Early Rehabilitation Strategies In AFM
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Rajashree Srinivasan, MD

Associate Professor, Department of PMR

UTSW, Dallas

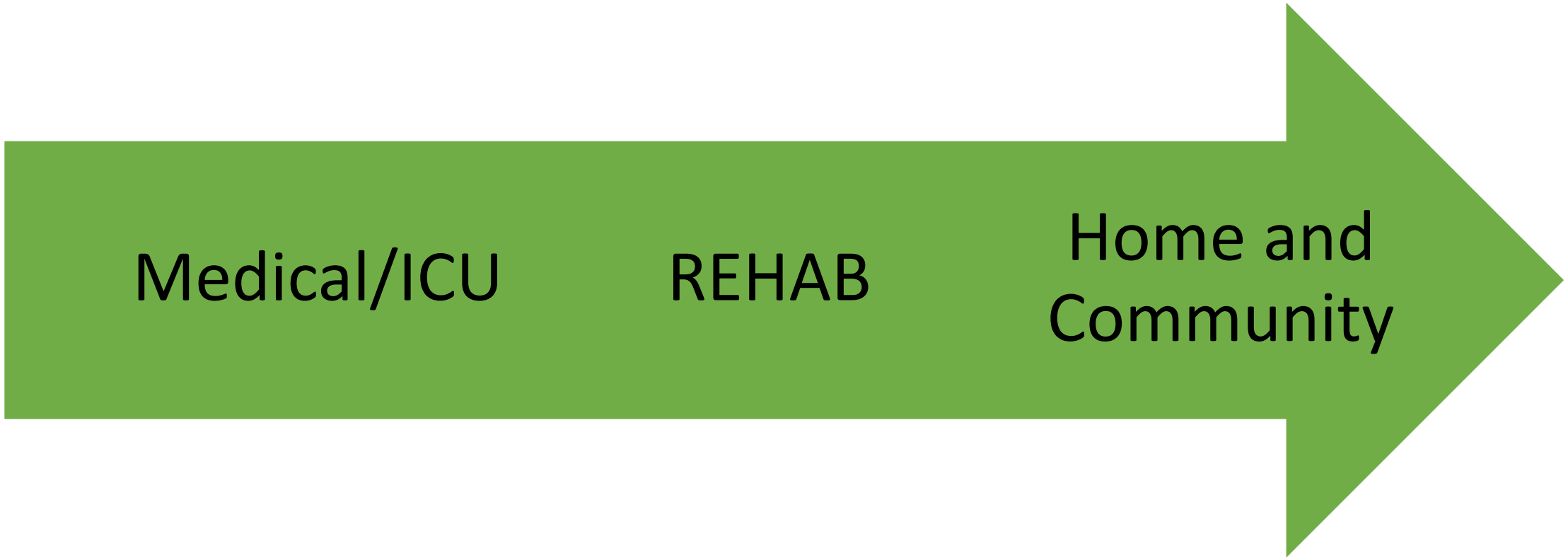
Disclosures

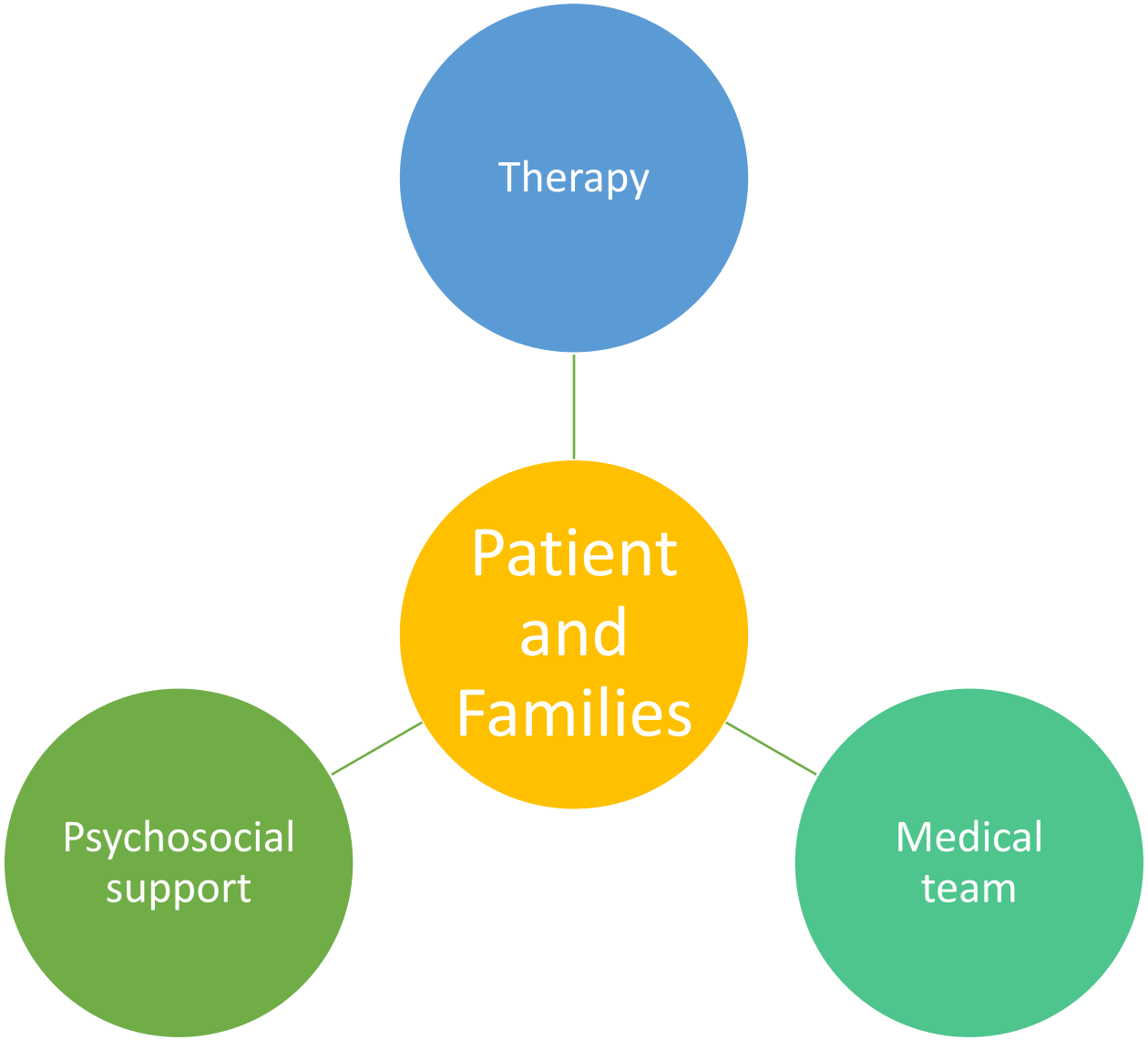
- I have no disclosures

Objectives/Take home points

- Early intervention of rehab is beneficial
- Functional improvement is the focus of rehabilitation
- Education of patients and families to become advocates for themselves and their loved ones is important

