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# INQUIRIES AND CHALLENGING QUESTIONS

By: Yvonne Smith

# Services the Foundation Offers Directly to Patients and Caregivers:

- Chapter Meetings
- Walk & Rolls
- Card Alerts
- Doctor to Doctor Consultation



# Two Ways to Respond to Inquiries

- Would you like to be contacted by a local Foundation Liaison for support?
  - *Yes, by phone OR email*
  - *Yes, by email*
  - *Yes, by phone*
  
- Phone or Email or Both
  - *Explain who you are*
  - *Share your story*
  - *Provide them with the names of your medical team*
  - *Let them know you empathize with them*
  - *Let them know they are not alone in their journey*

# Know That Everyone Will Respond Differently

- You may speak to someone that expresses:
  1. *Anger*
  2. *Frustration*
  3. *Sadness*
  4. *Loneliness*
  5. *No response*
  6. *Hopefulness*
  
- Let them know that you understand how they feel, and tell them that they are not alone. Inform them of the services the Foundation can offer them, ask them if you can send their information to the Card Alert Team. Invite them to a Chapter Meeting or Walk & Roll.

# Challenging Questions:

## ■ When will I get better

1. *You can tell them what your experience was, but also ensure them that everyone is different and you can not answer that question with an exact date. You can also provide them with GBS and CIDP statistics (attached in invite).*

## ■ What is this condition exactly

1. *Chronical Inflammatory Demyelinating Polyneuropathy (CIDP) [CIDP](#)*
2. *Multifocal Motor Neuropathy (MMN) [Multifocal Motor Neuropathy](#)*
3. *Guillain-Barré syndrome (GBS) [GBS](#)*
4. *Anti-MAG Peripheral Neuropathy [Anti-Mag](#)*
5. *Miller Fisher Syndrome (MFS) [Miller Fisher Syndrome](#)*

## ■ Will I ever walk again

1. *You cannot provide them with a direct answer to their question. However, you can share what you went through and what your experience was*

## ■ Should my doctor increase my dosage

1. *Inform them that you are not a doctor, and if they are questioning their treatment plan encourage them to see another doctor, (make an appointment at a Center of Excellence (COE)). Tell them to ask their doctor to participate in a Doctor to Doctor Consultation.*  
[Centers of Excellence](#)

## ■ Should my physical therapist do certain exercises with me

1. *Again we can not give out medical advice, however, you can share what you did and you can share the names of your Physical Therapists. We also have [a PT & OT Booklet](#) they can read.*

## ■ My insurance is not covering my treatment cost

1. *Tell them to call a social worker at the hospital, connect them back with the Foundation, ask them to reach out to their local Social Services office*

## ■ I cannot pay my premium

1. *Tell them to contact Patients Service Incorporated, call their local Social Service Office, or refer them back to the Foundation*  
PSI - 1-800-366-7741

It Is Okay to Say, “I Don’t Know” or “Let me look into that and I will get back to you”.



You can always refer them back to the Foundation!

# Foundation Publications:

- [Foundation Publications](#)