# AFM: Putting the pieces together from admission to discharge

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**Brain Institute** 

### Disclosures

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- Dr. Greenberg is an unpaid member of the Siegel Rare Neuroimmune Association





## The symposium thus far and upcoming.....

- AFM the disease
- Epidemiology of AFM
- Parents perspective
- The virus
- Differential diagnosis
- Imaging
- Electrophysiology
- Natural history
- ICU management
- Respiratory issues
- Rehabilitation





## Putting the pieces together..... Who? What? How? Why? When?







#### The Current State of Needs







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#### The Current State of Needs













## **Deciding Priorities**

- Future patients
  - Immediate recognition and acute therapy protocols
  - Long term vaccine development
- Existing patients
  - Immediate Rehabilitation approaches, nerve-transfer data collection
  - Long term stem cell development





#### How do we get it done?







#### What Promotes Success

- Advocacy from patients/families targeting....
  - Patients (even those who recovered)
  - Clinicians
  - Government officials
- Resources for organized efforts
  - Look for opportunities to partner (the value of SRNA)
- Sacrifice and dedication (time, data on top of an already full plate)





## Putting the pieces together..... Who? What? How? Why? When?



#### There is a lot of work to be done, but we are stronger together