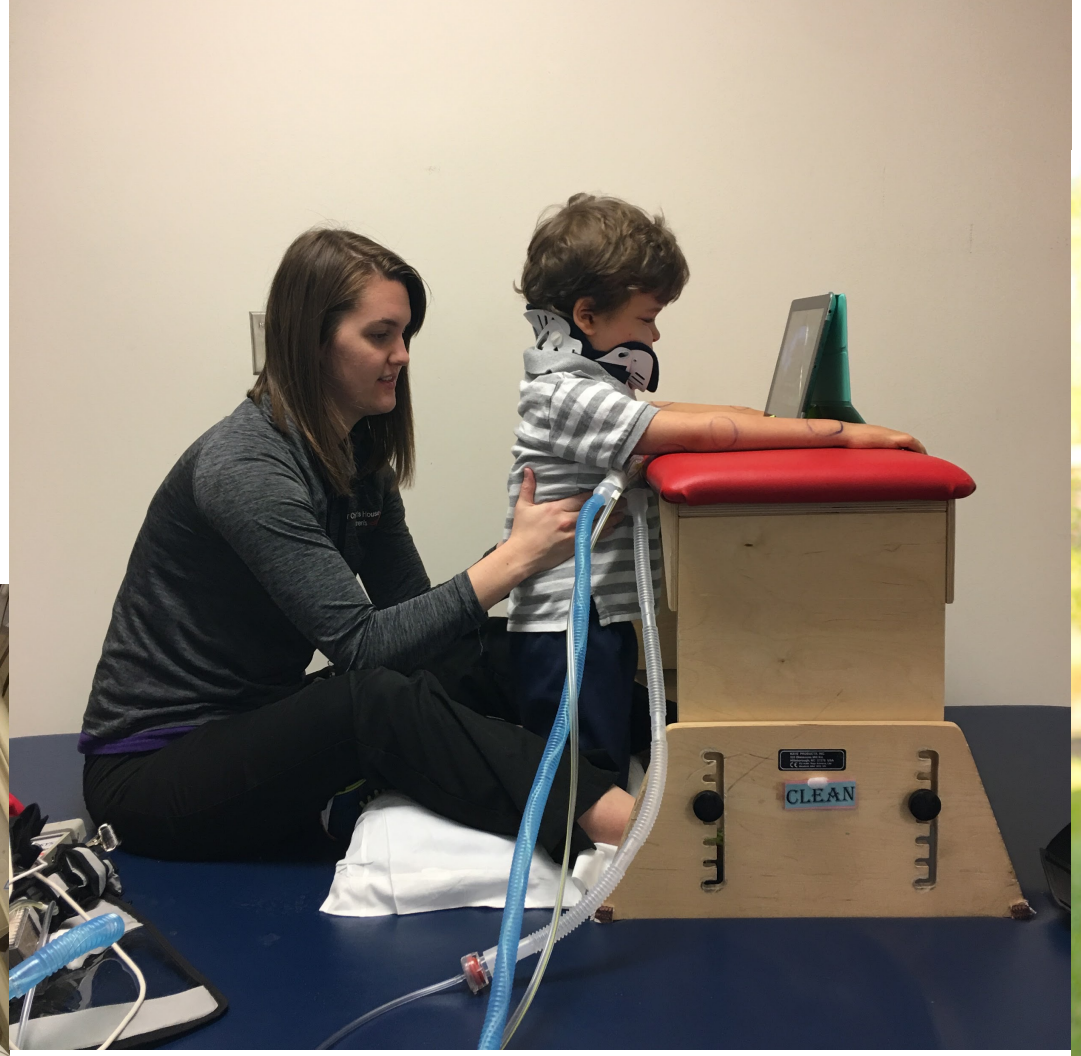
Rehabilitation in AFM-




Therapy
Patient and Families
Psychosocial support
Medical team

BLS

- BLS presented on July 4th, 2016, with emesis and decreased appetite. He was seen in the ER and was admitted for decline in status. He was life flighted to Houston on July 9th, 2016.
- He was treated with 5 rounds of IVIG and PLEX
- Due to ongoing respiratory insufficiency, he underwent a tracheostomy and G tube placement on 7/16/16.
- He was transferred to inpatient rehab in Dallas where he received PT,OT,ST from 8/24/2016 to 2/8/2017. at time of discharge from IPR, he was able to take a few steps with maximum assistance, continued to have drooling, and was still on the vent, but able to tolerate PMV. He had some recovery in left arm.


