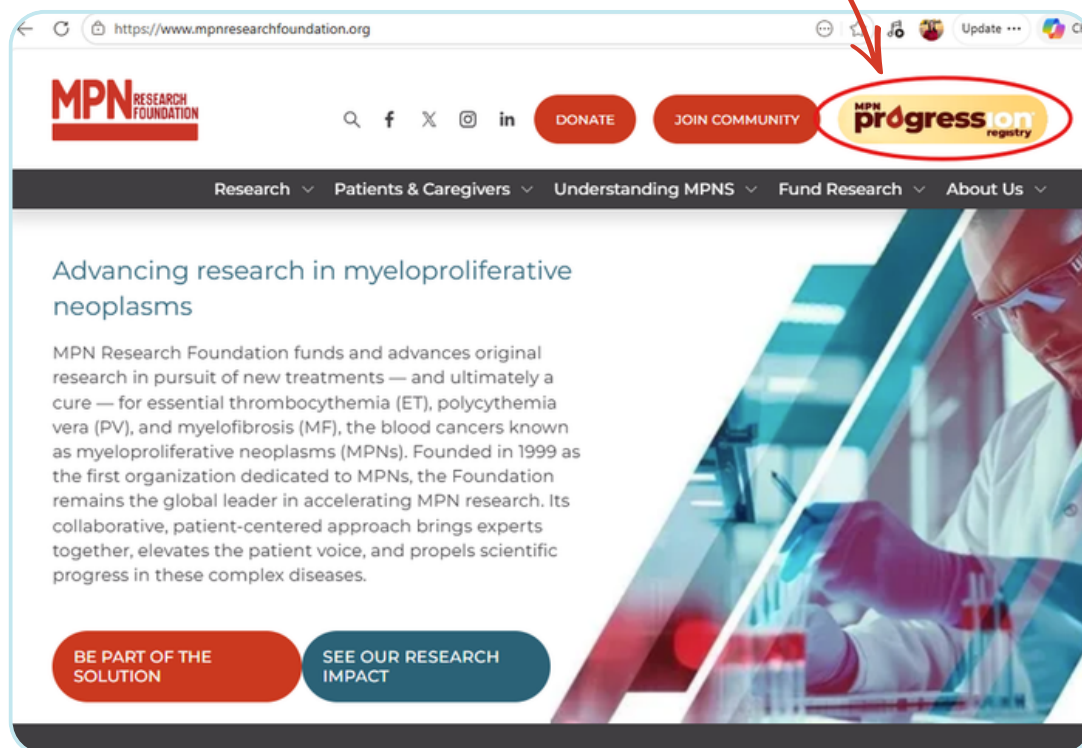


mpnresearchfoundation.org

To begin enrollment in the MPN PROGRESSION Registry®, start by visiting the MPN Research Foundation website at **mpnresearchfoundation.org**

Once you are on the homepage, locate the **MPN Progression Registry** button in the top right corner of the screen.

Select this button to navigate directly to the MPN Progression Registry page.

