ALS, Communication & All That Jazz

June 9 - 10, 2017

New Orleans, Louisiana

LSU Health - Human Development Center
411 South Prieur Street
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HUMAN DEVELOPMENT CENTER
BUILDING CAPACITY • INSPIRING CHANGE

37 TEAM GLEASON

LSU Health NEW ORLEANS
School of Allied Health Professions

ALS, Communication & All That Jazz
June 9-10, 2017

AGENDA

Day 1	Friday, June 9, 2017
8:15 – 9:00 **1st Floor Lobby**	**REGISTRATION and Continental Breakfast**
9:00 - 10:45 **Auditorium #130**	**Plenary** **John Costello, Boston Children's Hospital** ***ALS and AAC: Proactive Assessment, System Design and Implementation***
10:45 – 11:00	**BREAK**
11:00 – 12:00 **Auditorium #130**	**Panel Discussion of pALS**
12:00 - 1:15 **Chancellor Dining Room #335**	**LUNCH** provided in Chancellor Dining Room #335
1:15 – 3:00 **Auditorium #130**	**Plenary Session** **Peggy Dellea, MS, OT/L, Boston Children's Hospital** ***Computer Access: A Mouse by Any Other Name***
Day 2	**Saturday, June 10, 2017**
8:30 – 9:00 **1st Floor Lobby**	**Continental Breakfast**
9:00 - 10:45 **Auditorium #130**	**Plenary** **Lisa G. Bardach, MS CCC-SLP, ALS of Michigan** ***Data-Driven Evals for pALS***
10:45 – 11:00	**BREAK**
11:00 – 12:00 **Auditorium #130**	**Austin Edenfield, Team Gleason** ***Environment Controls: Access and Implementation Overview for All Budgets***
12:00 - 1:15 **Chancellor Dining Room #335**	**LUNCH** provided in Chancellor Dining Room #335
1:15 – 2:30	**Break-Out Sessions**
Auditorium #130	**Lisa G. Bardach, MS CCC-SLP, ALS of Michigan** ***Hands On! Demo and Practice with Communication Technology***
Room #335	**Peggy Dellea, MS, OT/L, Boston Children's Hospital** ***Get in Position to Communicate: Seating, Mounting, and Physical Access***
Room #231	**Austin Edenfield, Team Gleason** ***Demonstration of Environment Controls and Home Automation***
2:30 – 3:00 **Auditorium #130**	**Closing Session**

PROGRAM

9:00 - 10:45
Plenary
Auditorium #130
John Costello, Boston Children's Hospital
ALS and AAC: Proactive Assessment, System Design and Implementation

This plenary will provide an overview of key augmentative communication considerations that ideally are introduced early and proactively but should be considered at any time a person with ALS is able to participate. Each consideration will be discussed in detail and as appropriate, further highlighted through video demonstration including: use of voice amplification; strategies to enhance speech clarity; introduction to message banking; definition and introduction to voice banking; introduction to the concept of 'quick access' low-tech tools created and designed in collaboration with each person; quick alternative access strategies including partner-assisted scanning and laser pointer with low tech boards; and assessment and feature matching for speech generating technology.

Learning Objectives:

1. List no –tech, low tech and high tech augmentative communication strategies.
2. Detail the steps for pro-active message banking.
3. Describe the feature matching process for assessment and evidence based trials.

1:15 – 3:00
Plenary Session
Auditorium #130
Peggy Dellea, MS, OT/L, Boston Children's Hospital
Computer Access: A Mouse by Any Other Name

As the ALS progresses, motor control declines for many and in some cases, speech may be relatively preserved while movement of the arms and legs is severely compromised. People with ALS leave their jobs, give up use of the computer, and accept assistance with even simple tasks as their abilities to engage in these activities are compromised.

Most people are unaware of the broad range of adaptations and devices designed to compensate for decreased motor control. Many patients can benefit from use of a head mouse, arm supports, or voice recognition software for example. Unfortunately, many patients come to our clinic with the declaration that they have stopped doing certain tasks because they are no longer able to. The truth is, they are still able to do these tasks, just need to be done in a different way.

Learning objectives:

1. Discuss benefits of proactive intervention to successful use of computer/AAC device strategies throughout the course of the ALS disease.
2. Describe at least four strategies for computer/AAC device access that can be introduced to people facing the loss of functional upper extremity motor control.

9:00 - 10:45
Plenary Auditorium #130
Lisa G. Bardach, MS CCC-SLP, ALS of Michigan
Data-Driven Evals for pALS

This presentation will demonstrate the use of evidenced-based practice in the evaluation process to determine the best technology and make appropriate recommendations for pALS who require Speech Generating Devices. It will show how practitioners can use the tasks deemed most important by the patient to drive those presented in the evaluation and to gather objective data regarding the performance of the patient with various SGDs. A template for evaluating individuals with ALS who need SGDs and documenting their performance by comparing features and parameters between devices will be provided. Videos of portions of evaluations and patients using their SGDs will be shown so participants can gauge the users' accuracy and efficiency.