CLEAN

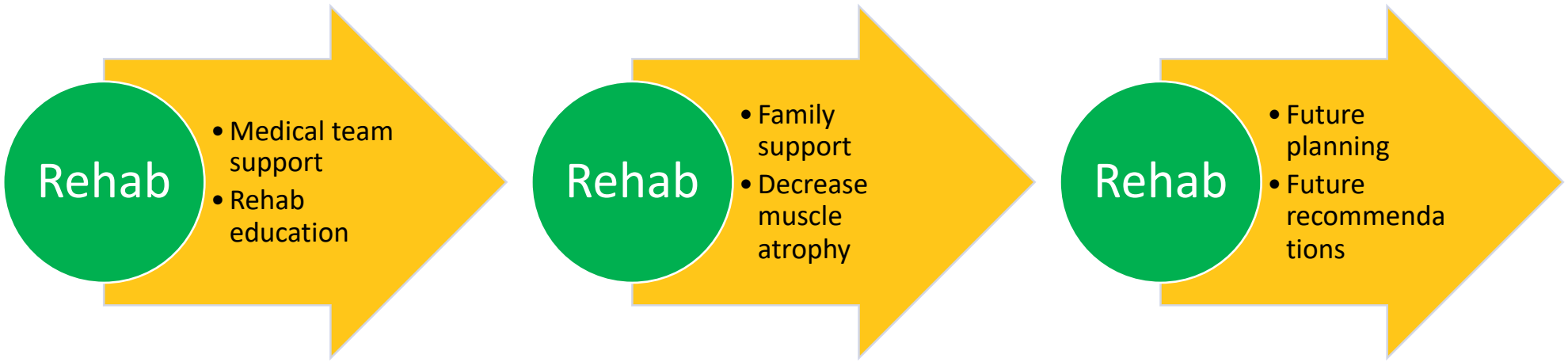
Rehabilitation in ICU

- Early rehab in ICU is safe-
  - Decreased LOS
  - Decreased disuse atrophy and muscle wasting
- Rehab specialists help provide
  - Specific knowledge about SCI, BI etc. from a functional aspect
  - Assessment, planning and coordination of transition to rehabilitation.
- Rehab is involved early in care, helping provide education regarding diagnosis, prognosis, treatment options
- Monitor condition and institute appropriate therapies-
  - Awareness of weakness pattern(Proximal > distal)
  - Stability and early recovery

Rehabilitation in ICU- Early stages

- Early contact with family and ICU teams-
  - Medical team-
    - Discuss with team about options regarding rehabilitation
    - Share information about support options
    - Establishing lines of communication with team is key
  - Families-
    - Integrate families as part of team
    - Educate about different options for rehabilitation
    - Educate families about what happens after (inpatient) rehabilitation

Role of Rehab in patient care



Rehab after diagnosis-

- Autonomic dysfunction-
  - Temperature dysregulation
  - Heart rate dysregulation
  - Blood pressure dysregulation
- Respiratory dysfunction/planning-
  - Diaphragm function
  - Diaphragm atrophy(vent weaning, ? Pacer)
  - Ventilator on rehab unit- challenging/barrier as not all units can accept patients on ventilators

ICU aspects

- Temperature dysregulation- large variation
- Heart rate instability- initial increased variation which settles to sinus tachycardia over 2-3 weeks.
- BP & HTN initially. Hypotension is seen in a rehab setting when starting to become upright, impacting weight bearing
- Bowel and bladder involved- urinary retention with difficulty initiating voiding, constipation and stool incontinence
- Pain can be neuropathic/MSK needing appropriate management

Medical concerns-

- Respiratory-
  - accessory muscle atrophy
  - Inability to cough
  - Tracheostomy and Ventilator dependent impacting communication (vent wean can delay therapy)
- Nutrition-
  - Dysphagia, Tube feedings, poor appetite, constipation
  - Poor oral intake, Food refusal
- Endocrine-
  - Risk of fractures due to immobility(can be seen early)

Support-

- Emotional stress
  - Loss of function is akin to a traumatic event like an MVA
  - Uncertainty about prognosis and delayed diagnosis
- Caregiver support-
  - Coping through the process of grieving the child's change in function
  - Support family and child as needed
  - Peer support
  - Sibling support and interaction

Therapy-

- SLP-
  - Swallowing – assessment, safety and progression of swallow function
  - Communication options
  - Breath support when appropriate
- PT/OT-
  - ROM, positioning(prone while on vents if stable), bracing to maintain joint position
  - Functional assessment- daily exam, coordinate with ICU team about out of bed activities
  - Atrophy of muscles should be addressed
  - Inpatient rehabilitation recommendations

Therapy

- Less strength lost, stronger while starting IPR
- Decreasing muscle atrophy-
  - 1. Uninvolved muscles-
    - Decrease loss of strength due to disuse
    - Functional activities when possible- AROM, Estim
    - Stronger muscles will need to support weak muscles
  - 2. Involved muscles-
    - Maintain muscle activity/strength as much as possible
    - Functional activities
    - Estim
    - Evidence for LMN activity

