

Rachel Scott, AFM Parent and Director of AFMA



Braden's Background



- **Braden was five in July 2016**
- **Story bears a strong resemblance to other AFM stories**
- **Had a cold leading up to AFM**

Initial Onset of Acute Flaccid Myelitis



- **July 4, 2016 - Symptoms began**
 - Threw up when he tried to eat
 - No energy
- **July 6, 2016 - Visit to ER**
 - Continued to decline
 - Received fluids, antibiotics and steroids
 - Admitted after no improvement
- **July 9, 2016 - Respiratory failure**
 - Intubated and flown to Houston



Diagnosis and Acute Management



- **July 11, 2016 - MRI**
 - One week after initial symptoms
- **July 12, 2016 - Acute Flaccid Myelitis**
 - Treated with five rounds of IVIg and PLEX
- **July 19, 2016 - second failed extubation**
- **July 29, 2016 - trach and gtube placement**
 - Hospital for almost two months before transfer to rehab

Inpatient Rehabilitation



- **August 24, 2016 - Transfer to inpatient pediatric rehab facility in Dallas**
 - Daily PT/OT/ST
 - In rehab for 5.5 months
- **February 8, 2017 - Discharged to home via ambulance**
 - Take a few steps with maximum assistance
 - Could not manage oral secretions
 - Sprinted a few hours off vent and tolerated PMV
 - Functional recovery in left arm, none in right arm

Continued Recovery



- **September 21, 2017 - Nerve Transfer in LA**
 - 15 months post-onset
 - Regain function in right hand
- **January/February 2018 - Intense Rehab at Kennedy Krieger Institute at Johns Hopkins**
 - 5 to 6 hours of daily therapy
- **September 10, 2019 - Nerve decompression in St. Louis**
- **September 19, 2019 - Decannulation**
- **Continuous Home nurses and therapy**

Braden's Current Recovery



- **Walks short distances independently**
- **Decannulated in Sept. 2019**
- **Regained some swallowing ability**
- **Still very cute and awesome**

Acute Flaccid Myelitis Community

- **Facebook community formed in 2014**
 - Grown to over 800 members
 - Provide emotional support
 - Suggestions for vent weaning, therapy, bracing, supplements, nerve transfers
- **Advocacy Efforts**
 - Nov. 2018 - Met with legislators and members of CDC in DC
 - Dec. 2018 - Shared perspective on CDC's AFM Task Force
- **Jan. 2019 - Formed Acute Flaccid Myelitis Association**
 - Provide support and advocate for families
 - Children's Book to help kids understand their diagnosis



Awareness Saves Lives



- **Corbin was exhibiting symptoms of AFM**
- **His mother reached out via social media**
- **She acted quickly and was connected with a knowledgeable neurologist**
- **Corbin walked out of the hospital**

Closing



- **Thank you so much for being here today!**
- **And thank you to Dr. Pardo and the team who made this possible.**

What is known about the epidemiology of AFM



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