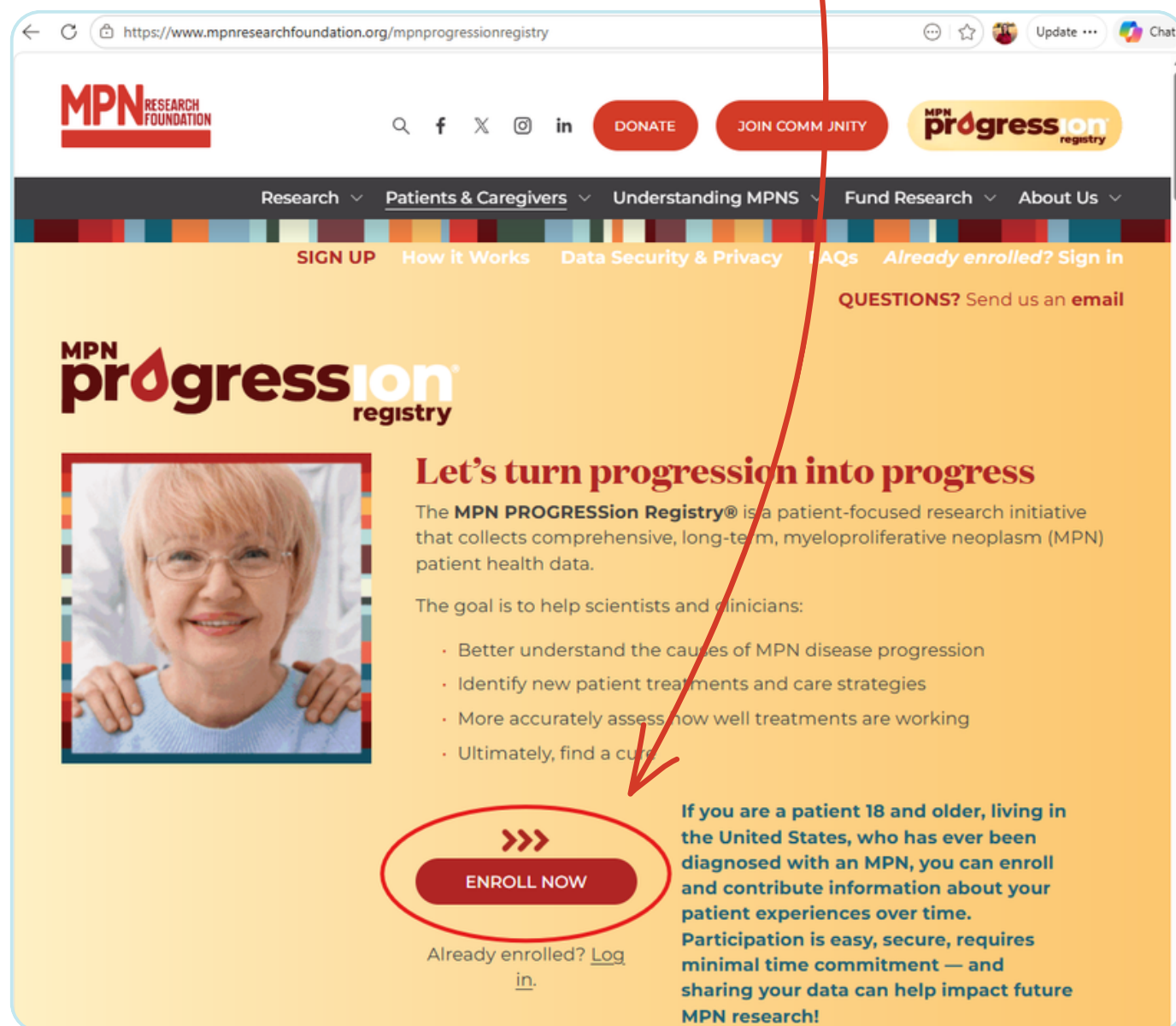


Step 2

Access the MPN PROGRESSION Registry® page

On the MPN PROGRESSION Registry® page, you can review information about the Registry.

When you're ready to begin enrollment, **select the Enroll Now button** to proceed with the registration process.



The screenshot shows the MPN PROGRESSION Registry website. At the top, there is a navigation bar with the MPN Research Foundation logo, social media icons, and buttons for DONATE and JOIN COMMUNITY. Below this is a secondary navigation bar with links for Research, Patients & Caregivers, Understanding MPNS, Fund Research, and About Us. A third navigation bar contains links for SIGN UP, How it Works, Data Security & Privacy, FAQs, and Already enrolled? Sign in. The main content area features the MPN progression registry logo, a photo of a smiling woman, and the heading "Let's turn progression into progress". Below this, a paragraph describes the registry as a patient-focused research initiative. A list of goals is provided, and a red arrow points from the text "select the Enroll Now button" to the ENROLL NOW button, which is circled in red. To the right of the button, there is a call to action for patients 18 and older. At the bottom left, there is a link for already enrolled users to log in.

