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ALS: A Clinical Population with Unique Communication Management and AAC Needs, Part 2

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Moderated by:

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ALS: A Clinical Population with Unique Communication Management and AAC Needs

Part 2

Hospital *for* *Special* Care

We Rebuild Lives.

Kim Winter, MA CCC-SLP

September 22, 2016

Disclosure Statement

- I received an honoraria from Speech Pathology.com to produce this presentation.
- I have no other financial or non-financial relationships to disclose.

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Learner Outcomes

1) describe the incidence and features of cognitive impairments in ALS

2) describe the considerations of physical functioning and its impact on AAC decision making

3) describe Medicare and funding considerations as they relate to procurement of a speech generating device

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COMMUNICATION IN ALS

"If all my possessions were taken from me with one exception, I would choose to keep the power of communication, for by it I would soon regain all the rest."

Daniel Webster

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AAC Assessment

"There is no standardized battery of tests that comprise an AAC evaluation…."

(ASHA 2004)

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AAC Evaluation Process

Part 1 - Complete an assessment of:

- Language - receptive and expressive
- Cognition – memory, executive functioning
- Speech/Voice – cranial nerve exam, speech intelligibility

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Language and ALS

- Generally intact – screening tools can be utilized, unless suspect more significant cognitive-linguistic impairments.
- "Economy of Wording"– Wilkinson, et al., (1995) demonstrated that individuals with ALS often use:
  - Fewer words
  - Shorter sentences
  - More incomplete phrases

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Cognition and ALS

- >50% of the non-bulbar ALS subjects and >67% of the bulbar subjects had deficits in at least 1 of 3 measures (verbal fluency, abstract reasoning, judgment), as compared with normal controls. (Flaherty-Craig, C., et al., 2006)
- Established an association between sleep disturbance and nocturnal hypoventilation and cognitive dysfunction (memory and executive function deficits). (Newsom-Davis, I., et al., 2001)
- 50% of patients had cognitive impairments (Ringholz, G. et al. 2005)
  - 30% were mild
  - 20% were classified as having dementia with the majority of subjects being classified as having Frontotemporal Dementia (FTD).
- FTD: "A neurodegenerative disorder causing atrophy of the frontal and anterior temporal lobes that can lead to disturbances in behavior and language". (Wheaton, M., et al. 2007, p.1411)

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ALS Cognitive Behavioral Screening Tool (ALS-CBS)

(Woolley et al. 2010)

- Brief measure of cognition and behavior in pALS
- Approximately 5 minutes to administer
- Can be completed either orally or in writing; can also have patients use an assistive communication system
- Working memory, mental manipulation, digit span reverse, verbal fluency, command following
- Score interpretation (cognitive section):
  - <17: 85% sensitivity and 69% positive predictive value for cognitive impairments
  - </=10 is suggestive of FTD: 100% sensitivity, specificity, positive and negative predictive value for FTD

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Cognitive & Behavioral Changes: Impact on AAC Abilities (Romaón & Levine 2006)

Cognitive Changes

- **Attention**
  - Ability to focus on conversation
- **Mental Flexibility**
  - Generalization of pre-stored phrases to a variety of communication situations
- **Set-Shifting**
  - Ability to use multiple modalities for communication
- **Concentration & Working Memory**
  - Ability to hold a message in mind during message formulation

Behavioral Changes

- **Disinhibition**
  - Social disinhibition and breaches of social etiquette
- **Repetitive Behavior**
  - Repetition of a limited repertoire of words or phrases on SGD
- **Decreased Insight**
  - Failure to see the necessity of communication interventions
- **Apathy**
  - Inability to follow through with treatment recommendations

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Motor Speech Evaluation

- **Speech Intelligibility Testing:**
  - Assessment of Intelligibility of Dysarthric Speech (AIDS): Yorkston, Beukelman & Traynor (1984)
    - Measures speech intelligibility for 50 single words and 20 sentences (5-15 words in length)
  - Sentence Intelligibility Test (SIT): Yorkston, Beukelman & Hakel (1996).
    - SIT is a single disk software package that allows the clinician and researcher to administer, score, and store results of a speech intelligibility measurement task.

