

## Guest Speaker Invitation Letter

February 7, 2009

Name  
Address  
City, State/Province Postal Code

Dear Doctor Johnson,

IMAGINE....

Having a cold or stomach flu and now you're in intensive care fighting for your life.

IMAGINE....

Waking up one morning unable to walk, or even stand. Your arms are paralyzed too...and you don't even understand what is happening!

IMAGINE....

Being totally helpless, uncertain of recovery...

It could happen to anyone at any age, anywhere in the world. It happens every day to men and women, children, babies and pregnant women.

The Name? Guillain-Barré Syndrome (**GBS**) and Chronic Inflammatory Demyelinating Polyneuropathy (**CIDP**)

Friday, May 5, 2000, the Guillain-Barré Syndrome Coastal Support Group Chapter will be holding its annual meeting at the Holiday Inn, Capital, Virginia. We invite you to be our guest and speaker for the evening. Informal discussion with a question and answer session on GBS, CIDP, and the Miller Fisher Variant as the subjects of interest.

Our chapter covers the area from Richmond to Virginia Beach and down to the North Carolina border. We have identified approximately 100 patients. In attendance at the meeting will be patients, medical professionals, family and friends of GBS/CIDP. A brochure is being prepared and will be distributed around April 15, 2000. Please advise me if your schedule will allow for you to attend our meeting.

Sincerely,

John Jones  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address

Letter to City Official - GBS/CIDP Awareness Month

February 7, 2009

Name  
Address  
City, State/Province Postal Code

Dear Mayor Adams:

The month of May has been designated GBS/CIDP Awareness Month for the purpose of educating the public and focusing attention on the disorders known as Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).

In Hampton Roads, we have identified approximately 60 patients affected with these disorders. At this time, we are aware of no local active in-patients. Our Support Group Chapter provides emotional support to patients and their families to include hospital visits and distribution of literature. All support group members are victims of the disease.

I hereby request that you designate May as GBS /CIDP Awareness Month in the City of Hampton. Please contact me if additional information is desired, and thank you for your support in this matter.

Sincerely,

John Jones  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosure: Proclamation

Letter to Television Station - GBS/CIDP Awareness Month

February 7, 2009

Ms. Mary Jones  
WABC TV Channel 4  
Address  
City, State/Province Postal Code

Dear Ms. Jones:

I am enclosing for your review information on Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), both rare disorders about which very little has been known over the years.

In communities across the nation, the month of May has been designated as GBS/CIDP Awareness Month to educate the public and focus attention on GBS and CIDP, these rare paralyzing and potentially catastrophic disorders of the peripheral nerves.

Here in (your location), council member Jane Smith has issued an official proclamation highlighting the observance of GBS/CIDP Awareness Day. Any announcement of this event on your television station would be greatly appreciated. Please contact me if additional information is desired.

Thank you for your support in this matter.

Sincerely,

George Johnson  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosure

Letter to Radio Station - GBS/CIDP Awareness Month

February 7, 2009

WABC  
Address  
City, State/Province Postal Code

Dear WABC:

I am writing to request that your radio station mention Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Awareness Month, which is the month of May.

I am enclosing Press Advisory, Press Release, and Public Service Announcement materials prepared for the occasion by the GBS/CIDP Foundation International located at 104 1/2 Forrest Avenue, Narberth, Pennsylvania 19072.

If you have any questions, please feel free to call me for any further information. Thank you in advance for your assistance.

Sincerely,

Anne Jones  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosures

Proclamation letter - GBS/CIDP Awareness Month

February 7, 2009

Name  
Address  
City, State/Province Postal Code

Dear Judge Executive Smith:

I am writing to request consideration of a proclamation recognizing May as Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Awareness Month. This has been established by the GBS/CIDP Foundation International as a national event to make the public aware of these neurological disorders which affect approximately one person per every 100,000 people in the population.

Any consideration that could be given to recognize the month of May would be greatly appreciated.

