

# MG Communicator

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## A Patient Guide to Immunoglobulin Therapy

Intravenous immunoglobulin (IVIG) is a safe, effective, and common therapy prescribed by many physicians to treat Myasthenia Gravis. Once your physician has prescribed IVIG therapy, you have the option of receiving this treatment at the hospital infusion center or at home. Both locations are a safe way to receive this therapy, and you and your physician can make this decision together.

The first step towards receiving IVIG therapy is to ensure that your insurance company has authorized it. The authorization process is a critical step to receiving your treatment because IG is an expensive therapy. Whether you are receiving your infusions at home or in the hospital infusion center, your physician's office staff will provide assistance with obtaining a written insurance authorization. Authorizations can sometimes take up to a few months to obtain and typically last six months to one year.

IVIG therapy is predominantly administered intravenously (when a needle is placed directly into a vein). The needle will be placed by a nurse, who will be in attendance during your whole infusion. The length of your infusion will depend on a few factors: the dose and the infusion rate. Because immunoglobulin is dosed according to the patient's body weight, the amount received as well as the rate of the infusion will determine how long the infusion will last. Your doctor, pharmacist, and nurse will determine the infusion rate for you, via an infusion pump, and infusions typically last from 2 to 5 or more hours.

While IVIG is extremely safe, several side effects can occur, and these side effects are usually related to the rate of the infusion. Most will occur within the first 30 to 60 minutes of the start of the infusion. The severity of reactions can range from mild to severe, however most side effects are very mild and transitory. The most common side effects are headache, nausea/vomiting, and fever/chills. Your physician and also your IG provider will review your medical information to ensure that your IG therapy is appropriate for you, minimizing side effects. Taking premedication such as Benadryl and prednisone may help to avoid side effects, and will also be prescribed by your doctor. Drinking plenty of water (6-8 8oz. glasses per day) the day before, during, and the day after your infusion is also important. Also try to avoid caffeinated beverages.

During your infusion, whether at home or at an infusion center, your nurse will stay with you during the whole infusion, periodically monitoring your vital signs and progress. Make sure to tell her immediately if you are starting to experience any type of side effect. Be prepared with a book or something else to do to pass the time. Also, remember to eat well balanced meals and continue your normal daily activities on the day of and surrounding your infusions.

IVIG therapy is mostly prescribed on a monthly basis, however each patient may respond a little differently to treatment, and your schedule may differ. Your doctor will evaluate your response and can customize your treatment plan to optimize your outcome. Remember, feeling the benefits of your IVIG infusion can take a little time. Make sure to communicate with your doctor, and together you can customize your treatment plan with IVIG and live life to the fullest.

Stephanie Bruce, Option Care

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# From Your Director

There is much work ahead as we become our own non-profit organization, independent from the Myasthenia Gravis Foundation of America. As the Myasthenia Gravis Foundation of Michigan (MG-MI), we continue to support Michigan patients and caregivers. "New Patient Packets" have been created and are being distributed to neurologist who treat patients with MG. These packets are especially helpful to those newly diagnosed.

We have several major fundraising events coming up:

- March 18—Horseshoe Smokehouse Restaurant—Grand Rapids
  June 18—the Eenhoorn 5K Run/Walk—Millennium Park
- August 6—the Hoon Open Golf Outing—Rockford

See the back page or our website (http://www.mg-mi.org) for more information. Participate, volunteer or donate!

Information and Support meetings have been scheduled for 2016 (see insert page). Check the schedule and save the page, then come to the next meeting that will be near you. Your presence at meetings provides support and hope to others. The meetings are planned for you; please attend.

I would like to hear from those of you who have had MG for over 10 years, as we will be doing something special to celebrate our 40<sup>th</sup> year as a foundation serving Michigan.

Susan Southerton, Executive Director

#### WE NEED YOUR HELP!

Are you still receiving a hard copy of the MG *Communicator* newsletter in the mail? Do you have an email address? If so, you can receive your newsletter electronically via email and help us save money! Currently, newsletters are printed and



mailed to about 850 patients, support givers, members of the medical community and friends, even though most recipients have email. Each edition costs the MG-MI about \$1,000 which includes printing and postage.

