

2024 MPN Challenge™ Awards: Patients and Caregivers Play an Active Role in MPN Research



Introduction & Aims

Today, it is essential for patients to be involved with research and drug developers as they progress through the various stages of bringing a new therapy to market. MPN Research Foundation (MPNRF) is committed to ensuring that patient participation is more than a ticked box for drug approval.

We actively work to incorporate the patient voice and experience early enough in the discovery and drug development process to allow for insights and input that might influence a clinical trial design, or how participants monitor their symptoms, or something about the treatment protocol itself that could lead to more meaningful benefit of the treatment.

The MPNRF Patient Impact Council (PIC) is one way we are incorporating patient and caregiver input into where the gaps are in MPN research. We want to better understand what the priorities are from a patient perspective, and widely share their expertise. And we want to identify what might be missing from the drug development process that hasn't been previously considered.

Members of the PIC are active participants in the review process for our 2024 MPN Challenge™ awards, MPNRF's open RFP research initiative that allows us to fund the most pressing MPN science through 2-year funding cycles.

MPN Research Foundation Patient Impact Council



Methodology

- Members of the PIC (13) were given a thorough MPN Challenge™ proposal review training that included: reviewing the submission timelines, application form, parts of a research proposal reviewing the proposal from a patient/caregiver perspective, and instructions for receiving proposals and submitting reviews.
- 2024 project applications went through the review process, including by a peer review committee and members of the PIC.
- Patient/Caregiver reviewers are asked to score the potential patient impact of each proposed project.
- They offer insight into why each project might be important to patients - regarding how they feel, function, or survive.
- They underscore how understandable the project's abstract is, helping researchers communicate their science in ways the general patient population will comprehend.
- They comment on whether the accomplishments of a specific project's aims advance our knowledge of MPN causes, prevention, or cure.
- Will the research add additional care burdens for a patient?
- Is it clear from the narrative that the research has the potential to impact patients?
- These and other opportunities for comment are part of the PIC members' participation in both the scoring analysis - using the NIH (National Institutes of Health) Grant Application Scoring System - and the live review process of final candidates.
- PIC and scientific reviewers met virtually to discuss the scores and reviews during a half-day MPNRF Peer Review Committee Session.
- Together the PIC and the scientific reviewers selected 6 proposals to fund.

2024 MPN Challenge™ Awardees



Results

Evaluations were sent out to both the PIC and scientific reviewers.

Key positive feedback included:

- Including patient reviewers provided insight that is usually missing from peer review and viewed positively..
- 83% of respondents felt peer review meeting was effective in fostering constructive discussion.
- Criteria for scoring well laid out.
- 88% of respondents felt their feedback was valued.
- Strong engagement of reviewers
- Review process was fair/transparent. Scoring system fairly represented the quality and relevance of the proposals.
- Reviewers are satisfied (4 & 5 stars) with their experience and 100% of respondents would participate in the process again.
- The goals of the foundation and its funding are clear.
- 94% of respondents felt it was an appropriate number of proposals to review and also felt there was enough time allocated to each proposal during meeting.
- 94% felt prepared (via materials and guidance) to complete reviews.
- Training/briefing was done well.
- Outcomes of peer review well communicated.

"Patient/caregiver reviewer added a unique perspective which I found interesting and valuable."

"I appreciated that many of the specific reviewers seemed to be matched to a proposal focused on a problem to which they had a personal connection"

Areas for improvement included:

- Final voting/review too long/reduce number of proposal that undergo full discussion
- Further, emphasize to applicants that language should be understandable by all. Could help with disparate scoring.
- Disparate scoring between scientific and patient scoring in a few cases. Resolve before meeting/scheduling call between those folks.
- To improve engagement and more consistent scoring, perhaps assign more proposals to each reviewer (less reviewers).
- More transparency on how proposals were ranked after peer review. (reviewer perspective)

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INSTRUCTIONS FOR MPN Horizons 2024 POSTERS

Posters can be sent to doneva@mpn-advocates.net and printed at the venue

REGARDING STYLE

- Size of the poster template: **A1: 59 x 84 cm**
- You can use this poster template or you can have your own design. Be creative as you like!
- Use at least 36 point font for your text and at least 48 point font for the title. Your font style should be legible also.
- We recommend to use images, tables, photos or graphs. Minimum recommended size is 300 dpi.
- Remember that viewers will typically expect information to flow from left to right and from top to bottom. Use arrows, pointing hands, numbers, or letters to help clarify the sequence or flow of the poster.
- Use headings and subheadings to label your information.

REGARDING CONTENT

- You can present an activity, project, initiative from 2023/2024 developed by your MPN patient organization.

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A GOOD POSTER SHOULD BE:

- **Readable.** Readability is a measure of how easy it is to understand the ideas and messages presented in the poster. If the text has lots of grammatical errors and misspellings, or contains complex or long sentences, it will be more difficult to understand.
- **Legible.** The text should be easy to read. A common error in poster presentations is use of fonts that are too small to be read from 1-2 meters away, a typical distance for reading a poster.
- **Well organized.** Spatial organization makes the difference between reaching 95% rather than just 5% of your audience: the poster should flow in a logical format – this means that the reader will not have to search out information and can spend more time learning about the initiative.
- **Succinct.** Studies show that you have only 11 seconds to grab and retain your audience's attention so make the punch line prominent and brief. Most of your audience is going to absorb only the punch line. Those who are really interested in the topic will seek you out anyway and chat with you!