ALS MULTIDISCIPLINARY CARE –PROVIDER PERSPECTIVES

OVERVIEW

- Importance of a multidisciplinary clinic
  - AAN
  - PALS
- Challenges to Providers
  - Cost
  - Administrative burdens
- Rewards to Providers

MULTIDISCIPLINARY CARE

- Part of the Practice Parameters defined by the AAN
- Part of the quality care metrics
- Prolongs survival, promotes independence and quality of life
- Reduces complications including falls, injuries, pneumonias, ED visits and hospitalizations

Multidisciplinary Care: A Team Approach

- Physicians
- Nurse
- Research
- Nutrition
- Psychology
- Social Work
- Physical Therapy
- Respiratory therapy
- Assistive Technology
- Occupational Therapy
- Speech and Language Pathology
- Family
- Friends
- Specialty Physicians (Pulmonary, Rehabilitation, GI, Genetics)
- Home Care Companies
- Community Organizations

A SURVEY OF THE ALS CLINIC COMMUNITY

- What Ancillaries are available at your clinic?
  - PT, OT and Speech Language Pathology 95-97%
  - Respiratory Therapists: 89%
  - Nutrition 87%
  - Nurse coordinator 80%
  - Research coordinator in 67%
  - Case management 67%
  - Mental health support 51%
  - Pulmonologists 28%
  - Palliative care 25%
  - Genetics 18%
  - Physiatrists 10%

WHAT ARE THE PREFERENCES OF PALS

- 259 PALS (from 42 states) completed an online survey
- PALS receiving care in a multidisciplinary non-triage setting(MDC) reported higher quality of life and increased attention to the AAN care parameters
- PALS in MDC more frequently reported their clinics addressing:
  - respiratory testing (84% vs. 53%)
  - speech therapy (83% vs. 61%)
  - screening for speech/swallowing (78% vs. 33%)
  - screening for cognition (59% vs. 37%)
  - developing/updating MDC plan (71% vs. 43%)
  - offering help with planning end-of-life (46% vs. 22%)
- Given the choice 88% of PALS would be extremely likely to choose to receive care in a non-triage clinic

CHALLENGES TO MULTIDISCIPLINARY CARE

- COVID
  - Telemedicine
  - Inability to really assess respiratory status
  - Functional status could be established
  - Making sure there were touchstones
- Duration of visits
- Ease of access
- Space
- Resources (Equipment Loan)
- Cost

