An Assessment of Fundamental Rights of People Living with ALS/MND Worldwide

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BACKGROUND

A guiding document for the Alliance is the Fundamental Rights of People Living with ALS/MND that states the aspirational rights of the global community. Originally conceived in the late 1990s as the “Baseline of Services for People Living with ALS/MND” these rights are updated each year by the Alliance’s PALS and CALS Advisory Council. In February of 2021, it was identified that the previously melded CALS and PALS rights needed to be in separate documents as the pandemic had exacerbated the Caregiver burden to the point where it was important to consider these rights separately. Therefore in 2021 the Fundamental Rights of Caregivers of People Living with ALS/MND was launched.

In addition, it was recognized that there needed to be a right added around Genetic Counseling and Testing which we now recognize is an important element to be considered at or near diagnosis. In 2023, a further review made further changes to the wording and made the first right “access to treatments”. Caregivers rights were expanded with the rights to ask for support when needed, to have direct communication with the medical team, and to be able to stay with the PALS when admitted to medical facilities.

These fundamental rights represent the ideal for individuals living with ALS/MND (PALS) and Caregivers (CALS) worldwide. Although the International Alliance and its representatives understand that some of these conditions might not be immediately attainable, this document represents the set of rights all Alliance member organisations should adopt and promote as conditions, systems and resources allow.

In April 2021, the Alliance decided to do a benchmark survey to ascertain the level of agreement that these rights were being respected for both PALS and CALS, and in May 2023, the second survey was launched to benchmark with the data captured in its first survey.

METHODS

The survey was done by Bramm Research an independent third party and it was launched both through our member organizations and on social media in May 2023. It was in the field for 60 days. We received responses from 54 countries. The survey was available in 16 different languages.

RESULTS

The assessment of the PALS rights indicates that they are not well respected globally with the median at 52%.

For more information on this project and others please contact us at alliance@als-mnd.org or visit us at als-mnd.org.