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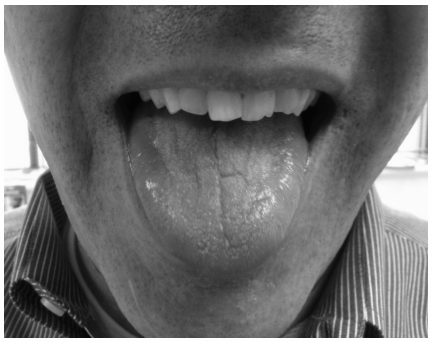
Normal Tongue Bulk vs. Atrophied Tongue due to ALS

Tongue Atrophy - ALS



Normal Tongue Bulk

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Tongue Fasciculations in ALS

http://www.nejm.org/doi/full/10.1056/NEJMicm1309849

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AAC Evaluation

Part 2 – Complete SGD evaluation:

- Medicare requires trials of a minimum of 3 different devices.
- Must consider the patient's current and future capabilities with regard to access (i.e. motor functioning).
- Original work by Yorkston et al. (1993), with updated considerations by Mathy et al. (2000), can assist with decision making.

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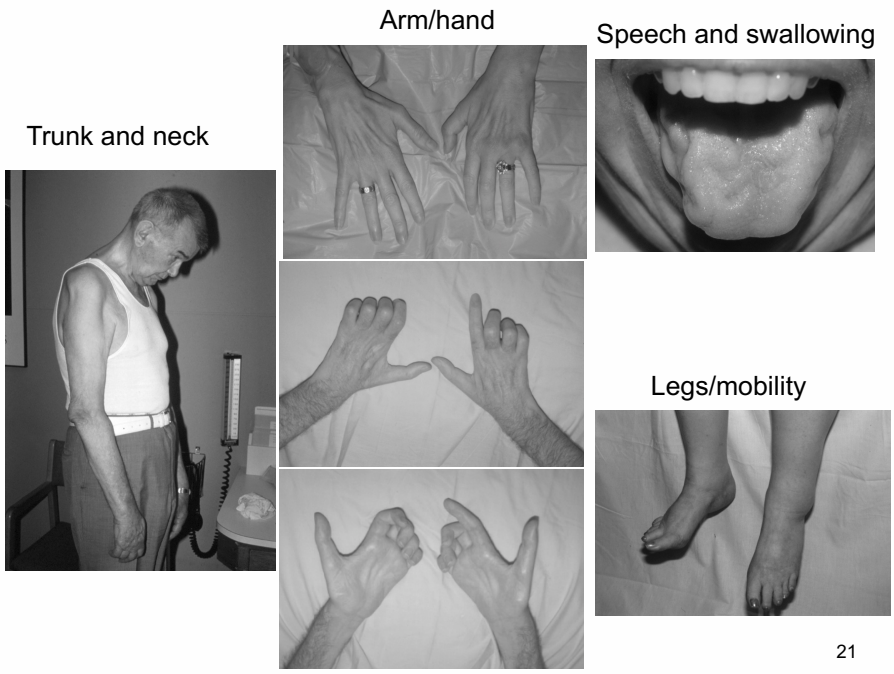

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AAC Considerations

- **Group 1: Adequate speech, adequate hand function**
  - Intervention: Monitor communication status; provide information to prepare for future communication needs
- **Group 2: Adequate speech, poor hand function**
  - Intervention: Alternative writing and keyboard access; provide information to prepare for future communication needs
- **Group 3: Poor speech, adequate hand function, adequate mobility**
  - Intervention: Alphabet supplementation; alternative writing; portable direct selection low-tech and high-tech AAC options

(Ball, L. et al., 2007, p.302-303)

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AAC Considerations Cont'd.

- **Group 4: Poor speech, adequate hand function, poor mobility**
  - Intervention: Similar to group 3 except that AAC options can be mounted to a wheelchair
- **Group 5: Poor speech, poor hand function, good mobility**
  - Intervention: Alternative access (scanning, head or eye tracking, eye pointing, eye linking); may or may not need AAC to be portable
- **Group 6: Poor speech, poor hand function, poor mobility**

  Intervention: Alternative access (similar to group 5). AAC options do not need to be lightweight because the system can be wheelchair mounted. (Ball, L. et al., 2007, p.302-303)

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AAC Methods

Unaided Communication Systems:

- No Tech: gestures, pointing, talking slowly, exaggerated speech movements.