COST OVERVIEW

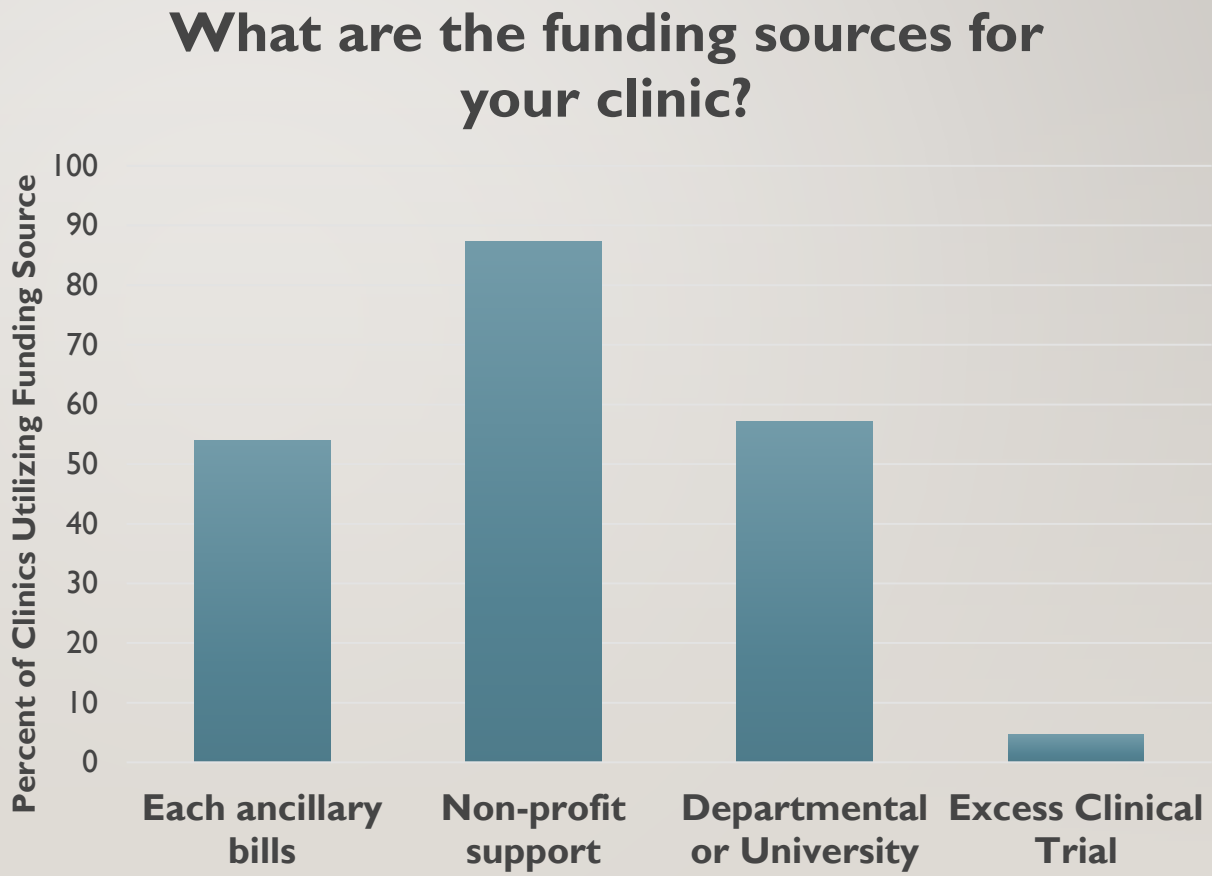
- Supporting the Temple Center
  - Total Cost (Clinic time plus time pre and post clinic plus space): estimated $487,333
    - Physicians Salary (2 at 40%) $100,000
    - Nursing: $ 97,800
    - PT/OT/SLP $ 70,000
    - Respiratory Therapy: $15,000
    - Nutrition: 15,000
    - Case Management $52,800
    - Mental Health/clinic and home visits : $116,500
    - Research Team (In clinic time): $ 20,000
    - Support staff (admin, MA): 70,000
    - Space: 7500
  - Cost/visit: $1015 (approx. based on 48 clinics/year and 10-12 PALS seen/clinic)
- Literature: 2015 paper up to $806/visit

SUPPORTING THE CENTER

- Billing
- MDA Grant:
  - Partial support of our PT/OT/Nurse/SLP
- Department of Neurology/Temple University
- ALS Hope Foundation/Neurodegenerative Disease Fund
- Discretionary Fund
- Clinical Trials (Research Team)