I am enclosing Press Advisory, possible Press Release, and Public Service Announcement materials that have been prepared for the occasion by the GBS/CIDP Foundation International located at 104 1/2 Forrest Avenue, Narberth, Pennsylvania 19072.

If you have any questions, please feel free to call me. Thank you in advance for your assistance.

Sincerely,

John Jones  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosures

Letter to Council Member - GBS/CIDP Awareness Month

February 7, 2009

Council Member Jones  
Address  
City, State/Province Postal Code

Dear Council Member Jones:

In the past, you have issued a proclamation declaring May as Awareness Month for the rare paralyzing and potentially catastrophic disorders of the peripheral nerves called Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).

I am asking again for you to designate the month of May as GBS/CIDP Awareness Month in order to inform the public of this event.

Thank you for your cooperation. It is not necessary for you to frame the proclamation. It can be mailed to me directly so as not to inconvenience you. If you have any questions, please feel free to call me for any further information.

Sincerely,

John Jones  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosure: Proclamation



The Central/Southern New Jersey Chapter cordially invites patients, their families, caregivers, and interested professionals to a chapter meeting.

Questions & Answers ■ Networking ■ Share GBS | CIDP | MMN Experiences ■ Refreshments

Please join us

**Saturday, May 17, 2014**

10:00 am

**Place:** Wheaton Pointe  
Springpoint Senior Living Building  
20 Lanning Blvd.  
East Windsor, NJ 08520

**Speakers:** Local medical experts who can answer all of your concerns.

**News! Learn more about our 2014 Symposium  
At Walt Disney World, Florida**

**Registration begins at 9:30 am .. Learn and heal and ease your mind. You  
will be with your GBS | CIDP family.**

SPECIAL NOTE: Support your local GBS | CIDP community in NJ and participate in the upcoming Walk and Roll! Invite your friends and family, register on-line at the GBS | CIDP website. Click on the Walk and Roll logo to pre-register or just show up May 4<sup>th</sup> at 10:00 am in Harry Dunham Park, Bernard's Township, NJ.

RSVP to Jim Yadlon [jim.yadlon@gbs-cidp.org](mailto:jim.yadlon@gbs-cidp.org) (preferred) by  
May 10, 2014  
609-947-2697

Handicap Accessible

Free Parking

Serving the communities of GBS ■ CIDP ■ MMN

Support Education Research Advocacy



The Philadelphia Chapter cordially invites patients, their families, caregivers, and interested professionals to a chapter meeting.

Questions & Answers ■ Networking ■ Share GBS | CIDP | MMN Experiences ■ Refreshments

*Please join us*

**Wednesday, May 14, 2014**

6:30-8:30 pm

**Place:** *The Crowne Plaza Philadelphia West*  
4010 City Avenue  
Philadelphia, PA 19131  
(215-477-0200)  
(Rte. 1 and 76)

**Special guest speaker**

Mark J. Brown, MD  
Professor of Neurology  
Hospital of the University of Pennsylvania  
Member, GBS/CIDP Medical Advisory Board

**Topic:** *Living with GBS, CIDP, MMN*

**News!** *Learn more about our 2014 Symposium  
At Walt Disney World, Florida*

**For more information contact:**  
Lisa Butler or Estelle Benson  
(610) 667-0131

*Handicap Accessible*

*Free Parking*

Serving the communities of GBS ■ CIDP ■ MMN

Support Education Research Advocacy





The \_\_\_\_\_ Central New York \_\_\_\_\_ Chapter cordially invites patients, their families, caregivers, and interested professionals to a chapter meeting.

Questions & Answers ■ Networking ■ Share GBS | CIDP | MMN Experiences ■ Refreshments

Please join us

**Saturday, June 7, 2014**

10:00 am -12:00 pm

**Place:** Manlius Public library  
1 Arkie Albanese Avenue  
Manlius, NY 13104

**Speakers:** Craig Andrianos

**Topic:** Confronting CIDP

**News! Learn more about our 2014 Symposium  
At Walt Disney World, Florida**

RSVP to Joan Armstrong at [medqa@aol.com](mailto:medqa@aol.com),  
315-391-6538

Handicap Accessible

Free Parking

Serving the communities of GBS ■ CIDP ■ MMN

Support Education Research Advocacy



The \_\_\_\_\_ Central New York \_\_\_\_\_ Chapter cordially invites patients, their families, caregivers, and interested professionals to a chapter meeting.

