

Calendar

Myositis Keep in Touch Support Meetings
Zion Lutheran Church 14205 Ida, Omaha, NE
Each meeting starts at 1 and ends at 3.

- Oct. 11, 2025
- Jan. 10, 2026
- April 11, 2026
- July 11, 2026

Meeting Agenda

Sharing

Topic *How are you doing? Group thoughts on how to help you where you are presently.*

Plans for future meetings

Visiting Plasma Center to thank Donors

Other New Business

Infusion Series Second Interview

Home Infusions

What preparation do you do for IVig treatment at home?

Before the treatment she cleans the house (more for her peace of mind than for the nurse) especially the bathroom, so she can relax during the days of the infusions. She has an organized area near her recliner for the supplies that will be needed for her infusions. The company sends the infusion supplies, and she stores them in a shelving unit near her chair. It is good to have a nice and bright area for the infusion with a chair for the nurse, also. She likes to have flowers for herself, cough drops, notebook, pen, Kleenex and the tv remote near her.

She also prepares herself physically for the infusions by hydrating for 2 days prior. For hydrating she drinks water and electrolyte drinks like coconut water. (Kirkland coconut water and Vitacoco coconut water) She also showers before the infusions the day before, so she doesn't need to worry about it the day of and can save her energy for last minute preparations.

What is the process for your treatment?

When her nurse comes, she organizes the supplies and makes sure she have all she needs. The nurse is also making sure the infusion is possible there. The nurse isn't judging you. As long as it is possible for a safe infusion; it is good. The home doesn't have to be perfectly clean.

When the iv is placed or the port is accessed a sterile environment is needed. So there needs to be no pets in the room or other people. Both the patient and the nurse wear masks during this process. When the needle is in place and a dressing is placed, then the sterile environment is not required.

ERs Aren't Ready for Patients with Rare Conditions

from IG Living Oct/Nov 2025

I have always avoided ER's if possible. I would rather wait and see a doctor who knows me and understands me than go to an ER. After reading this article I found out I am not alone.

While medical students are trained to look for horses instead of zebras, when a zebra (person with a rare condition) comes in they are often misunderstood, delayed, and sometimes ignored entirely. Usually the patient knows more about their disease and condition with it's problems than the doctor in the ER does.

There are risks of being misunderstood. Symptoms that most people can and do ignore a zebra needs to take care of in the early stages. Delays or incorrect treatment can escalate quickly into a life threatening situation. Also symptoms do not always present in the usual way. Like they may not develop a fever like the usual patient.

So how do you prepare for the ER? 1) Carry an emergency information sheet. I short summary of the diagnosis (diagnoses), medications, allergies and emergency instructions specific for the diagnosis. 2) Use a medical ID. A medical alert bracelet, wallet card, or digital medical ID app can help ensure medical information is available if the patient can not speak for themselves. 3. Keep a current medication list. It can also be stored on a smartphone. 4. Know and assert your rights. Patients have the right to ask for a second opinion, request a specialist consultation or ask for documentation of the care they have received. You can also request that they contact your own doctor. 5. Bring an advocate.

Take one visit at a time. While it is not easy and is exhausting, sharing your story with each medical provider spreads awareness and improves ER care for you and others. Remember the medical providers want to help.

So the pets can come back, (interview continued) and other people can be around. She has switched from an iv in her arm to using a port. She says the change is for the positive; now there are no more multiple attempts to place the IV.

Next she gets premeds tylenol (she usually takes the tylenol before the nurse arrives) and Benadryl. Then she gets saline for hydration. 30 minutes after the premeds the IVig starts. Each person is different for rates. It depends on the person, their weight and other factors. Usually it is a step process. It starts slow and the rate is increased to the tolerance of the patient. She gets 50 grams of Privigen. Then the nurse caps off the tubing and she keeps in the needle overnight and through the entire 3 days. For her it takes about 7 1/2 hours for 3 days in a row, every 4 weeks. Sometimes if the IV site is not comfortable, she creates a large cushion of gauze or tefla, especially when she sleeps. The nurse will help if the patient has problems with the port or iv in the arm with more bandaging or cushioning. After the needle is removed she keeps it covered with gauze and tape for 24 hours.

What tips do you have for people that have infusions in your location?

Don't be too stressed about someone coming into your house. Do not worry about it being really clean. Do make sure the bathroom is clean, the nurse will have to be able to use it. A nice organized area for you and your nurse and supplies is all you really need. Have snacks, flowers, something(s) that bring you joy during your infusion. Good lighting, comfortable clothing that can allow easy access for your IV or port, a light blanket, things that make you comfortable.

What do you do to pass the time?

We chat, remember you can be completely laid back. Personally, she likes puzzles, watching TV or movies, and playing games.

What other things would you like to share?

No matter where you are having your infusion, hydrate, wear comfortable clothes, and advocate for yourself. Make sure that the nurse knows about changes in medicine. Ask questions of your doctor about how can I tell this is helping me, Know that there is copay assistance, from the IVig company and/or from the nurse's office. Most insurance companies only cover 8 hours of nursing at home per day. If your infusion is going over ask for another day.

IVig has been the thing that helped her the most. Tell your friends to donate plasma.

How to manage money as a caregiver

Caregiving can be many things, some of which can be financial. Paying bills, navigating benefits, protecting your and their financial futures. Right now I manage our finances, because I want the future to be easy for my caregiver I am also looking at this article from Thrivent Magazine (Fall 2025 p. 23 ff) for help. Their first step is taking an inventory of your loved one's financial situation. "Locate key documents, such as wills, trusts, power of attorney, insurance policies, and bank statements." "Identify assets and income sources, and determine if there's an updated estate plan clearly outlining their wishes." If they have a financial advisor a meeting with them is important.

The financial advisor can help with the financial plan. Contacting an elder law attorney can help counsel you on potential government benefits, estate planning needs, guardianship and support for caregivers. The caregiver also needs to do an assessment of their own health, finances, goals and values.

Financial Caregiver roles are paying daily and monthly bills, managing income, making decisions on investments, pays insurance premiums on time and makes sure life and health insurance documents are up to date. Keeping clear records helps the next person stepping into the role.

Some situations require more diligence. Set up transaction alerts, credit freezes, and limit account access. Only use verified websites and trusted providers. Set transaction limits that require conversation or dual signatures. Regular audits and providing other family members with view only account access are also steps to take. "Get a clear understanding of their income and expenses. Have open conversations about their goals and wishes. Establish parameters for spending (needs vs. wants) and gifting. Create a budget and stick to it. Do not co-mingle assets. Maintain separate accounts. Always act in the best interest of the older adult. Maintain well-organized financial records that support any expenditures. ..."