



Stakeholder Engagement in the Solution

Kapila Viges
MPN Research Foundation



MPN Horizons 13-15 October **Understanding the New Complexity of MPNs**





- The path to solving the problems of disease, especially MPNs, is complicated
- Engaging all the stakeholders along the journey is essential
- Remove our biases, skepticism, and motives to focus on the solutions





13-15 October Zagreb, Croatia 2023

2023 - COO





Robert Rosen was diagnosed with polycythemia vera in 1997.

He pulled together the few MPN patients he could find and established the MPN* Research Foundation in 1999.

MPN RESEARCH FOUNDATION

MISSION

The mission of the MPN Research Foundation is to stimulate original research in pursuit of new treatments — and eventually a cure — for the blood cancers polycythemia vera, essential thrombocythemia, and myelofibrosis, known collectively as myeloproliferative neoplasms (MPN).







MPNRF has three unique roles in the MPN Community that advance the research mission

Research

Identify, fund, and support novel research to accelerate the discovery and development of effective MPN treatments

Convene

Facilitate global engagement across patient and caregiving, research and clinical, and industry stakeholders

Advocate

Advance patient and researcher perspectives on the development of new treatments



Researchers

Clinicians

We have a neutral convening role to

- Facilitate varied perspectives
- Break-down information siloes
- Align objectives

Convene to Capture Unmet Needs

Biopharma Industry





Example: MPN Disease Progression

Patients and Caregivers

- Uncertainty and unpredictability
- Difference in disease experiences
- Differences in clinical experiences

Scientists and Clinicians

- Evidence to build consensus and confidence in signs of progression
- Large-scale data due to heterogeneity
- Natural history and prospective to study infrequent events

Industry and Health Authorities

- Interventional endpoints to address progression
- Real-world evidence of the impact of treatments on progression



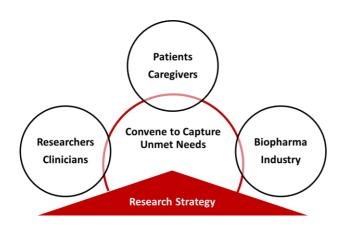


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PROGRESSION RESEARCH NETWORK

A global network of researchers collaborating on the prevention and treatment of disease progression to:



Result

Define MPN Progression Criteria

What do we mean by MPN progression and is there sufficient consensus to define it beyond transformation to more aggressive disease

Validate predictive markers

What clinical factors indicate who might progress and when

Define new clinical trial endpoints

What clinical outcomes are measures of progression with sufficient evidence to be recognized by regulatory authorities

Develop new care guidelines

With new information, how should treatment approaches be updated and communicated