The international Alliance of ALS/MND Associations supports the following fundamental rights for caregivers of people living with ALS/MND (CALS).

These fundamental rights represent the ideals for CALS worldwide. This document is meant to be a framework for discussion and action.

Although the International Alliance and its representatives understand that some of these conditions might not be immediately attainable, this document represents the extent of rights that Caregivers feel are absent or underrepresented.

The pandemic has caused an increase in burden on Caregivers and there has been anecdotal evidence that Caregiver rights are not supported in many jurisdictions. Respect of the Fundamental Rights of Caregivers (CALS) is essential. Caregivers have little right to remuneration (27%) and even less so than the PALS (40%). We know that a person living with ALS/MND needs a high level of agreement that these rights were being respected for CALS.

**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 Rights for People Living with ALS/MND” (CALS), the survey was translated into 10 different languages. 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 August and it was in the field for 40 days. We received responses from 32 countries. The survey was translated into 10 different languages.

**HYPOTHESIS**

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**METHODS**

We would like to thank the 1000+ people who responded to the survey, particularly People Living with ALS and their Caregivers. We would also like to thank the PALS and CALS Advisory Council of the International Alliance of ALS/MND Associations who provided feedback and guidance on each iteration of this survey as it was developed.

**RESULTS**

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**DISCUSSION**

Overall the figures are low with a median of 30% of Fundamental Rights being respected for Caregivers, which is significantly lower to the companion survey for PALS which had a median of 45%. Caregivers feel an overall lack of support in all areas. Some specific findings that merit discussion are:

- **Figure 1.** The Fundamental Rights of People Living with ALS/MND
- **Figure 2.** The assessment of CALS rights indicates that they are not well respected globally with the median at 30%.
- **Figure 3.** Although 61% receive adequate education and access to resources, and 37% received counseling, less than 30% reported that they had support for legal, time for themselves, and palliative care support. This may be a discrepancy between what we want and what is reasonably achievable based on time constraints and lack of supplemental support.
- **Figure 4.** The ability to plan for my own future
- **Figure 5.** Caregivers and PALS are consistent in their disagreement that they have the right to input or to advocate in their healthcare systems. The data in all of these categories indicates the feeling of a lack of voice.

**ACKNOWLEDGEMENTS**

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