Questions & Answers ■ Networking ■ Share GBS | CIDP | MMN Experiences ■ Refreshments

Please join us

**Saturday, June 7, 2014**

10:00 am -12:00 pm

**Place:** Manlius Public library  
1 Arkie Albanese Avenue  
Manlius, NY 13104

**Speakers:** Craig Andrianos

**Topic:** Confronting CIDP

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RSVP to Joan Armstrong at [medqa@aol.com](mailto:medqa@aol.com),  
315-391-6538

Handicap Accessible

Free Parking

Serving the communities of GBS ■ CIDP ■ MMN

Support Education Research Advocacy

## Letter to Nursing Managers

February 7, 2009

Hospital Name  
Nurse Managers  
Address  
City, State/Province Postal Code

Dear Nursing Managers:

I am a registered nurse who is a contact person for the GBS/CIDP Foundation International. My goal is to provide information regarding support services available for patients and their families who have this disorder.

Enclosed are pamphlets explaining GBS and CIDP for patient education and a brief description of the Support Group Chapter functions.

Thank you for your assistance.

Sincerely,

Anne Jones RN BSN  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosures

## Letter to Social Work Services

February 7, 2009

Social Work Services Department of Neurology  
Hospital Name  
Address  
City, State/Province Postal Code

RE: Hospital Visits to GBS and CIDP Patients and/or Their Families

Dear Social Work Professionals:

Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) can be very frightening to patients and their families. Not only have they never heard of it, they can't even pronounce or remember the name of the disorder.

As former Guillain-Barré patients, Mary Jones MSW and I (Director of Professional Education with the American Heart Association for 27 years) are prepared and competent to share our positive experiences with people who have GBS/CIDP.

Enclosed are copies of a poster that you could show to patients and their families. We have found that the information is most needed and effective when the patients are still in ICUs, intermediate units and on the general neurology floors.

Please do contact us if you require additional information or more posters. Thank you for your support.

Sincerely,

John Jones  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosures

## Letter to Neurologist

February 7, 2009

Neurologists (By name)  
Hospital Name  
Address  
City, State/Province Postal Code

RE: Hospital Visits to Guillain-Barré Patients and/or Their Families

Dear Neurologist: (by name)

Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) can be very frightening to patients and their families. Not only have they never heard of it, they can't even pronounce or remember the name of the disorder.

As former Guillain-Barré patients, Mary Jones MSW and I (Director of Professional Education with the American Heart Association for 27 years) are prepared and competent to share our positive experiences with people who have GBS/CIDP.

Enclosed is a copy of a poster that you could show to patients and their families. We have found that the information is most needed and effective when the patients are still in ICUs, intermediate units and on the general neurology floors.

Please contact us if you require additional information or more posters.

Thank you for your support.

Sincerely,

Anne Smith  
Manhattan Co-Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosures

## Letter to Medical Staff

January 5, 2009

Kassandra Ulrich (your name)  
Liaison/Midwest Regional Director GBS/CIDP Foundation International (your title)

To: (medical staff member title)

I want to briefly introduce myself to you. I am Kassandra Ulrich (your name), the liaison/Midwest regional director for the GBS/CIDP Foundation International (your title). The GBS/CIDP Foundation International is the only voluntary, non-profit organization that provides support to patients of GBS and CIDP and their families, awards grants to researchers, and offers education to the public and professional communities. Liaisons are not qualified medical persons and do not provide medical advice.

I was admitted to a local hospital with GBS in 1981 following the birth of my son (make this story your own, be brief). My GBS involvement included paralysis in all four quadrants plus I was ventilated for one week and had 20 Plasmapheresis treatments. Four months later, I was able to go home to continue my rehabilitation. This was all possible because of the dedicated team of Doctors, Nurses, and Therapists that were there for me. Life after GBS is more precious than before. Now I do my best to assist medical staff and patients and their families in understanding GBS and CIDP and to help them create a positive environment for the patient's successful improvement.