<https://www.mpnresearchfoundation.org/mpnprogressionregistry>

MPN RESEARCH FOUNDATION

DONATE JOIN COMMUNITY

MPN progression registry

Research Patients & Caregivers Understanding MPNS Fund Research About Us

SIGN UP How it Works Data Security & Privacy FAQs Already enrolled? Sign in

QUESTIONS? Send us an email

MPN progression registry

Let's turn progression into progress

The **MPN PROGRESSION Registry®** is a patient-focused research initiative that collects comprehensive, long-term, myeloproliferative neoplasm (MPN) patient health data.

The goal is to help scientists and clinicians:

- Better understand the causes of MPN disease progression
- Identify new patient treatments and care strategies
- More accurately assess how well treatments are working
- Ultimately, find a cure

>>> ENROLL NOW

Already enrolled? [Log in.](#)

If you are a patient 18 and older, living in the United States, who has ever been diagnosed with an MPN, you can enroll and contribute information about your patient experiences over time. Participation is easy, secure, requires minimal time commitment — and sharing your data can help impact future MPN research!

Step 3

Complete the initial contact form



Access the form here:
tfaforms.com/5190961

Please complete the initial patient contact form to continue with enrollment in the MPN PROGRESSion Registry®.

This form collects basic information such as your name, date of birth, contact details, and MPN diagnosis. It allows the MPN Research Foundation to contact you and support your enrollment in the registry.

This form is separate from your medical records and is used only for internal tracking and communication. It does not provide access to your medical record data.

After completing all required fields, **select Submit to continue.**

You will then be redirected to the secure MPN PROGRESSion Registry® platform to complete the rest of your enrollment.

Please note: You will be asked to enter similar information again during the enrollment process.

Example Form:



Thank you for your interest in MPN PROGRESSion Registry™ enrollment. Your participation will play a vital role in helping us to expand understanding of MPN disease progression and shape the future of MPN treatments and research. We greatly appreciate your time and trust.

Please fill out the initial patient contact form below. Completing this form ensures that MPN Research Foundation has accurate, authorized information for those seeking enrollment in our patient registry. By entering your information, you agree to be contacted by MPN Research Foundation regarding the MPN PROGRESSion Registry.

After you submit this form, you'll be redirected to the secure MPN PROGRESSion Registry platform to complete your enrollment and may be asked for similar information.

At this time, only patients 18 and older, living in the United States, who have ever received an MPN diagnosis are eligible to participate.

First Name * Last Name *

Date of birth Email Address *

Phone Street

City

Postal Code Country * State

What is the patient's MPN diagnosis? *

- ☐ Polycythemia Vera (PV)
- ☐ Essential Thrombocythemia (ET)
- ☐ Primary Myelofibrosis (PMF): Diagnosed without a prior history of another MPN
- ☐ Secondary Myelofibrosis (sMF): Develops as a progression of ET or PV
- ☐ Secondary Acute Myeloid Leukemia (sAML): Arises as a progression of a MPN
- ☐ Other:
- ☐ Prefer not to answer

☐ I'm not a robot 

reCAPTCHA helps prevent automated form spam.
The submit button will be disabled until you complete the CAPTCHA.

Step 4

Continue to registration

After submitting the contact form, **you will be redirected** to the MPN PROGRESSION Registry® welcome page.

Review the information on the screen and **select “Sign up”** to begin the registration process.



Welcome

Welcome to the MPN PROGRESSION
Registry™

Select country



United States of America



Please select your language preference



English (United States)



To create your account, select sign up and provide your profile preferences.

Sign up

Sign in

Step 5

Answer eligibility questions

Before continuing, **please answer a few questions to confirm your eligibility** for the MPN PROGRESSION Registry®.

Select the appropriate response from each dropdown menu:

- Are you at least 18 years old?
- Do you currently live in the United States?