The Foundation mails 2-3 newsletters a year, packets about our major fundraisers and postcard reminders for support meetings account for about 10% of our budget. This money could instead pay for patient information packets that are distributed to doctors' offices and given to newly diagnosed patients. \$1,000 could fund student interns to assist our executive director in the office and at fund raisers throughout the year. It could pay for informational brochures and educational programming at support groups.

The Board of Trustees is asking for your help by choosing to receive most of your communication from the MG-MI via email. For electronic newsletters, support meeting notices and information about fundraisers, please visit the MG-MI website at http://www.mg-mi.org/ click on the "Get UPDATES – Keep informed" tab and sign up. You may also email the office at myasthenia.info@gmail.com and ask for email newsletters. Thank you for your assistance.

Priscilla Walden, Treasurer

### **Donating, Processing and Receiving Plasma**

Some of you may be wondering about the process of immunoglobulin preparation. Plasma is collected at certified centers of which there are over 400 in the U.S. Donors receive a small financial compensation, typically \$15-\$40 per donation. Donors must be at least 18 years old, over 110 pounds and in good health. Donors are screened through lab work and are excluded for such things as a new tattoo, a recent long stay out of the country, or having had cancer or other medical conditions. There is a national database which is maintained to verify eligibility across the country.

A donation of plasma is similar to donating blood but the donor receives their red blood cells back and only the plasma is collected. Plasma is the pale yellow part of the blood which aids in circulation of red and white cells. The plasma is typically held for 60 days, tested to verify that it is viral free and discarded if it is not safe. After the 60 day hold, the good plasma is pooled from numerous donors, purified and processed. Specific plasma proteins are extracted for a particular health benefit such as MG. The whole process takes between 7 to 9 months. Individuals with primary immune deficiency, neurologic disorders or autoimmune disease can be treated with these plasma protein therapies. Millions of liters of plasma are donated and manufactured into these IG medicines.

Administration of IG can be any of these three ways: Intravenous (through the vein), Intramuscular (into the muscle) or Subcutaneous (under the skin). The administration method is chosen by the amount of IG required for the type of medical condition. IVIG is used in MG because immunoglobulins in a person may not be functioning properly. With autoimmune disorders the body produces enough immunoglobulin but there is an error and the body attacks itself. IG's goal is "to stop the immune system from attacking itself by binding the antigens of the bad cells and destroying them." IG Therapy can be given at home, hospital or treatment center.

For Further information see: *Option Care's A Patients Guide to immunoglobulin Therapy*, 10-22-2015, http://www.optioncare.com/infusion-services/immunoglobin-therapy/ and *IG Living Magazine*, Dec-Jan 2016, "Savings Lives through Plasma Donation."

#### **Plasma Donation Centers**

Some common Plasma Centers in Michigan include: Biomat USA, CSL Plasma, Talecris Plasma Resources, Octapharma Plasma, BioLife Plasma Services and Michigan Blood. To find one in your area, visit http://donatingplasma.org/donation/find-a-donor-center.





....to our MG (sports car) enthusiasts and University Motors Ltd for inviting us to your 41st Birthday Party on January 23, 2016. The celebration honored our MG-MI Foundation with a donation of \$170. Thank you, John Twist, for your support!



# **MG-MI**

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### CHANGE SERVICE REQUESTED

Horseshoe Smokehouse for Good Food, Good Company, Good Cause!

333 Grandville Ave SW Suite #100 • Grand Rapids, MI 49503

Saturday, June 18, 2016 at Millennium Park

Teams and individuals welcome! Sign up online at www.mg-mi.org

Save the date! More information soon on our website, www.mg-mi.org

Did you know you can now sign up to have our newsletters, support meeting

Hoon Open—Saturday, August 6, 2016

notices, and event information sent to you electronically?

Monday, March 14, 2016

Join us for dinner from 5:00 to 8:00 p.m. with 50% of food sales benefitting our foundation!

Eenhoorn 5K Run and Walk

1415 Maynard Ave SW • Walker, MI 49534 Family activities, food, prizes and networking

North Kent Golf Course—Rockford, MI

Check it out—www.mg-mi.org

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