

## Consultation for Difficult Pediatric Demyelinating Cases via Nation-wide Webinar

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### Background

It can be challenging to distinguish between MS, NMO and mimics of demyelination, especially in children. Correct diagnosis is critical as treatments differ.

To assist with these diagnostic and treatment conundrums, a monthly Difficult Case Webinar was established in 2012, which is a collaboration between the National Multiple Sclerosis Society (NMSS) and Network of Pediatric MS Centers.

### Objectives

Characterize Difficult Pediatric Demyelinating Case webinar participants and cases presented to date.

### Methods

The one hour webinars alternate monthly between Mondays at 12:00 EST, and Fridays at 16:00 EST. Two weeks in advance, request for cases is sent to the webinar email list (>100 pediatric and adult neurologists). To join webinar, participants and presenters

- Dial into conference call
- Log onto Adobe Connect website
- Presenters "share my screen" from their computer and present clinical summary with de-identified neuroimaging

#### Data Collection:

- Webinars recorded since December 2012 were reviewed and summarized with respect to cases and participants

- Survey of webinar utility sent to all addresses on webinar email list (includes all webinar callers; many non-callers)

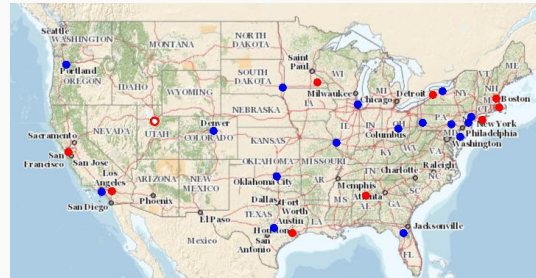
### RESULTS

**Monthly Webinars:** ~1 hour; usually 3 cases per webinar (range: 1-5 cases)

**Participants:** 45 callers from 23 institutions logged in 189 times

- Mean # callers logging in per webinar: 9 (range: 5-17)
- Mean # webinars attended per caller: 4 (range: 1-20)
- >50% (n=23) presented 1-7 cases; 70% of presenters (n=16) trained <10 yrs ago

- US Network of Pediatric MS Centers (40%)
- non-network sites (60% callers)



#### Network of Ped MS Ctrs

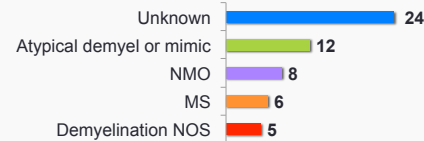
- Univ California-San Francisco
- Loma Linda University
- Mayo Clinic-Rochester, MN
- Texas Children's-Baylor
- Univ Alabama at Birmingham
- Boston Children's
- Massachusetts General
- State Univ New York-Buffalo
- State Univ NY-Stony Brook
- Data Coordinating Center: Univ Utah

**Cases:** 60 cases presented from Dec 2012-Aug 2014

- Mean age of patients: 11.2 y

Presenter request:	% (n)
Help with diagnosis	>70% (n = 44)
Management of known dx	10% (n = 6)
Example of atypical demyelination or mimic	17% (n = 9)
Webinar discussion results:	
Change in diagnosis	29%
Change in workup	55%
Change in treatment	57%

#### Consensus Diagnosis

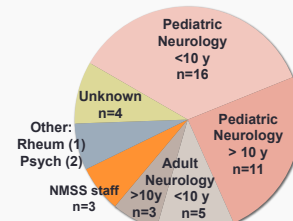


#### Diagnoses of atypical demyelination or mimics

<b>Atypical Demyel</b>	Schilder's Disease; TM+GBS
<b>Autoimmune</b>	Abs to GABA-B Receptor, NMDA-R, ACh ganglionic + striational
<b>Mitochondria mutations</b>	Alanyl tRNA synthase-2 (AARS-2); methionyl tRNA formyltransferase
<b>Tumor</b>	Atypical T-cell lymphoma
<b>Inflammatory</b>	Susac disease; T-cell infiltration
<b>Infection</b>	Cryptococcus

### Webinar Participants

Caller subspecialty and years since completing training



>60% neurologists trained <10 years ago

### Survey of Webinar Use

July 2014: Survey of webinar list (>100 addresses) Including all webinar callers + >70 never-called

- 17 respondents (15 Ped Neuro, 2 Adult Neuro)
  - 82% survey respondents (14 of 17) had called in on 1 or more webinars
    - 10 participated in 3 or more webinars
  - Survey respondents who called in (n=14) represented 40% of neurologists on calls
  - 12 of 17 respondents presented ≥1 case
  - 11/12 applied suggestions from webinar. 11/12 reported advice was helpful.

### Conclusions

- Webinar format enables nationwide access to expertise in pediatric demyelinating disorders.
- Main barrier to participation is webinar timing
- Future goals: Improve access by posting case online via secure website. Provide follow-up on prior cases.