Resource Committee Updates – September 2014

JAMA Neurology

Comparison of Plasmapheresis and IVIG as Maintenance Therapies for Juvenile MG

May 2014

http://archneur.jamanetwork.com/article.aspx?articleid=1834621&resultClick=24

Objective

To determine whether PLEX or intravenous immunoglobulin (IVIG) therapy is more effective as maintenance therapy in this disease.

Design, Setting, and Participants

This retrospective analysis over a 33-year period involved 54 children and adolescents with juvenile MG at a specialized neuromuscular clinic and electromyography laboratory at a tertiary care academic pediatric hospital.

Conclusions and Relevance

This study provides evidence that PLEX and IVIG both have high response rates as maintenance therapies and are reasonable therapeutic options for juvenile MG. Plasmapheresis may have a more consistent response rate than IVIG in this setting. These findings will provide some guidance regarding the approach to therapy for juvenile MG, especially as the results differ somewhat from those of studies focusing on adult MG.

ClinicalTrials.gov

Phase II Trial of Rituximab in Myasthenia Gravis: Actively Recruiting July 29, 2014

http://clinicaltrials.gov/ct2/show/NCT02110706?term=myasthenia+gravis&rank=15

The specific primary objective of this study is to determine whether rituximab is a safe and beneficial therapeutic for MG that warrants further study in a phase III efficacy trial.

Estimated Enrollment: 50

Study Start Date: May 2014
Estimated Study Completion Date: December 2017

Subcutaneous Ig Maintenance Therapy for Myasthenia Gravis: Actively Recruiting

July 25, 2014

http://clinicaltrials.gov/ct2/show/NCT01828294?term=myasthenia+gravis&rank=5

The study is being done with patients with Myasthenia Gravis (MG), age 18-80 years, positive acetylcholine receptor antibody, receiving greater than 30mg of prednisone daily. Patients may or may not be receiving anticholinesterase agents. This study is being done to test if giving IVIG in a subcutaneous form (into the fat of the abdomen, legs and thighs) will be better tolerated for patients with Myasthenia Gravis.

Estimated Enrollment: 10

Study Start Date: October 2011 Estimated Study Completion Date: May 2015

Exercise for Stable Myasthenia Gravis: Actively Recruiting

August 19, 2013

http://clinicaltrials.gov/ct2/show/NCT01047761?term=myasthenia+gravis&rank=16

Generalized fatigue in myasthenia gravis results in physical deconditioning that reduces fitness and increases risk of obesity, hypertension, elevated cholesterol and type 2 diabetes. This study will examine how active and fit are 30 individuals with chronic, generalized myasthenic subjects. This study will also determine whether a 3 month home exercise program with aerobic, resistive, and pulmonary training can improve physical activity, strength, fitness, lung function and reduce cardiovascular disease risk.

Estimated Enrollment: 30

Study Start Date:January 2010Estimated Study Completion Date:December 2020

Other trials in active recruitment include:

- Safety and Efficacy of Eculizumab in Refractory Generalized MG
- Evaluation of Belimumab in MG
- Efficacy and Safety of Leflunomide or Azathioprine Therapy in MG Patients After Expand Thymectomy
- Innovative Measures of Speech and Swallowing Dysfunction in Neurological Disorders
- Therapeutic Plasma Exchange in MG

Upcoming trials not yet recruiting:

- Benefits and Tolerance of Exercise in Patients With Generalized and Stabilized MG
- Open Label Study of Subcutaneous Immunoglobulin (SCIg) in MG
- Therapy of Antibody-mediated Autoimmune Diseases by Bortezomib (TAVAB)
- Perception and Multisensory Integration in Neurological Patients Using fMRI

MGFA 2014 National Conference in Philadelphia

http://www.myasthenia.org/LivingwithMG/MGFAConferenceVideos.aspx

Facebook Groups

- Myasthenia Gravis
- Myasthenia Gravis Won't Stop Me
- Snowflake Wellness closed group; focused on holistic healing

Nutrition

- Eliminate processed foods
- Eats whole foods
- Eliminate white foods
- AIP Autoimmune Protocol (Paleo)
 - o The Paleo Mom http://www.thepaleomom.com/autoimmunity/the-autoimmune-protocol
 - o http://autoimmune-paleo.com/the-paleo-autoimmune-protocol-an-elimination-diet-for-autoimmune-disease/
 - o Book on AIP The Paleo Approach, Reverse Autoimmune Disease and Heal Your Body
 - By Paleo Mom (Paleo Mom also has a cookbook coming out at the end of the month)

Discounted Prescriptions

www.goodrx.com – I have not used this, but have heard about it via FB support groups.

Alternative Treatment / Types of doctors

Holistic doctors
Functional Medicine doctors
Nutritionists
Function Neurology/chiropractic neurology

Exercise Ideas - know your limits

- Swimming
- Aquatic Zumba
- Water aerobics
- Yoga
- Stretching