29 January 2025

The Neurodegenerative, Palliative Care and Rare Diseases Advisory Group ((NPRAG) met online on 29 January 2025.

The Chair, Ms Prue Coroneos, General Manager, Policy, Evidence and Practice Leadership, National Disability Insurance Agency (NDIA), welcomed everyone to the meeting. Ms Coroneos thanked the group for supporting the NDIA to hear the voices, perspectives and gain a better understand of the unique challenges of people living with neurodegenerative, palliative care needs and rare diseases.

Focus of the meeting

The meeting covered:

- Member reporting – creating an ongoing agenda item for members to raise items or issues faced by their community to the Agency
- Quarterly reporting – inviting Actuary to hear member data or reporting needs
- Practice improvements - increase frontline staff knowledge of neurodegenerative and rare diseases.
- Improvements to the access pathway - including how the Agency will map primary diagnosis to impairment categories. This item was postponed for a future meeting.

Member reporting

NDIA proposed a new ongoing agenda item, inviting members to table issues on behalf of their communities. Members raised issues which were logged for discussion at future meetings.

Quarterly Reporting

NDIA Actuarial Insights and Monitoring Branch attended to hear the members requests for ongoing data updates specific to their communities. Members discussed data questions collected prior to the meeting as well as data limitations and possibilities. The Chair agreed to come back to members with a proposal for quarterly data updates.

Practice improvements

NDIA Technical Advice and Practice Improvement Branch shared with members recent activities to increase frontline staff knowledge of neurodegenerative and rare diseases. Members were updated on proposed next steps and were asked for their expertise, including relevant and appropriate training resources and opportunities.

Improvements to the access pathway

This agenda item was postponed for a future meeting.

NPRAG Next Meeting;

The NPRAG will meet online again on 26 March 2025.

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- Neurodegenerative, Palliative Care and Rare Diseases Advisory Group communique

Neurodegenerative, Palliative Care and Rare Diseases Advisory Group Meeting November 2024

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