

The RNDS Community: Past, Present and Future

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Number of RNDS Symposia Prior to 1999:



Number of RNDS Symposia After 1999

14

- TMA International Symposium, August, 1999
- TMA International Symposium August 2001
- California Transverse Myelitis Conference, hosted by the Cody Unser First Step Foundation and Reeve-Irvine Research Center, 2002
- Neurological Information Day for Health Care Professionals, MS Society of Ireland, Speaker, July 2002, Galway, Ireland

- Children's Transverse Myelitis Workshop, Columbus OH 2003
- Rare Neuroimmunologic Disorders Symposium. August 2004. Baltimore, MD
- Second International Biennial Rare Neuroimmunologic Disorders Symposium, Baltimore MD 2006
- Southwest Neuroimmunologic Symposium. Sponsored by The Cody Unser First Step Foundation and the Governor's Commission on Disability. University of New Mexico. Albuquerque, NM. April 2007

- Victory Junction Gang Camp Fall 2006
- AAP California RNDS Symposium 2007
- London UK TM Group Meeting 2007
- Scotland TM Group Meeting 2007
- Victory Junction Gang Camp Summer 2007
- Seattle RNDS International Symposium 2008

Seminal Events in RNDS History

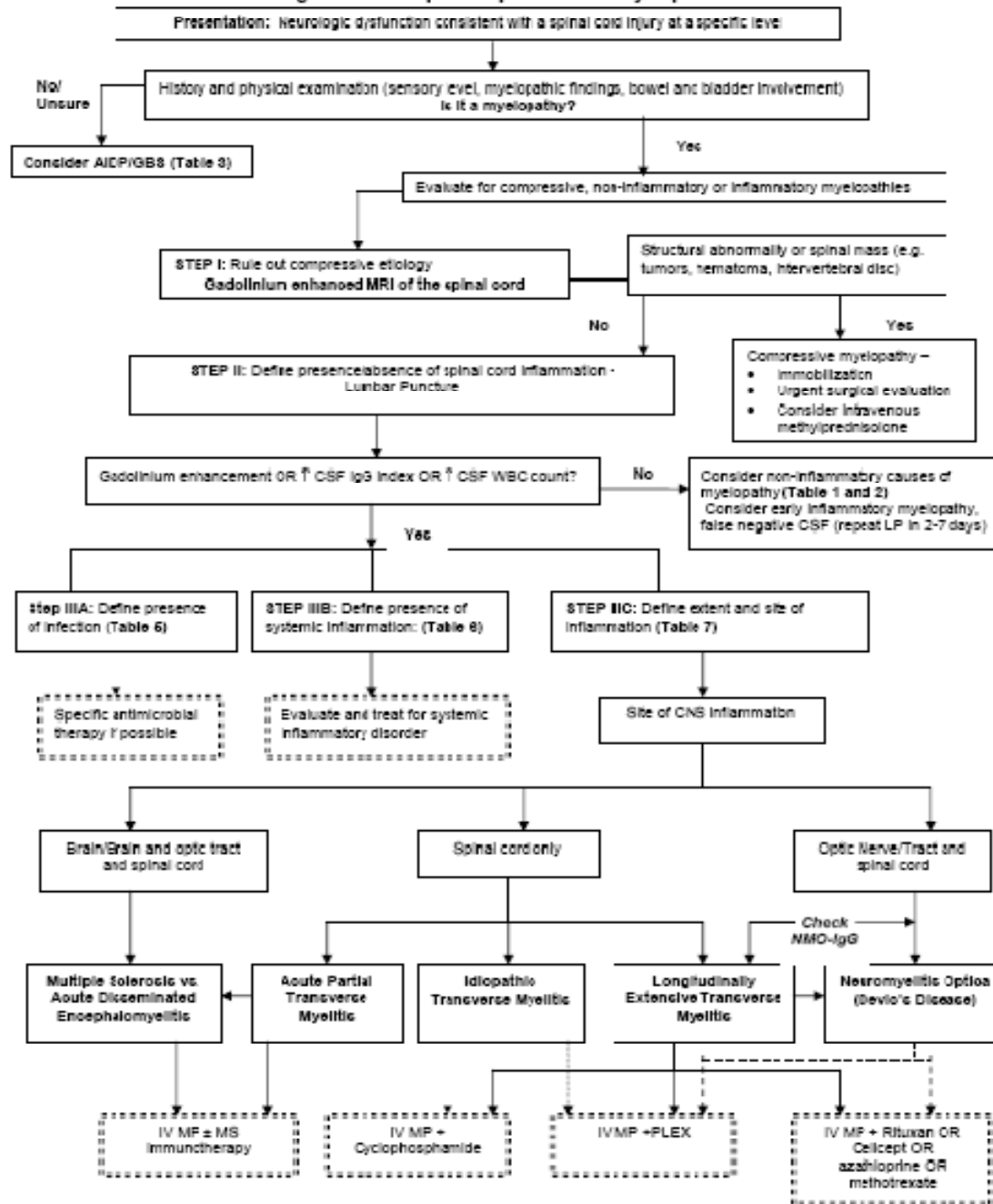
- Bastian 1881
 - Acute Myelitis as vascular or immune mediated
- Rivers 1929
 - Post-vaccinial TM cases in the UK
- Suchet-Kaye 1948
 - “acute transverse myelitis” was first used to describe a case of rapidly progressive paraparesis with a thoracic sensory level, occurring as a postinfectious complication of pneumonia
- Berman 1981
 - TM Incidence and Etiologic Considerations

