MG NEWSLETTER

Myasthenia Gravis Association of British Columbia
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The Myasthenia Gravis Association of BC

Welcome to Fall 2022!

Fall Support Group Meeting

October 23rd at 1:30 ***2805 Kingsway Room 307***

Your hard working board of directors has been in touch with the neurologists at the **Myasthenia Gravis Clinic** to find a suitable doctor to do a Fellowship in Myasthenia Gravis. There is an interested candidate who seems very interested in MG. We are hoping that she will be available to come to this meeting to talk about herself and her commitment to Myasthenia Gravis.

Otherwise, please come with your questions, concerns and experiences with our favorite topic: MG.

Looking forward to seeing everyone!
Refreshments will be served afterwards.

Brenda Kelsey

2022 MGABC Symposium Update

To date, there are still no plans to reschedule the **Myasthenia Gravis Symposium**. Given the easing of Covid restrictions, Vancouver Coastal Health may be able to increase occupancy regulations. When we have more information, we will send it along.

2022/23 Membership Drive and Fundraising Begins!

Every October we ask MGABC members to renew their memberships. The annual cost is $20/member. This fee includes a bi-annual newsletter, free information pamphlets, notification of special programs of interest to Myasthenics, support group meetings with speakers as well as staff willing to help and support you. Memberships renewed after September 30th will be good for the coming year. If for any reason this fee poses a financial hardship, please let us know and we will extend your membership free of charge.

PLEASE HELP US REDUCE PRINTING AND POSTAL COSTS BY READING THE NEWSLETTER ONLINE ON OUR WEBSITE - Myastheniagravis.ca.

Send us an email with *Newsletter* in the subject line and we will be sure to inform you when it has been posted.

Articles contained in this newsletter are for information only. The MG Association of BC does not give medical advice. In matters of medical treatment, patients should consult with their physicians.

Subcutaneous IG Found Effective for MG Adults in Small Study

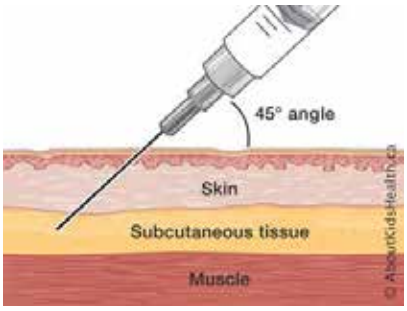
All patients remained stable or improved clinically after treatment

by Steve Bryson, PhD | September 6, 2022

Subcutaneous immunoglobulin therapy (SCIg) — given by under-the-skin injection — was well-tolerated and effective in the management of adults with myasthenia gravis (MG), a small study has found.

Although the therapy is approved for other diseases related to immune system deficiency, and is currently under investigation as an MG treatment, it is not yet officially recommended for MG due to lack of data.

This study supports the use of SCIg as an alternative to the standard **intravenously immunoglobulin therapy (IVIG)**, which is given by infusion directly into the bloodstream. Researchers noted that further studies are needed to confirm these findings.



The study, **"Usefulness of subcutaneous immunoglobulin therapy in the management of myasthenia gravis: a retrospective cohort study,"** was published in the ***Journal of Neurology***.

In MG, self-reactive antibodies target and damage the neuromuscular junction, which is the region where nerves communicate with the muscles they control. As a result, people with the condition experience symptoms of weakness and fatigue that may affect muscles in the eyes, face, throat, limbs, and those involved in breathing.

Immunoglobulin (IG) therapy, consisting of immune globulins (immune proteins), is a treatment for MG patients with severe or rapidly worsening symptoms and is mainly administered intravenously. Although the mechanism of IVIG is unclear, it is thought to suppress the immune system and reduce the levels of harmful self-reactive antibodies.

Study compared 16 adults with generalized MG before and after SCIg

Due to the lack of data about SCIg for MG, researchers at the University of Bordeaux, in France, examined the medical records of 16 adult patients with generalized MG (11 female and five male patients), ages 19–83, and compared the severity of their symptoms before and after SCIg.

By the end of the study period, 11 had stopped SCIg, while nine were still being treated. The surgical removal of the thymus gland — a procedure called thymectomy — was performed on five patients.

All participants had been treated with IVIG six months before SCIg, and 13 received at least one immunosuppressive therapy when SCIg was started.

Reasons for starting SCIg included difficulties accessing veins and IVIG dependence — a condition in which there is a notable deterioration in symptoms during IVIG withdrawal. Because of low levels of immunoglobulins in the bloodstream or a lack of response, the average weekly SCIg dose was increased from 0.4 to 0.46 g/kg in 37.5% of patients.

SCIg response was measured by comparing the Myasthenia Gravis Foundation of America (MGFA) clinical classification before and after SCIg.

