







Together,
individual drops of
data can make
an ocean of change.



The **MPN PROGRESSION Registry™** is a patient-focused research initiative that gathers comprehensive myeloproliferative neoplasm (MPN) patient health data over 5-10 years. The goal is to help provide better understanding of MPNs — a group of rare blood cancers that include polycythemia vera (PV), essential thrombocythemia (ET), and myelofibrosis (MF) — and why they can progress in severity from one disease to another, and, more rarely, to secondary acute myeloid leukemia (sAML).

If you are 18 or older, live in the U.S., and have ever been diagnosed with an MPN, you can join and share your health journey over time. By participating, you'll help researchers and clinicians:

-  Better understand what causes progression: when MPNs progress to more aggressive forms of the disease
-  Discover new treatments and care strategies
-  Measure how well care treatments work
-  Move us closer to a cure for MPNs

Enroll today

ARE YOU AN MPN PATIENT LIVING IN THE U.S.?

You can impact MPN research!
Participation is easy, secure, and
requires minimal time commitment.



[MPNRESEARCHFOUNDATION.ORG/
MPNPROGRESSIONREGISTRY](https://MPNRESEARCHFOUNDATION.ORG/MPNPROGRESSIONREGISTRY)

***Your data is part
of the solution!***

"As both an MPN patient and a scientific researcher, I view this registry as an invaluable tool which will be utilized to direct the next generation of MPN-related scientific discovery."

— Tyler Parsons, PhD
Chair, MPN PROGRESSION Registry Patient
Engagement Advisory Council (PEAC),
PV patient, and researcher, Washington
University School of Medicine



Let's turn progression into progress.

We still have a lot to learn about how MPNs progress.

ENROLL TODAY!

DESIGNED TO KEEP YOUR DATA ANONYMOUS & SECURE

The **MPN PROGRESSION Registry™** system:

- Securely stores and protects any health information you share
- Meets strict HIPAA medical privacy laws
- Meets National Institutes of Health (NIH) standards for privacy & confidentiality
- Is reviewed each year by an independent ethics board (IRB) to ensure patient rights and safety
- Keeps your personal information separate from your health data

None of your identifying information will be used for research. Only anonymous data, without your name or personal details, will be shared with carefully approved research teams.



ARE YOU 18 OR OLDER, LIVING IN THE U.S., AND HAVE YOU EVER BEEN DIAGNOSED WITH AN MPN?

JOIN THE REGISTRY
MPNRESEARCHFOUNDATION.ORG/MPNPROGRESSIONREGISTRY

MPN
progression
registry™

Questions? Email research@mpnrf.org

How does it work?

1.

Enroll online, designate your care center & consent to share your electronic medical records — it's fast and easy.

2.

The Registry system automatically and securely pulls your records, with more health updates added over time.

3.

Log in to your portal to answer regular, brief surveys about your MPN health journey & experiences.

4.

No names. No personal details. Only anonymous data is shared — and only with approved partners.