- Brocke and Steinman 1983
 - Superantigens and EAE
- Tippett 1991
 - Relapsing TM
- O’Riordan 1996
 - NMO
- Jorens
 - Superantigen from ear infection triggered severe TM in infant
- Scott 1998
 - Severe vs partial TM and risks of MS
- Weinshenker 1999
 - PLEX for severe neuroimmunologic disorders

- Wingerchuk 1999
 - NMO history and clinical classification
- De Seze 2001
 - Acute myelopathies and classification
- Defresne 2001
 - High dose steroids in TM
- Transverse Myelitis Consortium Working Group 2002
 - Definition and Classification of TM and treatment algorithm
- De Seze 2005
 - Application of 2002 TMCWG Criteria
- Kaplin 2005
 - Interleukin 6 and TM: Biomarker and causative factor

- Wingerchuk 2006
 - Revised NMO Criteria including NMO-IgG
- Krishnan and Kaplin, UpToDate 2007
 - Revised diagnosis and treatment algorithm to account for NMO, Lupus, infectious myelitis and proposing treatment
- Greenberg 2007
 - Treatment of idiopathic and disease-associated TM
- Pidcock 2007
 - Pediatric TM
- Birnbaum 2008?
 - Lupus and myelitis, classification and treatment

Figure 1: Work up of Suspected Acute Myelopathies



So What's Missing? (i.e. Why Aren't We Done These Darned Disorders?)

- We've got to understand them before we understand how to treat them!
- Humans are hard to experiment on and animals don't fit the bill very well in many cases!
- Our tools are pretty blunt sometimes and the diseases are pretty shifty!
- Heck, TM discovered in 1881, we've been at it since 1999, give us a break!

Necessary Steps-Preclinical

- Animal Models of NMO, ON, TM etc
- Cell culture models of immune-mediated neural injury
- Understanding of pathophysiologic processes
 - Triggers
 - Accelerators
 - Final common pathways
- Testing new drugs
 - High throughput
 - Rationale design
- Collaborative Cross Pollination

Necessary Steps-Clinical

- Multi-Center Consortia
 - Decision on outcome measures
- Muti-Center Consortia
 - Therapeutic trial
- Commercial Investment
 - RND therapy is NOT commercially viable
 - Must be a model of something commercially viable OR
 - Must allow a therapy “in’ as a therapy for orphan disease
 - Additional patent protection
 - Lower bar for clinical trial
 - Lower clinical bar for efficacy

So, Why Are We Here Together (I.e. Why Study These Darned Diseases Jointly?)

- The trigger mechanisms for immune-mediated neural injury are shared
- T-lymphocyte immune-effector mechanisms are shared.
- B-lymphocyte immune effector mechanisms are shared.
- The mechanisms by which immune cells traffic into the central nervous system are shared.
- The mechanisms of neural injury are shared.
- The mechanisms of neural regeneration are shared.

But Why Have Clinicians, Researchers, Patients and Caregivers Here Together?

- BECAUSE SOME MAGICAL TRANSFER AND ADVANCEMENT OF KNOWLEDGE AND ENERGY OCCURS WHEN PEOPLE OF VARIOUS WALKS OF LIFE ARE THRUST TOGETHER FOR A COMMON PURPOSE: TO ERADICATE THESE AUTOIMMUNE DISORDERS.

Rules of the Symposium

- DON'T TALK TO PEOPLE YOU KNOW: THEY ARE BORING AND YOU'LL TALK ABOUT THE SAME OL' CRAP
- NO QUESTION IS TOO STUPID
- FOR EVERY QUESTION ASKED OF YOU, ASK ONE BACK. YOU'LL LEARN SOMETHING
- BELIEVE THAT THIS WILL CHANGE THE FUTURE: FOR SCIENCE, FOR YOU AND FOR THE COMMUNITY.