Aided Communication Systems:

- Light Tech/Low Tech: eye gaze boards, writing, laser light pointers on an alphabet or communication board.
- High Tech: computers and speech generating devices (SGDs).

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Light Tech/Low Tech Options

- LCD Writing Tablet

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Light Tech/Low Tech Options

- Alphacore Communication Board

(Amy Roman; http://amyandpals.com/)

A	About	All	Also	An	And	Any	Are	As	At	Be	Because	Been	Before
But	By	Can	Come	Could	Did	Do	Does	Don't	Down	Even	Feel	For	From
Get	Give	Go	Good	Had	Has	Have	He	Hello	Help	Her	Him	His	How
I	I am	If	In	Is	It	Just	Know	Let	Like	Look	Make	Many	May
Maybe	Me	Might	More	Most	Move	Much	Must	My	Need	No	Not	Now	Of
Off	Okay	On	One	Only	Or	Other	Ouch	Our	Out	Over	Please	Put	Rest
Said	Say	See	She	Should	So	Still	Such	Take	Talk	Than	Thanks	That	The
Their	Them	Then	There	These	They	Think	This	A	B	C	D	Delete Letter	•
Those	Time	To	Too	Up	Under	Us	Use	E	F	G	H	Space	That's not what I meant
Want	Was	We	Were	What	When	Where	Which	I	J	K	L	M	N
Who	Why	Will	With	Would	Yes	You	Your	O	P	Qu	R	S	T
					?	!	,	U	V	W	X	Y	Z
					$	:	Message Code	-s	-ed	-ing	Hold On....	Start Over	I'm Finished
1	2	3	4	5	6	7	8	9	0	Please say/write each letter/word as I point to it.		Do not look directly into the light source of the laser beam	

Please do not laminate this board if it is used with a laser pointer

AlphaCore Extreme © Amy Román

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Light Tech/Low Tech Options (www.lowtechsolutions.org)

Head Mounted Laser Pointer

Handheld Laser Pointer

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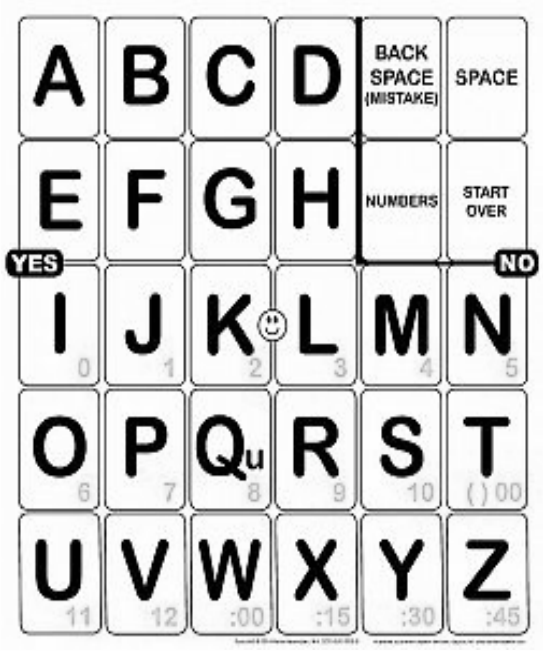
Light Tech/Low Tech Options

EyeLink 2

Northern Speech Services

$29.00



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Light Tech/Low Tech Options

Speakbook

FREE!

www.speakbook.org

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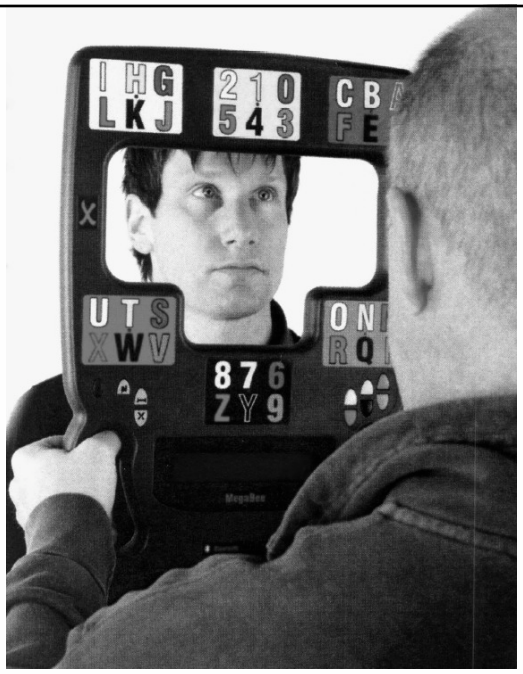
Light Tech/Low Tech Options