After answering both questions, **select Continue** to proceed.



Answer the following questions about you or
the individual diagnosed with MPN.

Are you at least 18 years old?

Yes, I am 18 or older



Do you currently live in the United States?

Yes



Continue



Important: To continue enrollment, you must have selected “**yes**” for both eligibility questions.

Step 6

Create your profile

Enter your information to create your MPN PROGRESSion Registry® account.

If you are completing registration as a legally authorized representative (LAR), enter your information as prompted.

Complete the required fields, including:

- First Name
- Last Name
- Email and Confirm Email
- Password and Confirm Password

Your password must meet the following requirements:

- At least 8 characters in length
- Includes a lowercase letter (a–z)
- Includes an uppercase letter (A–Z)
- Includes a number (0–9)
- Includes a special character (e.g., ! @ # \$ % ^ & *)

Review the Terms and Conditions and Privacy Policy, then **select both checkboxes** to proceed.

When all required fields are complete and both checkboxes are selected, the Sign Up button will become active. **Select Sign Up to continue.**



Create your Profile

**If you are a legally authorized representative (LAR), please complete this profile using your information

Passwords must:

- ☐ Have at least 8 characters in length
- ☐ Lower case letters (a-z)
- ☐ Upper case letters (A-Z)
- ☐ Numbers (i.e. 0-9)
- ☐ Special characters (e.g. !@#\$%^&*)

☐ I have read and agree to the [Terms and Conditions](#)

☐ I have read and agree to the [Privacy Policy](#)

< Back

Step 7

Check your email

After creating your account, you will be asked to **verify your email address**.

Check your inbox for an email from the MPN PROGRESSion Registry® with instructions to complete your sign up.

If you do not see the email, check your spam or junk folder.

If needed, select Resend email to receive another verification message.

Check your email

We sent you an email with instructions on how to complete your sign up.

If you do not see an email in your inbox, please check your spam or junk folder.

smithjane@yopmail.com

Resend email

[Back to create your account](#)

Step 8

Verify your email address

Open the email you received from the MPN PROGRESSion Registry® and **select Verify email** to confirm your email address and continue registration.

If you do not see the email, check your spam or junk folder.

Hello Jane,

Thanks for taking the first step to join the MPN PROGRESSion Registry!
Please click the link below to confirm your email address and continue your registration.

Verify email

Please add our email address to your email contacts, so your Registry emails do not go into your spam or junk folders.

Thank you,

The MPN PROGRESSion Registry Team

This email was sent on behalf of the MPN PROGRESSion Registry team. Please do not reply to this email. This inbox is not monitored.

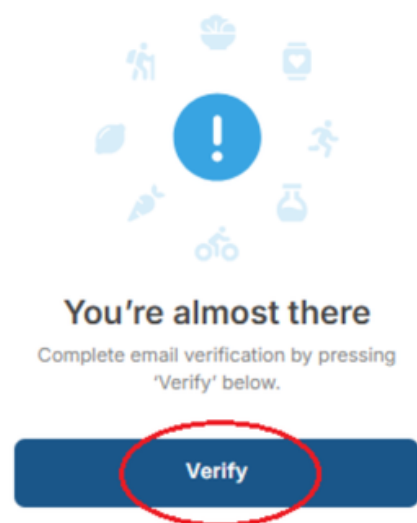
Example verification email

Step 9

Complete email verification

After selecting Verify Email in your email, **you will be redirected** back to the MPN PROGRESSION Registry® to complete verification.

On this screen, **select Verify** to confirm your email address and continue enrollment.



