Alliance Purpose

The Alliance is a global network of ALS/MND associations informed by PALS/CALS, that builds capability for its members and connects to external stakeholders.
PCAC

• The PALS and CALS Advisory Council (PCAC) is charged with helping the Board of Directors (BOD) of the International Alliance of ALS/MND Associations consider and include in its work the wide-ranging opinions and ideas of people with ALS/MND and caregivers to people with ALS/MND from across the globe.
Council Members- Administration

- Calaneet Balas- Chair of the IAAA
- Cathy Cummings- ED of the IAAA
- Sara Feldman- PCAC Chair
- Gudjon Sigurdsson- Board Liaison
Council Members - Caregivers

- Ajay Gupta - India
- Mia Mahy - Belgium
Council Members - People living with ALS/MND

- Doug Clough - USA
- Charles Malcolm - UK
- Carol Skinner - Canada
Background/Timeline

• Strategic Plan for 2016-2019
• PALS Inclusion Committee
  ▫ Rob Goldstein, Barbara Newhouse, Kiki Qu
  ▫ December 2016 to December 2017 Board Meetings
  ▫ First Quarter 2018 Call for Nominations
  ▫ Second Quarter 2018 5 members of PCAC chosen
• PALS/CALS Advisory Council
  ▫ Board Liaison
    • Evy Reviers
    • Stepped down in May 2019
    • Gudjon Sigurdsson
First Steps

• Scheduled Virtual Calls/Meetings Once a Month
• Reviewed “The Fundamental Rights of People with ALS/MND” on the website
  ▫ No changes were recommended
• Amended the Terms of Reference
  ▫ Increase the number of Council members*
Current Activities/Work

• Reviewing
  ▫ Economic Burden

  ▫ Care Surveys
    • Impact ALS- ALS Association
    • Improving MND Care –MNDA

  ▫ Landscape Project

  ▫ Library on Website
Call for nominations

• Current PALS and CALS
  ▫ Not on Board of Directors of Alliance
  ▫ Not a paid staff member of an ALS/MND organization
    (may be a volunteer)

• Qualities
  ▫ Advocates/Want to be involved
  ▫ Have an understanding of the Alliance mission and goals
Call for nominations

• Time Commitment
  ▫ Once a month conference calls (~1 hour)
  ▫ Review and comment

• 2 Year Renewable Term

• Nomination form will be open on the website after the symposium through January 15, 2020
Thank you!