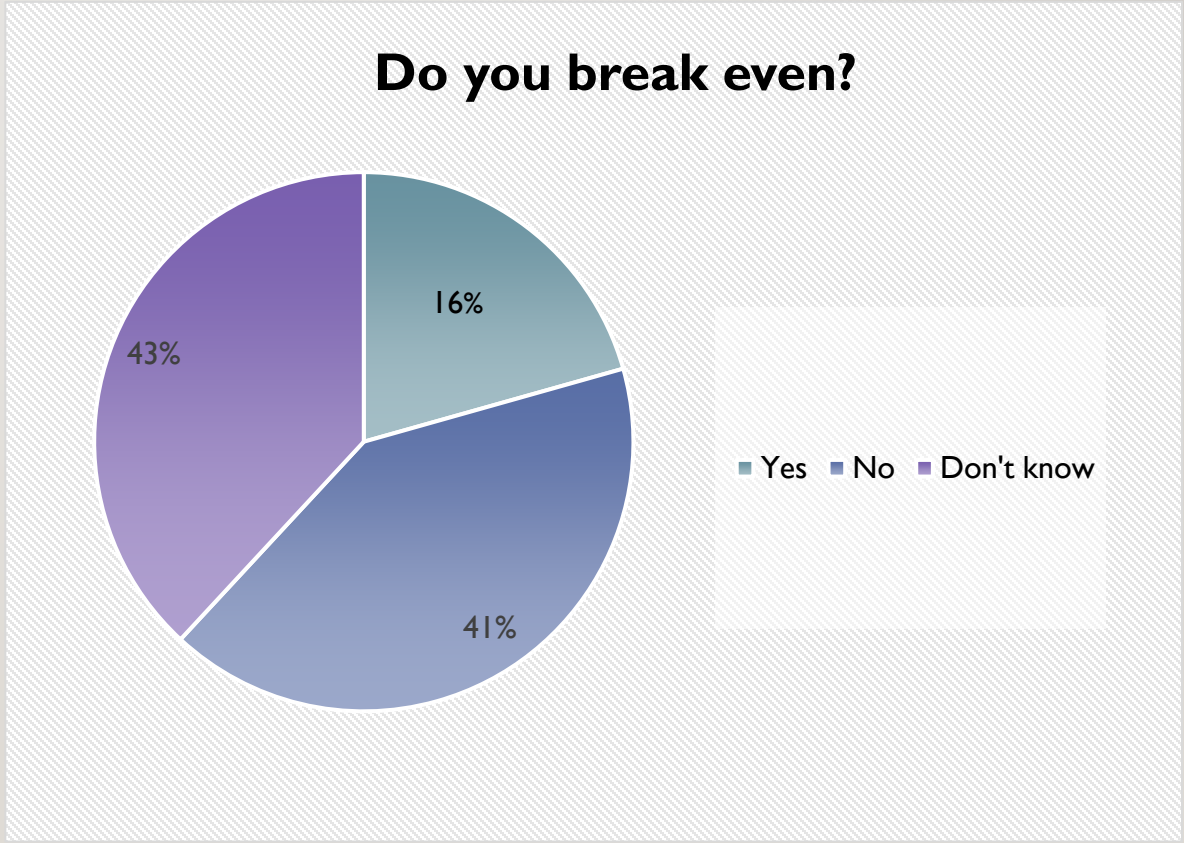
A SURVEY OF THE COMMUNITY

- Individual Billing 54%
- Nonprofits and philanthropy 92%
- Departments or organizations 59%
- Discretionary funds 5%



A SURVEY OF THE ALS COMMUNITY

- Break even 16%
- Deficit 41%
- Unsure 43%



WHAT ARE WE DOING?

- Project in progress across 35 centers to establish the true cost of running a multidisciplinary center
- Introduction to Congress a Bill for CMS supplemental payment for ALS Multidisciplinary Care

PROPOSED BILL

- Goals:
  - Provide supplemental coverage of ALS –Related services with an alternative payment model
  - Under Medicare program

- Summary of Proposed Bill
  - $800/visit to a multidisciplinary clinic for people diagnosed with ALS to supplement billing year 1
  - In year 2: Adjustment of single payment based on cost analysis of multidisciplinary care by the Secretary and based on analysis of payment recommended by the Comptroller Gerneral
    - This analysis will recommend a single payment for ALS related services taking into account the average amount of payment for each item or service
  - Subsequent years will increase payments based on the percentage increase in services cost

ESTIMATED COST

- Based on 4 visits/year and 12,000 PALS in multidisciplinary care: 38,400,00
- If all PALS are able to attend a multidisciplinary clinic based on 15,000-20,000 PALS: 64,000,000

ADMINISTRATIVE BURDENS

- Affect all members of the team: nursing, administrative assistant, physicians
- Multiple levels
  - Precert for medications
  - Precert for procedures
  - Finding resources

REWARDS TO CLINICIANS

- Making a difference
- Hearing the words “Thank you”

IMPROVING ACCESS TO HIGH QUALITY CARE

- Improve the support of multidisciplinary clinics
- Reduce the administrative burdens
  - Uniform approval process and forms