Step 10

Enter your contact information

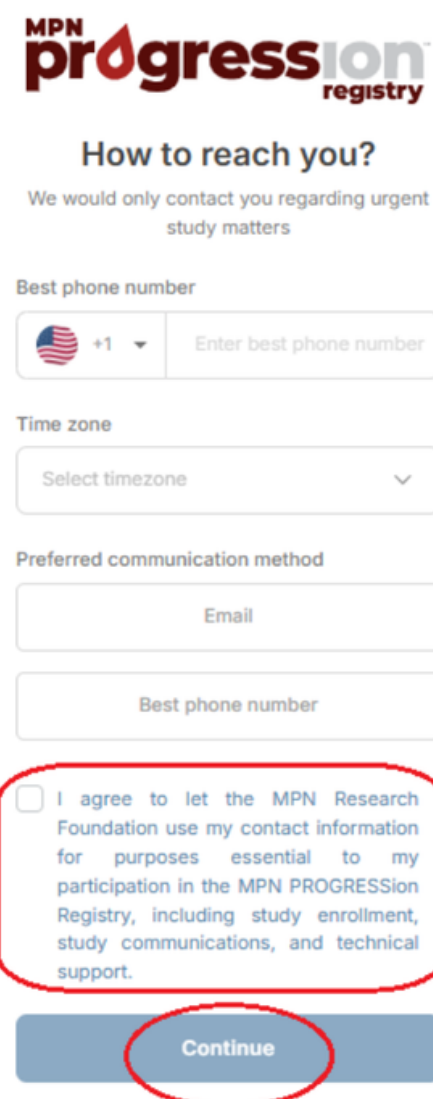
Provide your contact information so the MPN PROGRESSION Registry® can reach you if needed.

Complete the required fields, including:

- Best phone number
- Time zone
- Preferred communication method

Review the consent statement, **then select the checkbox** to agree.

When all required fields are complete and the checkbox is selected, **click Continue** to proceed.



Step 11

Enter your personal information

Provide your personal details to complete your Registry profile.

If you are a legally authorized representative (LAR), please complete this section using your information.

Complete the required fields, including:

- First Name
- Last Name
- Date of birth
- Address information

Optional fields may also be completed if applicable.

When all required fields are complete, **select Continue** to proceed.

Example form



Personal Information

Personal Information for your profile. **If you are a legally authorized representative (LAR), please complete using your information.

First Name

Middle Name (optional)

☐

I don't have a middle name (optional)

Last Name

Date of birth



Alternate Email (optional)

State



City

Zip

Street address

Continue

Step 12

Select your relationship to MPN

Indicate your role by selecting the option that best describes you.

Select one of the available options, then **click Save & continue** to proceed.

Step 12a

If you selected “A person diagnosed with MPN, answering for myself”

You will be directed to review and sign the informed consent form. **Continue to the next step.**

Step 12b

If you selected “Legally authorized representative for a person diagnosed with MPN”

You will be asked to **provide information for the individual diagnosed** with MPN before continuing.

Enter the required details, which may include:

- Name
- Date of Birth
- Contact information
- Demographic information

After completing all required fields, **select Save & continue** to proceed to the consent step.



Relationship to MPN

Which role best describes you?

☒ A person diagnosed with MPN, answering for myself

☐ Legally authorized representative for a person diagnosed with MPN

Save & continue

Step 13

Review and sign consent

To participate in the MPN PROGRESSion Registry®, you must **review and sign** the informed consent form.

Select Review & Sign to open the consent document and continue.

MPN
progression
registry

Please review and sign your consent to join research

Study participation requires that you review and sign the following document(s)

Informed Consent

Consent

Version no. v4.1

Version date: 03-27-2025

The consent form explains the study including the risks and benefits of participation.

REQUIRED

Review & Sign

Step 14

Complete the consent form in DocuSign

The consent form will open in a secure DocuSign window.

Select Start to begin reviewing and completing the consent form.

Follow the prompts in DocuSign to complete the form:

- Review the informed consent document
- Select Sign where indicated
- Confirm your full name, initials, and electronic signature
- Select Adopt and Sign
- Continue reviewing the document and complete the remaining required fields

When all required fields are complete, **select Finish to submit your consent** and return to the MPN PROGRESSion Registry®.

