MPN PATIENT BILL OF RIGHTS

This Bill of Rights helps establish and promote awareness of care elements that are crucial to quality MPN care. It is our hope that patients will use this document to learn about their disease and participate actively in their care.

AS AN MPN PATIENT, YOU HAVE THE RIGHT TO:

1. RECEIVE A CLEAR, UNDERSTANDBLE DIAGNOSIS AND TO SEEK A SECOND OPINION FROM AN MPN SPECIALIST.

2. ASK YOUR DOCTOR TO COMMUNICATE YOUR TREATMENT PLAN (AND IT’S POTENTIAL IMPLICATIONS) IN A WAY YOU UNDERSTAND.

3. BE INFORMED AS TO HOW YOUR DIAGNOSIS AND TREATMENT MAY IMPACT YOUR REPRODUCTIVE HEALTH.

4. ACCESS MEDICATIONS AND TREATMENTS AS DEEMED APPROPRIATE BY YOUR DOCTOR, NOT YOUR INSURANCE.

5. FIND SOURCES OF FINANCIAL INFORMATION AND ASSISTANCE, UNDERSTAND HOW YOUR INSURANCE COMPANY PRIORITIZES CARE, AND HOW YOU CAN SUBMIT MULTIPLE APPEALS IF YOUR INSURANCE DENIES A TREATMENT OR APPOINTMENT.

6. ACCESS ACCURATE INFORMATION FROM REPUTABLE SOURCES INCLUDING ACADMIC INSTITUTIONS, HEALTHCARE PROFESSIONALS, PATIENT ADVOCACY ORGANIZATIONS, ONLINE PATIENT COMMUNITIES AND ELSEWHERE.

7. KEEP YOUR DOCTORS INFORMED ABOUT SYMPTOMS AFFECTING YOUR QUALITY OF LIFE, AND RECEIVE INFORMATION DIRECTED AT IMPROVING THOSE SYMPTOMS.

8. INCLUDE YOUR CAREGIVERS, FAMILY, AND FRIENDS IN CONSULTATIONS WITH HEALTHCARE TEAMS.

9. DISCLOSE OR NOT DISCLOSE YOUR DIAGNOSIS TO YOUR EMPLOYERS, AND PREVENT OR STOP UNLAWFUL DISCRIMINATION OR JUDGEMENT DUE TO YOUR CONDITION.

10. ACCESS CLINICAL TRIAL INFORMATION AND PARTICIPATE IN THOSE TRIALS IF YOU MEET THE ELIGIBILITY CRITERIA.

LEARN MORE AT MPNRESEARCHFOUNDATION.ORG/PBDR

Created in partnership with the MPN Research Foundation, MPN Marching & Education Initiative, Leukemia & Lymphoma Society, MPN Education Foundation, Patient Power, ClinicalCare, National Organization for Rare Disorders, Cancer Support Community, and PB & Partners.