Recumbent FES bike

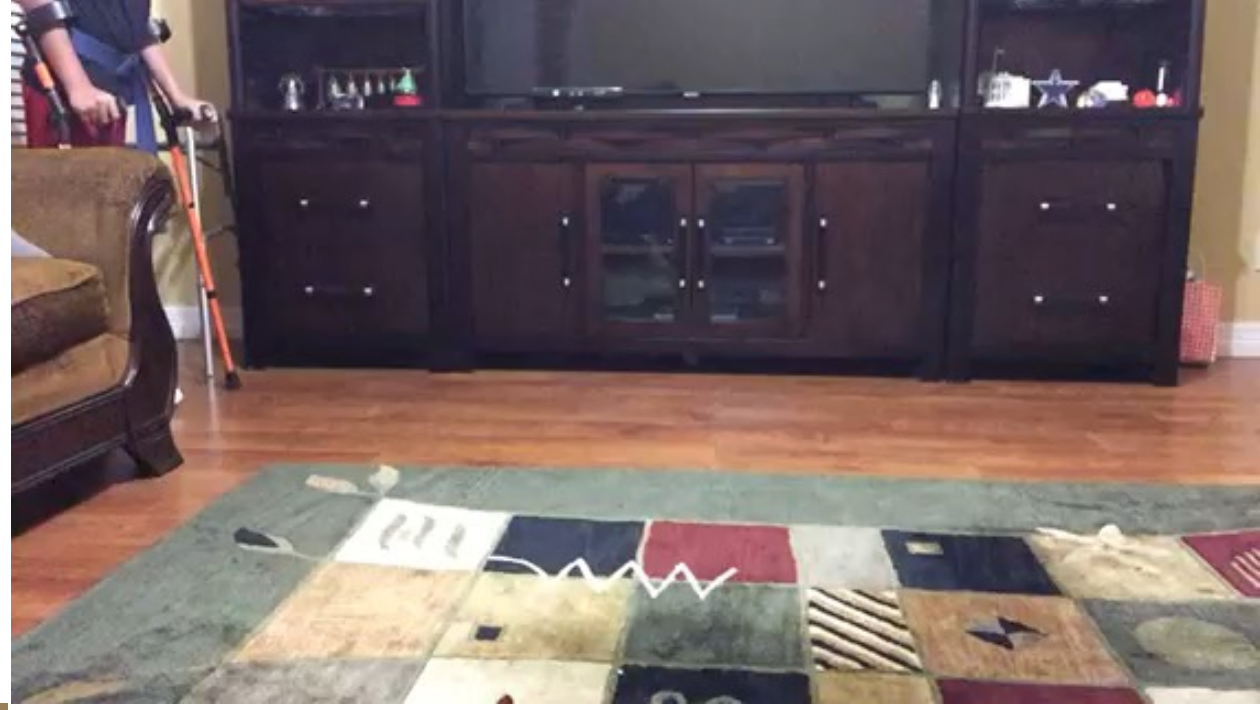
Xcite electrical stim machine- portable with 12 channels

IPR planning

- Early planning- get care coordinator/case manager, social workers involved
- Can the rehab floor take patient from ICU
- Planning of admission to ensure hat the patients are adequately cared for
- Discuss and address barriers
- When are patients appropriate for rehab- variable depending on the unit. Need to have stable vital signs, respiratory status, IV medications, is pain a factor in participation?
- Coordinate with acute rehab team
  - Appropriate hand offs
  - Helping bridge care needs between acute and rehab units
  - Ongoing collaboration during rehab stay
  - Educate about long term consequences

AAD

- Presented to the ED in 9/2018 with upper respiratory illness which progressed to inability to walk and pain in lower extremities and presented with paraplegia. Infectious workup was unremarkable.
- Lab work was negative-(9/10)- enterovirus, adenovirus, CMV, mycoplasma, VZV, HSV, West Nile, EBV in CSF; (9/14): quantitative TB, HIV.
- Neuromyelitis Optica and anti-MOG: negative
- CDS negative
- CSF: 288 nuc cells, protein 50
- MR Spine(9/11): extensive non enhancing central cord signal abnormality on T2 weighted images most consistent with a demyelinating process. With extensive signal abnormality, neuromyelitis Optica would be a consideration.
- MR Brain(9/10): Demyelinating process involves the lower medulla and midbrain. With the extensive cervical involvement, the possibility of neuromyelitis Optica remains.



References-

- 2nd AFM Virtual Symposium, 3rd Session-Rehabilitation
- Patient families
- Colleagues