DocuSign Envelope ID: 9C050D07-D1F0-800E-826E-2FC2E852445B

Start

RESEARCH SUBJECT CONSENT FORM

TITLE: MPN PROGRESSion Registry™ (PROGRESS-MPN): A U.S.-Based Observational Study Tracking Symptoms, Treatments, Clinical Outcomes, and Disease Progression in Myeloproliferative Neoplasms (NCT07362225)

PROTOCOL NO.: MPN-PROG-2025-002
WCG IRB Protocol #20251868

Step 15

Continue after consent

After completing the informed consent form, you will see a confirmation message.

Select Continue to proceed with enrollment.



Consent accepted

Thank you for signing your study document(s)

Continue

Step 16

Answer Additional Eligibility Questions

Please **answer the following questions** to complete your enrollment in the MPN PROGRESSion Registry®.

Respond to each question based on your situation or, if applicable, the individual diagnosed with MPN. Some questions may allow you to select more than one option.

When all questions are complete, **select Continue** to proceed.

Step 14 continues on the next page.

Example eligibility questions



Answer the following questions about you or the individual diagnosed with MPN.

Have you ever been diagnosed with a myeloproliferative neoplasm (MPN) by a healthcare provider?

Select

Which type of MPN have you been diagnosed with? (Select all that apply, including both current and any previous MPN diagnoses. If your diagnosis has changed over time, please select all that have ever applied to you.)



Polycythemia Vera (PV)



Essential Thrombocythemia (ET)



Primary Myelofibrosis (PMF)



Post-Polycythemia Vera Myelofibrosis (Post-PV MF)



Post-Essential Thrombocythemia Myelofibrosis (Post-ET MF)



Pre-fibrotic Primary Myelofibrosis (pre-PMF)



MPN-Unclassifiable (MPN-U)



MPN in Accelerated Phase (MPN-AP)



MPN in Blast Phase (MPN-BP)

Has your MPN diagnosis ever changed after further testing or evaluation?

Select

Do you currently receive, or have you ever received medical care for your MPN?

Select

Do you currently have access to your electronic medical records (EMR) from one or more participating healthcare institutions?

Select

Has a doctor ever told you that your blood counts might be high for reasons other than an MPN (for example, due to infection, inflammation, or another temporary cause)?

Select

Are you currently enrolled in a clinical trial that does not allow your medical records to be shared with other research studies?

Select

Are you able to provide informed consent, or do you have a legally authorized representative (LAR) who can provide consent?

Select

This registry requires long-term participation, including data sharing, surveys, and follow-up over multiple years. Do you understand and agree to these terms?

Select

Continue

Step 16 (Continued)

If you see a message that you do not meet eligibility:

If your answers indicate that you may not meet the eligibility criteria to participate at this time, **a message will appear** letting you know.

- **Select “Change my Information” to review and update** your answers if needed. *This can sometimes happen if a question was answered incorrectly so we recommend reviewing your responses carefully.*
- If your answers are correct, you may not meet eligibility criteria to continue with enrollment at this time. **If you believe this is incorrect, please email us at mpnprogressionregistry@mpnrf.org.**

Step 17

Optional: **Add an alternative contact**

You may choose to add an alternative contact who can be reached if you are unavailable.

- **Select Add new contact** if you would like to provide an additional contact now or
- **Select Add later to skip this step** and continue enrollment

You can add or update an alternative contact at any time after enrollment.



Alternative contact

Who can we contact if we can't reach you?

+ Add new contact

Add later

Step 18: Final step!

Complete enrollment

Once you have finished all required steps, you will see a **confirmation message**.

Select Continue to complete enrollment.

After selecting Continue, you will be taken to the MPN PROGRESSion Registry®, where you can begin completing activities.



Congratulations!

You successfully completed the onboarding process

Continue

Questions or need help?

If you have any questions or need help connecting your medical records, our team is here to help. Please email us at mpnprogressionregistry@mpnrf.org.

MPN
RESEARCH
FOUNDATION

