

# MPN Pathways: Empowered Voices in Research

## MPN Research Foundation Patient Research Advocate Certification Program



### INTRODUCTION & AIMS

The **MPN Pathways: Empowered Voices in Research Certification Program** is a multi-year, disease-specific educational initiative developed by the MPN Research Foundation to prepare patients, caregivers, and advocates to actively and confidently engage in myeloproliferative neoplasm (MPN) research. Through **nine expert-led webinars** presented quarterly from 2024-2026, the program offers structured, accessible training on core research concepts, including:

- Clinical trial design and regulatory pathways
- Patient-reported outcomes and real-world data
- FDA processes and ethics in research
- Best practices for patient engagement

#### Aims:

- Increase research literacy within the MPN community to enable meaningful participation in research design, review, and advocacy.
- Demystify the research process and reduce barriers caused by medical jargon, power imbalances, or lack of formal training.
- Build a network of informed, empowered advocates who can serve on advisory boards, co-design studies, and bring lived experience to scientific decision-making.
- Sustain engagement by recognizing participants who complete all sessions with a formal certification, fostering credibility and ongoing involvement in research initiatives.

This initiative reflects the Foundation's commitment to power-sharing—ensuring that those most affected by MPNs are central to shaping the future of MPN research.

### METHODOLOGY

#### Program Structure:

- **Nine webinars** (2024-2026), each 60-90 minutes, led by advocates, research, clinical, and regulatory experts.
- Topics selected in collaboration with patients, caregivers, and research professionals to ensure relevance.
- Webinars delivered live **via Zoom** with interactive Q&A and recorded for on-demand access in the Foundation's online Webinar Library.

#### Participation & Certification:

- Open to all MPN patients, caregivers, and advocates worldwide, free of charge.
- Participants complete a short **online evaluation** after each session to reflect on learning, provide feedback, and confirm attendance.
- Certificates awarded to individuals who view all nine webinars and submit all evaluations.

#### Data Collection & Evaluation:

- **Quantitative data:** Registration, attendance, geographic reach, and evaluation responses.
- **Qualitative data:** Open-ended survey feedback and participant testimonials to assess knowledge gained, confidence, and perceived relevance.
- Findings used to continuously refine content and format for maximum community impact.

By combining structured education with active evaluation, the program both tracks progress and fosters a growing cohort of research-ready MPN advocates prepared to contribute meaningfully to the research enterprise.

### MPN Pathways Program Sponsors:

Bristol Myers Squibb, Geron, GSK, Incyte, Karyopharm, Merck, Morphosys, PharmaEssentia, Protagonist, SOBI, and Sumitomo.



Year	Topic	Speaker
<b>Year 1: Foundational Knowledge</b>	Intro MPN Research Foundation & MPN 101	Sara Douglas, MSN, RN, OCN
	The Life Cycle of Drug Development	Scott Weir, PharmD, PhD
<b>Year 2: Clinical Insights and Patient Advocacy</b>	MPN Clinical Trials 101	Christina Persaud, RN, BSN, CCRP
	FDA 101	Sarah Wicks
	Patient and Caregiver Voices in Research	Patty Spears, BS, FASCO
<b>Year 3: Advanced Topics and Practical Skills</b>	Clinical Trial Research Protocol 101	Jane Perlmutter, PhD, MBA
	Informed Consent	TBD
	A Patient's Guide to Scientific Presentations	TBD
	Patient-Reported Outcomes and Quality of Life in MPNs	TBD

### RESULTS & CONCLUSIONS

The MPN Pathways: Empowered Voices in Research Certification Program is already making a measurable and personal impact across the MPN community – educating, equipping, and elevating patients and caregivers to play a more informed role in research.

#### Program Highlights:

- **Launched:** 2024
- **Reach so far:** Over 2,800 registrants across 6 webinars
- **Inaugural session attendance:** 716 patients, 93 caregivers, 90 healthcare/industry professionals
- **Global Impact:** Participants from 52 countries
- **Content ratings:** Accessible, relevant, and empowering

#### Impact by the Numbers:

- 90%+ agreed sessions were easy to understand, engaging, and applicable
- 80%+ found content confidence-building and relevant
- Dozens of live questions each session show high engagement

#### Participant Voices:

- "Sometimes living with an MPN you feel like things are out of your control. This is a great way to feel empowered by learning more about it and what you can do to advocate for yourself and your treatment." – Session 1 Attendee
- "I have a better understanding of risks/rewards of participating in clinical trials, and a realistic time frame for drug approval." – Session 2 Attendee
- "Join. Learn. Your life depends on it. Educated patients get better treatment." – Session 3 Attendee
- "Not only will I hopefully be able to assist others – I am learning more about my own journey." – Session 4 Attendee

#### Looking Ahead:

By 2026, the program will feature **9 sessions** and award **certification** to participants who complete all webinars and evaluations – creating a **cohort of informed, research-ready MPN advocates** ready to:

- Serve on advisory boards
- Contribute to trial design
- Share lived experience to shape future research

The MPN Research Foundation is committed to a future where patients are not only informed but central to driving progress in MPN research.