Every case of GBS/CIDP is different. However, I know firsthand how it can affect the patient and the patient's family. My goal is to be able to help provide physicians, nursing staff, and therapists with information regarding support services and the information available for patients and their families. I have literature and video presentations that are available for staff in-house training.

For current and former patients and their families, I share my positive experiences and give them inspiration and hope for the future. For the current patient, a visit by someone who has experienced GBS or CIDP can be just as important the medical treatment they are receiving.

Please contact me if I can be part of your team helping these patients or to provide you additional information.

Sincerely,

Kassandra Ulrich (your name)  
Midwest Regional Director GBS/CIDP Foundation International (your title)  
330-555-2608 (your phone)  
KassandraU1@sbcglobal.net (your email)

## Letter to Care Management

July 11, 2009

Care Management/Social Worker  
Hospital  
Street Address  
City, State, Zip

Dear (Care Management Worker)

Guillain-Barré Syndrome (GBS) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) can be very frightening to patients and their families. Not only have they never heard of it, they can't even pronounce or remember the name of the disorder.

The Hampton Roads Support Group Chapter of the GBS/CIDP Foundation International is made up of former/current patients of GBS and CIDP who share our positive experiences with people who have this syndrome. We visit patients and their families, distribute literature, do in-service training and try to put the patient and family at ease.

Enclosed are copies of a poster that you could show to patients and their families. We have found that the information is most needed and effective when the patients are still in ICUs, intermediate units and on the general neurology floors.

Because of the Privacy Act, I know you cannot release patient names. However please give GBS/CIDP family members information enabling them to contact me.

Thank you for helping to make your patients and their families aware of our GBS/CIDP Support Group Chapter and the support we can provide.

Sincerely,

Liaison  
Street Address  
City, State, Zip  
Phone, email address

Enclosure

## Liaison Letter of Introduction

February 11, 2009

Dr. Allen Jones  
Caro Neurology Associates  
Address  
City, State/Province Postal Code

Dear Dr. Jones,

I am the liaison for the newly formed Caro GBS/CIDP Support Group Chapter. In July 1999, I had Guillain-Barré Syndrome. I was in the SICU at Reese Healthcare for 17 days totally paralyzed. I was on a respirator, with a P.E.G. and unable to communicate except by blinking my eyelids. Following hospitalization. I went to BayMed Rehab Center for 12 days where I learned to walk and eat again. Today, I am fully recovered and have no lingering effects from this inflammatory disorder of the peripheral nerves.

The GBS/CIDP Foundation International, founded in 1981, has more than 175 chapters in the United States, Canada, Europe, Australia, and South Africa. Its goals are to help GBS/CIDP patients and families by providing emotional support, information booklets, and visits to patients.

As liaison for the Caro Support Group Chapter, I am interested in making local active or former GBS and CIDP patients and their families aware of our services. Because of the Privacy Act, I know you cannot release patients' names. However, please give GBS/CIDP family members information enabling them to contact me.

Once the chapter has developed a network of GBS/CIDP patients, there will be regular annual meetings. At these meetings, a guest speaker from the medical community will present information on pertinent subjects. We hope you will participate in our meetings and agree to speak to the group when invited.

Thank you for helping to make your patients and their families aware of our GBS/CIDP Support Group Chapter the support we can provide. Please let me know how I can help.

Sincerely,

Shirley Johnson  
Chapter Liaison  
Street Address  
City, State, Zip  
Phone, email address



## Thank You Note to Guest Speaker

February 11, 2009

Name  
Address  
City, State, Zip Code

Dear Dr. Allen Stamey,

I would like to express my sincere appreciation and thanks for the wonderful presentation you delivered to the Hampton Roads GBS/CIDP Support Group Chapter members and guests at our meeting last week. Your remarks were informative, inspiring, and most appropriate for the occasion.

