Twins help progress and diagnosis of rare myasthenia
Marc Aderghal
July 22, 2014
http://www.youris.com/Health/Genetics/Twins-Help-Progress-And-Diagnosis-Of-Rare-Myasthenia.kl

Fourteen pairs of identical twins joined the EU funded medical project “Fight-MG,” to fight Myasthenia Gravis. This rare autoimmune disease leads to abnormal fatigability of various skeletal muscles.

FIGHT-MG (http://www.fight-mg.eu/) is a European consortium aiming to shed light on the course of Myasthenia Gravis (MG) disease, but also on the etiological and pathological mechanisms of MG.

Coordinated by the French National Institute of Health and Medical Research (INSERM), the project links together 11 leading teams from France, Greece, Israel, Switzerland, Germany, Norway and Italy.

Survivin as a Potential Mediator to Support Autoreactive Cell Survival in Myasthenia Gravis: A Human and Animal Model Study
http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0102231
July 22, 2014

The mechanisms that underlie the development and maintenance of autoimmunity in myasthenia gravis are poorly understood. In this investigation, scientists evaluated the role of survivin, a member of the inhibitor of apoptosis protein family, in humans and in two animal models. They identified survivin expression in cells with B lymphocyte and plasma cells markers, and in the thymuses of patients with myasthenia gravis.

Thymuses of patients with myasthenia gravis had large numbers of survivin-positive cells with fewer cells in the thymuses of corticosteroid-treated patients. Application of a survivin vaccination strategy in mouse and rat models of myasthenia gravis demonstrated improved motor assessment, a reduction in acetylcholine receptor specific autoantibodies, and a retention of acetylcholine receptor at the neuromuscular junction, associated with marked reduction of survivin-expressing circulating CD20+ cells.

Subcutaneous Ig Maintenance Therapy for Myasthenia Gravis: Actively Recruiting
July 25, 2014
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  
**Estimated Primary Completion Date:** May 2015

**Other trials currently recruiting include ‘Phase II Trial of Rituximab in Myasthenia Gravis,’ ‘Exercise for Stable Myasthenia Gravis,’ and ‘Safety and Efficacy of Eculizumab in Refractory Generalized Myasthenia Gravis.’ Details can be found on clinicaltrials.gov.

**MGFA 2014 National Conference in Philadelphia**  
http://www.myasthenia.org/LivingwithMG/MGFAConferenceVideos.aspx

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**Facebook Groups**
Myasthenia Gravis  
Myasthenia Gravis Won’t Stop Me  
Snowflake Wellness – Closed group; focused on holistic healing

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**Nutrition**
Eliminate processed foods  
Eats whole foods  
Eliminate white foods  
AIP – Autoimmune Protocol (Paleo)

- The Paleo Mom  
  http://www.thepaleomom.com/autoimmunity/the-autoimmune-protocol
- 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