After SCIg, eight individuals (50%) improved across all levels of MGFA classifications, including three dropping from stage 4 to 3, reflecting a change from severe to moderate general muscle weakness. One patient improved from stage 4 to 1, or minimal symptoms; two from stage 3 to stage 2, with mild symptoms; one from stage 4 to stage 2; and one from stage 3 to 1.
The remaining eight individuals (50%) remained stable, with four in stage 4 and four in stage 3. None of the patients worsened clinically.

Hospitalizations, ICU visits, and intubations were reduced after SCIg

The number of days spent in the hospital per month was significantly reduced following SCIg relative to the period preceding treatment initiation. Time in the intensive care unit and the number of days intubated to assist breathing were also significantly reduced after treatment.
There was no change in the average number of daily treatments with anticholinesterase therapy, which is designed to improve nerve-muscle communication at the neuromuscular junction.
The median number of immunosuppressant treatments dropped from 2 to 1.5 at the end of SCIg, though this difference was not statistically significant. Yet, the dosage of anti-inflammatory corticosteroids was significantly reduced after SCIg treatment.
Further, the proportion of participants treated with the immunosuppressant azathioprine decreased, whereas the median number of rituximab treatment courses significantly increased.
After starting SCIg, fewer patients experienced myasthenic crises — a medical emergency when MG affects the muscles that control breathing. Less use of IVIG and plasma exchange for removing harmful antibodies from the bloodstream was also reported.
The median duration of SCIg treatment before needing IVIG, which occurred in seven patients (43.8%), was 21.4 months (a little less than two years).
Eight out of the 10 patients who attended a follow-up visit were still being treated with SCIg and were in favor of continuing treatment. One individual requested SCIg be given at home and IVIG in the hospital, one wanted to resume SCIg due to IVIG-related adverse effects, and one showed an interest in using skin patches to reduce injection pain and improve comfort.

The main reasons for stopping SCIg included a lack of response and interrupted SCIg supply.
Adverse effects such as deep skin lesions (subcutaneous nodules) were observed in eight participants after SCIg, rash at the injection site in four patients, headache in four, and itchy skin in two. Diarrhea, bruising at the injection site, medicine leakage, physical weakness, and a lung blood clot were each reported by one patient.
"We describe the successful management of MG patients using SCIg, which was validated by MGFA classification … , ICU hospitalizations, and the use of [intubation] in 16 patients," the researchers wrote. *"Further large-scale prospective studies [over time] are needed to confirm these results."*

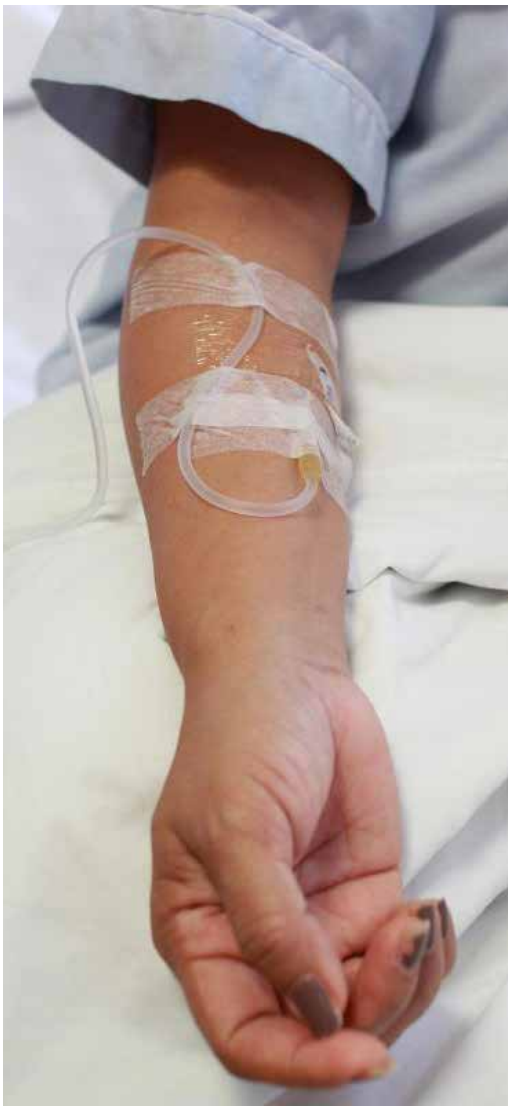
Steve *holds a PhD in biochemistry from the Faculty of Medicine at the University of Toronto, Canada. As a medical scientist for 18 years, he worked in both academia and industry, where his research focused on the discovery of new vaccines and medicines to treat inflammatory disorders and infectious diseases. Steve is a published author in multiple peer-reviewed scientific journals and a patented inventor.*

Spherix Analyzes Reviews of gMG Therapies, Vyvgart, Ultomiris

The two treatments were rated well for effectiveness, but differed in dosing schedule, safety profile

by Lindsey Shapiro, PhD | September 1, 2022

Neurologists find both **Vyvgart** (efgartigimod) and **Ultomiris** (ravulizumab-cwvz) effective for treating generalized myasthenia gravis (gMG), but believe Ultomiris has a more convenient dosing schedule while Vyvgart may have a better safety profile.