Megabee

Various vendors

Approximately $1,200-$1,500



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What types of AAC are used?
(Mathy, P. et al., 2000)

Bulbar Onset

- Facial expressions
- Gestures
- Respond to yes/no questions
- Handwriting
- High technology SGD

Spinal Onset

- Facial expressions
- Respond to yes/no questions
- Partner dependent scanning
- High technology SGD

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Psychosocial Issues and AAC Acceptance/Use
(Lasker, J. & Bedrosian, J. 2000)

- **Partner acceptance and expectations:**
  - Will they be responsible for maintenance and programming?
  - Do they have realistic expectations?
- **Communication Environment:**
  - 1:1 versus group settings; familiar versus unfamiliar communication partners
  - Time of day – fatigue issues

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Psychosocial Issues and AAC Acceptance/Use Cont'd.

- **Technology skills & age:**
  - Are they technology "savvy"?
  - "Anyone younger than age 30 in 2000 who eventually acquires a communication disorder may respond more favorably to technology-based AAC systems". (Lasker, J. & Bedrosian, J., 2000, p.115).
- **Individual personality**
  - Respect patient desires to NOT use AAC.

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Psychosocial Issues and AAC Acceptance/Use Cont'd.

- "The key management issue is frequently not device selection, access/interface or vocabulary selection but forced adaptation to altered communication style, loss of spontaneity and potential loss of control".

  (Carroll-Thomas, S. 1995, p. 282)

  "In clinical practice, some patients choose to communicate to the few close persons who can understand their severely dysarthric speech, or to use the cheapest communication aid (i.e. writing on a piece of paper, alphabet chart). There are also patients who do not use the communication support provided and prefer to remain mute. Their wishes should be respected". (Tomik, B. & Guiloff, R. , 2010, p. 9)

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General Considerations During the AAC Evaluation

- Similar to the "car buying" process – many SGD options with many similarities.

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General Considerations During the AAC Evaluation Cont'd

- SLPs do NOT need to know everything about every device – use your vendors to help you.
- SLPs DO need to provide patients/families with information regarding the benefits and limitations of SGDs in light of their ALS diagnosis.
- "Because most individuals with ALS are adults with intact literacy skills, they benefit most from AAC aids and strategies that provide the ability to generate messages through spelling".

(Mathy, P., n.d., para. 16)
http://www.asha.org/public/speech/disorders/ALSChallenge.htm

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General Considerations During the AAC Evaluation Cont'd.

- The goal of all AAC is SNUG: Spontaneous Novel Utterance Generation
- Limitations of Pre-Programmed Vocabulary
- Limitations of Rate Enhancement Techniques:
  - Word Prediction – saves keystrokes, but doesn't necessarily increase communication rate
  - Abbreviation Expansion – limited use observed, but the texting generation may change that! (LOL, BRB, TTYL, JK, IDK)

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Impact of Mechanical Ventilation on AAC Decision Making

- Small percentage overall, but some report it is growing.
- Extends their life expectancy and duration of AAC use.
  - Bulbar onset: mean of 25.2 months (3-118 months range)
  - Spinal onset: mean of 32.1 months (2-160 months range)
  - Data variables: late referrals (<125 wpm speaking rate) & impact of mechanical ventilation (Ball, L. et al., 2007)
- Progression of physical limitations will require consideration of how to modify the selected SGD given motor control decline.

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Specific AAC Considerations

Access Methods –

- Direct selection: pointing, joystick, headtracker, eye gaze
- Indirect selection: scanning

Direct selection methods are always preferable over scanning

- Eye gaze: 43.80 seconds/sentence; 4.16 words per minute
- Switch scanning: 112.22 seconds/sentence; 1.62 words per minute (Gibbons, C. & Beneteau, E. 2010)

- Regardless of method, access point needs to be consistent and reliable (>80%-90%)
- Fatigue and progression factors

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Eye Gaze Considerations

- How it works: A camera emits an infrared signal that tracks eye movements via retinal reflection.
- Trials of more than 1 system is recommended prior to purchase due to variances in eye gaze accuracy.