Learning Objectives:

1. State 5 mainstream tasks people with ALS rate as highly important in addition to verbal communication.
2. Identify 3 parameters (hardware and software) that can be changed on various SGDs to facilitate access.
3. Explain 2 ways the Communication Needs Questionnaire can be used to provide data for an AAC evaluation.

11:00 – 12:00
Auditorium #130
Austin Edenfield, Team Gleason
Environment Controls: Access and Implementation Overview for All Budgets

There's a million options available for pALS and their families to choose from regarding environmental controls. With so many options and data, families can get bogged down in a tiresome pursuit of something that will work for their pALS. This session will provide an expansive overview of environment controls, home automation systems, and access methods. The different protocols used (i.e., Infrared, X10, Z-Wave and Z-Wave Plus, Wi-Fi) will be presented along with the relative strengths and weaknesses of each. Picture and video examples of pALS using environmental controls and home automation will be shown.

The session will provide a list of typical and useful products used for environmental controls, along with helpful resources to share with pALS and care takers for discussion. The session will discuss the installation and monitoring of environment controls using a dedicated vendor versus self-installation. This will include the typical budget as well as the strengths and weaknesses of each option. Resources will be provided for implementing a DIY install of environmental control products.

Learning Objectives:

1. State the definitions for environmental controls and home automation.
2. Describe the different protocols used in environmental controls.
3. Discuss the strengths and weaknesses of a self-install versus using a company to install.
4. Identify resources to help facilitate discussion with pALS and care takers.

1:15 – 2:30
Auditorium #130
Lisa G. Bardach, MS CCC-SLP, ALS of Michigan
Hands On! Demo and Practice with Communication Technology

This session will give participants an opportunity to try out different communication systems with various access methods, including head pointing and eye gaze. The instructor will spend the first 30 minutes demonstrating various tasks and activities, including access to internet, cell phones, and social media as well as face-to-face communication. Speech Generating Devices (SGDs) from multiple manufacturers will be available. Participants will then be encouraged to form small groups and use each other as subjects, setting up systems and selecting appropriate tasks for evaluation.

Learning Objectives:

1. Describe 3 tasks that would be appropriate for evaluating communication skills in pALS.
2. Demonstrate the ability to set up and calibrate a high-tech SGD.
3. State 3 considerations in calibrating a high tech eye gaze system.

1:15 – 2:30
Room #335
Peggy Dellea, MS, OT/L
Get in Position to Communicate: Seating, Mounting, and Physical Access

It is one thing to use a communication device within an ALS clinic, but it is quite another to use AAC at home and within the community. Successful use of AAC depends on appropriate positioning of the device relative to the user. Consideration must be given to the seating and mobility system in use as well as to the input method. This session will explore barriers and opportunities to mounting and positioning that allow use of AAC devices in all environments.

Learning Objectives:

1. Discuss at least four considerations regarding mounting/positioning of AAC devices.
2. Describe at least four AAC positioning devices and strengths/challenges inherent in the design.

1:15-2:30
Room #231
Austin Edenfield, Team Gleason
Demo: Environment Controls

This session will provide demonstrations of Environmental Control Products. The following Environmental Control Access Methods will also be demonstrated:

- Head
- Eyes
- Direct Select
- Voice
- AAC Software (Grid 3, Website, etc.)

Learning Objectives:

1. Discuss considerations regarding Environment Control and Home Automation Systems.
2. Describe the various access methods that can be used for Environmental Controls and Home Automation.

BIOS

Lisa Bardach

Lisa Bardach is the SLP at ALS of Michigan, where she developed and implemented a regional clinic to provide AAC and Assistive Technology services to pALS throughout Michigan. She is nationally recognized for her expertise in AAC, specifically in helping people with severe physical challenges gain access to communication technology.

John Costello

John Costello is the director of the Augmentative Communication Program and ALS Augmentative Communication Program at Boston Children's Hospital where he has been a speech language pathologist for 32 years. John developed the first of its kind AAC service for the pediatric ICU in the early 90s where he developed the concept of message banking. He has lectured nationally and internationally on topics in augmentative communication and authored or co-authored several articles and chapters. John teaches graduate level courses in AAC at Boston University and MGH Institute of Health Professionals.

Peggy Dellea

Peggy Dellea works at Boston Children's Hospital within the ALS Service providing assistive technology services with a focus on computer and AAC access. She has participated in research regarding use of a brain-computer interface as a communication tool. She has an OT and a Biomedical Engineering degree from Boston University.

Austin Edenfield

Austin Edenfield joined Team Gleason in 2015 as the Technology and Care Coordinator. Edenfield's primary focus is to help provide technology, equipment, and support to people living with ALS so they can live more productive and purposeful lives. He is also engaged with Team Gleason's efforts to partner with technology companies to foster innovative communication devices and other advanced technology and equipment for people with physical limitations. Before joining Team Gleason, Edenfield spent several years working for Apple and Microsoft.