That's according to a recent analysis by the market intelligence firm **Spherix Global Insights**. Spherix's analysis of the two treatments was part of **Launch Dynamix**, a service that provides monthly benchmarks of new products during the first 18 months that they're commercially available.

Both Vyvgart and Ultomiris earned U.S. approval within the past year for treating gMG patients who have antibodies against the acetylcholine receptor (AChRs), the most common MG-causing antibodies.

Even though they're approved for the same indication, the two treatments have different mechanisms of action.

Argenx's Vyvgart is designed to block a protein called neonatal Fc receptor (FcRn) that normally helps stabilize antibodies circulating in the bloodstream, including those involved in MG attacks. By doing so, the therapy aims to accelerate the destruction of MG-causing antibodies and ease symptoms.

Ultomiris works by blocking a critical protein in the body's complement system involved in driving the inflammatory damage seen in MG. It was originally developed by **Alexion Pharmaceuticals**, which was acquired by **AstraZeneca** last year.

Spherix reported in a press release that neurologists in the U.S. noted Vyvgart's effectiveness and safety as its greatest advantages for treating gMG, whereas Ultomiris' advantages were its effectiveness and convenient dosing schedule.

The dosing of Ultomiris was deemed more convenient than Vyvgart's. After an initial loading dose, Ultomiris is delivered as an into-the-vein infusion every eight weeks.

"I definitely like the every-eight-week dosing interval. It takes the guesswork out of it," a neurologist said.

Vyvgart is administered as an infusion once weekly over a four-week treatment cycle. Subsequent treatment cycles are determined based on clinical evaluations.

"The bad thing is it's kind of like an as-needed medication," one neurologist said. *"After you give the first cycle, then you have to wait and see if there's deterioration. Sometimes patients get nervous. I can get nervous, especially in a patient who when they do deteriorate, they immediately go into crisis. That's why I choose my patients as to who I should give it to."*

But Spherix noted Vyvgart outperforms Ultomiris in overall safety. Ultomiris comes with a boxed warning for serious meningococcal infections that can quickly become life-threatening if not treated. Vyvgart has not been associated with a similar risk. In the U.S., Ultomiris is only available through a restricted access program called **ULTOMIRIS REMS**.

Some neurologists who were interviewed indicated they didn't find that warning to be a significant deterrent to Ultomiris' use, which was sometimes attributed to their past experience prescribing **Soliris** (eculizumab), another approved gMG treatment that comes with a similar infection warning. Similarly, the REMS program was not seen as a major deterrent to using Ultomiris.

Whether a patient was comfortable with the medication's safety risks significantly influenced neurologists' prescribing decisions.

Some interviewees also noted the safety profile of Vyvgart may be different in clinical practice than it was in the Phase 3 ADAPT Phase trial (NCT03669588) that supported its approval.

"The biggest concern I have is about the safety: we are absolutely, 100% going to be giving the drug [Vyvgart] more often than what was given in the clinical trial because I think they didn't conduct their studies the way they should have," a doctor said. *"The re-treatment criteria were way too strict … Therefore the safety data is not valid for the way it's going to be used."*

Nevertheless, Vyvgart was generally deemed to fulfill an unmet need for gMG patients, and its use is expected to expand significantly in the next six months, Spherix said.

An under-the-skin injectable formulation of Vyvgart is expected to launch in 2023.

Lindsey *earned her PhD in neuroscience from Emory University in Atlanta, where she studied novel therapeutic strategies for treatment-resistant forms of epilepsy. She was awarded a fellowship from the American Epilepsy Society in 2019 for this research. Lindsey also previously worked as a postdoctoral researcher, studying the role of inflammation in epilepsy and Alzheimer's disease.*

DONATIONS as of August, 2022...

James Harris
Sandra Trimble
Brett Simpson
Allan Thorp
Velma Cotten
James Postnikoff
Lorna Andrews
Serina Charleson
Isabella Hui Lui
Tom & Jean Tronsgard
Joan McLaughlin
Linda Briggs
Tom Barrett*
Mark Revell
Jody Garneau

** Tom is making **monthly contributions** through **Canada Helps***

Three anonymous donations - with thanks!
Provincial Employees Community Service Fund
United Way of B.C
Hudson Social Group
Research Donations: Kip Wilson

In Memoriam:

Anita Mountjoy and Michael Wasuit *in memory of* Constance Bjorkquest.

Darlene Heigel and the Garibaldi Jersey Inc. *in memory of* Dorothy Symons.