It is gratifying to know that you support the goals of the GBS/CIDP Foundation and share our continued interest in the well being of GBS and CIDP patients and their families. Again, thank you for contributing your valuable time and expertise.

Sincerely,

John Jones  
Chapter liaison  
Street Address  
City, State, Zip  
Phone, email address

**“GBS/CIDP Long Island Day Conference”**

**SAVE THE DATE!!!!**

**SATURDAY APRIL 5, 1997**

**(All Day Seminar with Hot Lunch Buffet)**

- |   |
|---|
| <ul style="list-style-type: none"><li>• <b>Huntington Hilton Hotel, Rte. 110, Melville, Long Island. NY</b></li></ul> |
|---|

- **Watch Your Mail for Invitation** (*to be sent in Feb.*)
- **Mark Your Calendar to Hold the Date**

**Informative Workshops:**

- 1 **Rehabilitation - Physical and Occupational Therapy**
2. **Pain Management/Nursing**
3. **Financial/Insurance, Healthcare, Social Security**
4. **Emotional Issues Faced by Patients and their Families**

**Keynote Speaker: Dr. Arthur K. Asbury**

*Professor of Neurology at University of PA School of Medicine  
Vice-President of the World Federation of Neurological Associations  
Past President of the American Neurological Association  
Author and Editor*

***Esteemed member of the GBS Foundation Medical Advisory Board***

**PLUS OTHER NOTED GUEST SPEAKERS**

**Chairs for this event:** Suffolk County Liaison: Murray Schlossman, Nassau County Liaisons: Bruce Hirschorn and Harriette Lion, Queens County Liaison Brenda Halper, NYC Liaisons: Helen Jacobs & Marilyn Guarch

December 12, 2010

Dr. Alan K. Jxxxxxx

The Symposium presented by the GBS-CIDP Foundation International on November 5-7, 2010 was a great success. It was sold out weeks before the opening date. Sessions were attended by close to 500 patients and neurologists from around the world. These sessions were recorded and now available on the foundation website—[www.gbs-cidp.org](http://www.gbs-cidp.org) <<http://www.gbs-cidp.org/>>. I hope you and interested personnel in your office will take the time to view these. I know you will find them interesting. One of the workshops videos covers the “Ask the Experts” session from the Symposium. Audience members ask the experts questions reflecting their concerns or their family’s concerns about their medical situation. These are questions you may have been asked by patients in your practice. The first time I have heard of “cure percentages” in connection with CIDP was during this session.

I am enclosing a program journal that was given to attendees. This journal includes a list and brief bio of the members of the Medical Advisory Board for the Foundation. All of these members welcome consultation with physicians at any time. They have a special interest and experience with GBS/CIDP and all the variants. They volunteer this service for the benefit of the patients.

In August I contacted you regarding the “Center of Excellence” designations by the GBS-CIDP Foundation International. The Centers of Excellence were proposed as a measure to provide patients with diagnostic facilities through out the USA (and other countries) with expertise in inflammatory neuropathy. The patient may want a second opinion if they feel they are misdiagnosed, not doing as well as they have been told they should, or if there is no specialist in their area that is familiar with the diagnosis or management of inflammatory neuropathy.

This not a measure to provide total care or follow up but instead to give an expert consult that will evaluate their diagnosis and treatment regimen and provide that information as well to their local neurologist. The centers will form a network of healthcare facilities to provide expert diagnosis and management of inflammatory neuropathies for patients who are unable to consult with medical experts in the field in their own communities.

I hope you are considering making this possible for this area. There is a very great need for something like this here. I see and am in contact with patients and their families from Toledo in the north to Cincinnati in the south and from Columbus to Indiana. It is currently necessary for patients to travel great distances to get expert advice for their conditions. Unfortunately too many are not getting the results that they should. I know of no way that you could benefit these patients more than by being part of the Center of Excellence program. There is a real need here for a Center of Excellence that would be available as a local consultation or second opinion location.

Please contact me if I can be of assistance to you in this effort.

Sincerely,