



PALS and CALS Council

Annual Report

December 1, 2019



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.



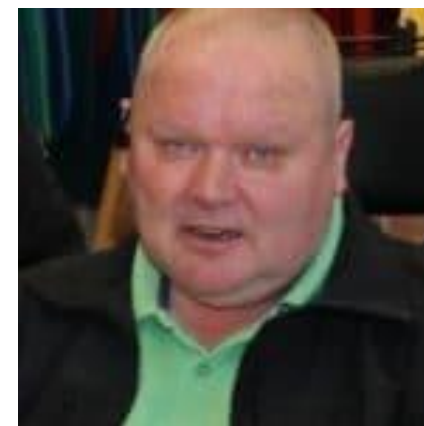
PCAC

- 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

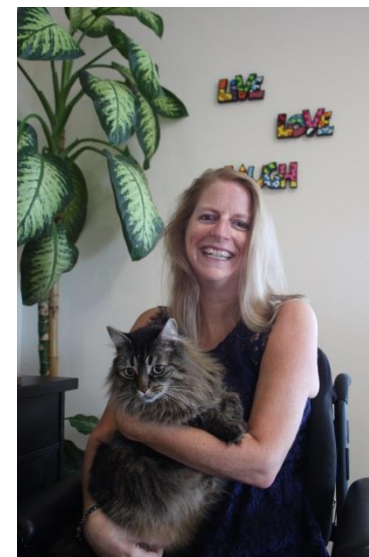
- Ajay Gupta-India
- Mia Mahy-Belgium





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 Reviere
 - 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!