Martin Murenbald *in memory* of Kip Wilson.

Beverly Butler *in memory of* Ken Butler.

Abtar Singh, Brenda Kelsey, Noel Edward Roddick, Margaret McLeod and Linda Briggs *in memory of* James Harris

James Harris and John Skalos, both active MGA members, passed away recently. Our sincere condolences to their families.

Jim was a devoted MGABC member who enjoyed the great outdoors atop his Harley Davidson. Jim will be missed by his many friends, family and grandchildren. Jim passed away on June 13. In lieu of flowers, Jim requested donations to the ***MGABC***.

John Skalos was the president of the Nanaimo branch of the MGABC. John passed away on Sept 30th, from Covid, primarily due to his Myasthenia Gravis and his compromised immune system. Our condolences go out to his wife, Lise, and their children. In lieu of flowers, donations are gratefully accepted by the ***Nanaimo Reginal General Hospital Foundation*** to help with the renovation of their ICU unit.

Donation Options!...

Vancity Community Foundation

PayPal

CanadaHelps.org giving made simple

WE APOLOGIZE FOR ANY ERRORS OR OMISSIONS.

LITERATURE ORDER

Name_____

Address_____

LITERATURE AVAILABLE:

1. Myasthenia Gravis Facts
2. MG Glossary: Definitions of medical terms used in M.G.
3. MG Survival Guide
7. Drug pamphlets:
   (a)Mestinon (b)Imuran (c)Prednisone (d)Cyclosporine (e)Cellcept
8. Drugs that aggravate MG - **2012**
9. Tacrolimus* - New drug for immunosuppresive medication
10. Plasmapheresis
11. IVIG - Intravenous Gamma Globulin
12. Ocular MG
13. Nutrition for Healthy Bones
15. Dentistry and the Myasthenic
16. Pregnancy and Myasthenia Gravis
17. Myasthenia Gravis in Children and Adolescents - **NEW**
19. Congenital Myasthenia Gravis
20. Emergency Care of Myasthenia Patient
21. Mestinon - A possible emergency measure
22. Assessment & Management of Speech & Swallowing in Myasthenia Gravis
23. Hospital Package: Nursing Care of the Myasthenic; Hospitals Can be Dangerous; Anesthesiology Drugs
24. Practical Guide to MG
25. Dr Oger's book for Family Physicians - free to MG members
26. MG ID Emergency Alert Card
27. Providing Emotional Support for patients with MG
28. Myasthenia Gravis Information for GPs **NEW**
29. Tips on applying for CCP Disability Benefits
31. Disability Tax Credit - Form T2201 **must be** downloaded at
    www.cra-arc.gc.ca/E/pbg/tf/t2201

BOOKS AVAILABLE:

- **My Imaginary Illness - Dr. Chloe Atkins, A Journey into uncertainty and prejudice in medical diagnosis (for short term loan or purchase through your local book stores)**

Please note: General Myasthenia Gravis information is now available in Mandarin. If you would like a copy, please contact our offices.

MEMBERSHIP and DONATIONS

MGABC'S membership year is January 1st to December 31st. Membership received after October 1st will be good for the following year. To donate, please complete the form below and return it with your cheque or money order (we cannot accept credit card payments and we ask that you do not send cash in the mail). Your donation and membership fees help defray operating costs, and entitles you to the following;

Newsletters biannually...MG literature and pamphlets
Notice of meetings...Up-to-date information on MG

You can Help find a Cure !

Your support can make a vital difference in the research for a cure for Myasthenia Gravis.
Please make your donation by cheque or money order to UBC - MG Research and mail to:

UBC - MG Research
c/o # 500 - 5950 University Blvd
Vancouver, BC V6T 1Z3

OR MAIL TO

MGABC
2805 Kingsway
Vancouver, BC V5R 5H9

If mailing to our offices, please be sure to indicate FOR MG RESEARCH on your cheque. Thank you !

Make Cheque payable to: MYASTHENIA GRAVIS ASSOCIATION of BC
Mail your cheque to: Myasthenia Gravis Association of BC
2805 Kingsway, Vancouver, BC V5R 5H9

Last Name_____First Name_____

Address_____City_____

Prov._____Postal Code_____EMAIL_____

Phone_____ MG Patient ☐ Yes ☐ No

Membership $20.00 $_____ **(no tax receipt will be issued)**

Donation $_____ (**a tax receipt will be issued for donations**)

TOTAL AMOUNT ENCLOSED **$_____**

Have you moved? Please send in the information as soon as possible!

Last Name_____First Name_____

Address_____

City_____Prov._____Postal Code_____

Phone_____ E - MAIL_____

If you are no longer interested in receiving our mailings, or would like to receive them by e-mail, please send your request to us at Myasthenia.Gravis@bc-cfa.org with the words **"E-mail request"** in the subject line. Thank you.