

## ALS Neuroscience Update – (Barohn)

### Introduction

- Got survey data last week, getting into REDCap for review
- Presenting this data at an international meeting in Dublin in December

### Survey background

- Wanted easily understood, patient relevant instrument to use in ALS studies
- Measuring disease impact
  - Current tool is ALS functional rating scale
- Get patient input on instrument –
  - does tool reflect their experience
  - can it be completed at home by patient/giver
  - can patients update their status in the EMR

### Step 1 – patient & caregiver focus group

- Suggested language modifications to enhance understanding
- Add questions re. pain & pseudobulbar affect (bouts of uncontrollable laughter/crying)
- Liked idea of completing form from home, via internet
- Interested in sending to clinic prior to their visit

### Step 2 – LEC conference

- Patient input gathered on survey tool, including
  - Rebranded tool as the “Patients activities of daily living scale” (PADL-ALS)
  - Additional survey question input - Also wanted to add question about faith & diagnosis

### Presentation of the PADL-ALS tool by Dr. Barohn

### Survey results

- 1079 surveys sent; 382 completed, 44.44% completion rate
- Completion rate disappointing; gap in people who didn't respond at all
- Patients completed form 68.7% of time; via caregiver 31.3%
- Patients completed survey at home either paper or computer/tablet, almost equally
- Caregivers showed preference for completing survey at home via paper (64%)

### New instrument (PADL-ALS) correlates well to ALSFRS-R used in clinic – KUMC

### Responses to questions added based on patient/caregiver input

- On faith – greater than 50% state religious/spiritual beliefs act as a source of comfort
- On interest in research - Over 80% willing to be contacted, or contacted on project by project basis
- On research they'd like to see – most frequent response was to investigate vitamins or diets (would be a hard study to design)

#### Future directions

- Issue: getting patients engaged with MyChart
- GPC publication policy – check page on GPC site, is it sufficient?

Tamara McMahon sent a follow up to the presentation:

- Here is the ticket where sites can add the number of patients returned from their EMR for the ALS survey and the number of patients sent a survey. If sites have not already submitted their numbers, please consider doing so.
- <https://informatics.gpcnetwork.org/trac/Project/ticket/304>