Generally NOT viable for individuals who have:

- Nystagmus
- Bifocal glasses, even if progressives – this varies for each different vendor product – try it out before ruling it out
- Inability to focus in one area for a brief period of time
- Rare instances of oculomotor apraxia with ALS

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Impact of Dry Eye/Droopy Eye on Eye Gaze Access

- Many patients have dry eye – may not be aware of it.
- OTC eye drops (e.g. Systane)
- If eyelid becomes droopy, camera can't pick up the "glint" (reflection) from the retina.
- LC Technologies – only eye gaze system currently that can counteract droopy eyelids, but is NOT a guarantee.

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Common technologies as AAC

Benefits

- Easily acquired/available
- Interim option while awaiting insurance funding
- Reusable technology
- Highly portable/compact
- Many options to trial
- Low-cost
- Nice option for bulbar-onset pALS

Limitations

- Limited tech support for troubleshooting
- Limited ability to adapt the device for physical limitations
  - Predictable – switch scanning
- Many options to trial
- Built-in speakers often not loud enough to be effective in high-vocal demand environments

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Communication Apps

iPad

- **Speak It!:** $1.99
- **Assistive Express:** $24.99
  - German, Italian, Dutch, Spanish
- **Touch Voice:** $19.99
  - Spanish
- **Verbally:**
  - Free Lite version
  - $99.99 Premium Version
- **Predictable:** $159.99
  - Switch accessible

Android

- **Say It!**
- **Speak It**
- **Text to Speech**
- **Type and Speak**
- **Voice-Text to Speech**

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Funding Considerations

- **Funding issues need to be discussed at the outset**
  - Medicare will pay **the lesser** of either 80% of their fee schedule or 80% of the cost of the device.
- **Medicare will NOT cover an SGD once the individual is in hospice care or is in a SNF**
- **Medicare requires a "dedicated" SGD**
  - Can do an "unlock" after received
- **Medicare "5 Year Rule" – Fact & Fiction**
  - "Usefulness" not <5 years
  - Will pay if second device is a different E code
- **Eye gaze access**
  - Have to rule out all other access options, even if eye gaze access is inevitable and/or more desirable due to efficiency issues.

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AAC Report Writing

- Natural speech: ineffective for meeting 100% of their daily medical, physical and social communication needs.
- Writing: Legibility, fatigue, effort, efficiency
- Low-tech communication: not viable for telephone or distance communications, or communicating with those who have reduced visual acuity/literacy
- Functional Limitations:
  - Dependent upon communication partners to interpret their communicative attempts
  - Abandonment of ideas
  - Reduced participation in daily communications
- SLP statement of no financial interest

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"I'm done with the AAC evaluation, now what?"

- Report writing and funding documents: Several online resources to assist
  - www.aacfundinghelp.com
  - http://aac-rerc.psu.edu/index-38242.php.html
  - http://www.asha.org/slp/healthcare/sgd/checklist.htm

If denied by insurance, may need to help with letter writing for an appeal.

Continue to monitor the patient's status – assist with obtaining an SGD loan while awaiting purchased device.

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What do I do if funding is a problem?????

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Role of AAC Lending Libraries

- Gleason Foundation
- Voice for Joanie
- ALSA

Benefits:

Immediate use while awaiting procurement of their own SGD

Assists those without a funding source or those in hospice/SNF

Limitations:

Overuse – formal AAC evaluations not completed

Limited SGD training for patients and families

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End Stage ALS and AAC Use

(Doyle, M. & Phillips, B. 2001; Ball, L., et al. 2007)

- Reduced motor function for physical access; increased effort.
- Communication often centers on wants/needs.
- Primarily communicating with familiar/trained caregivers.
- Unaided and light/low tech AAC is often used.
  - Yes/no questions
  - Partner-assisted scanning

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Take Home Points – AAC and ALS

- Remember that ALS is a moving target.

- Have to consider communication needs and physical abilities today and for the future.

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Take Home Points

If you have a patient with a confirmed or possible Neuromuscular Disease that you are not familiar with or are not sure how to manage, please consider contacting your local Neuromuscular Clinic (ALSA or MDA).

THANK YOU!!

Kim Winter: 860-827-1958 ext. 2035 kwinter@hfsc.org
www.hfsc.org

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