

Grassroots Advocacy Handbook 2010



GBS/CIDP Foundation International

Presented by Ed Gdula
Director of Advocacy
(consultant)

ed.gdula@gsb-cidp.org



Contact Us

Contribute

Guillain-Barré Syndrome · Chronic Inflammatory Demyelinating Polyneuropathy

Our focus is on providing information and support for patients, family members, and healthcare professionals

Community outreach is, without a doubt, one of the Foundations greatest challenges !

So, what is Advocacy and how will it help ?



Observations

- The GBS/CIDP Foundation International is populated with highly successful Advocates/Lobbyists- you just don' know it! Your Foundation is filled with them ! Beginning in 1980 grass roots effort have built a strong international organization with 30,000 members in 160 chapters on five continents, self funded with a hand full of highly motivated and dedicated staff.
- The Foundations Medical Advisory Board , staffed with dedicated men and women at the top of their fields of specialty, champion the superb medical education and research interests of the Foundation.
- The Foundation has and will continue to engage Advocacy and Lobbying efforts at the Federal and State level.
- As successful as you have been, there is a burning desire and strong need to expand Grassroots Advocacy/Outreach at the field level

Why this handbook ?

- Validate all the good advocacy work that has been done
- Give more detail on the political side of advocacy and lobbying
- Raise advocacy activities to the next level -for some of you
- Raise sensitivity to GBS/ Foundation International field exposure
- Identify and discuss barriers to expanding advocacy efforts

So how does the world define Grassroots Advocacy ?

The general promotion of an idea, proposal, or cause through education, outreach, and grassroots organization

- Advocacy is a means by which we can move our concerns to create change
- Advocacy may include lobbying



What is Lobbying ?

- Asking an elected official to take a particular position or vote a certain way on a specific piece of legislation or rule
- Under certain conditions, nonprofits can lobby , however.....
- There are very specific rules and regulations governing the lobbying activities of for- profit organizations versus nonprofit

Considering the sensitive and often complex rules governing lobbying, any and all lobbying efforts must be coordinated through the Foundation's headquarters in Narberth, PA.

Most non-profit organizations can - and should - lobby for their cause, as long as they follow the IRS's rules.

Under the provisions of the Internal Revenue Code (IRC) 501h, most [501c3 nonprofit organizations](#) (with the exception of churches and church-affiliated organizations):

- Can appeal directly to state legislatures regarding public policy they'd like to see happen or legislation they'd like to see defeated or repealed. The organization can write letters, make phone calls, or meet face-to-face with the legislator.
- Can lobby for issues-based initiatives. For instance, half of the states in the U.S. allow citizens to take ballot initiatives directly to the voters, and 501c3 nonprofits can campaign in those instances.
- Cannot support specific candidates or parties in races for elected office, known in IRS-speak as “political campaign activity”. **More specifically, the organization cannot endorse a candidate or contribute to a campaign with money or time.** (Employees can, of course, donate or volunteer on their own time).

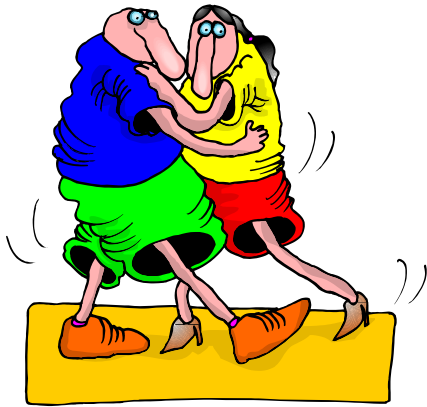
cont.....

- Can sponsor an educational event such as candidate's forum, so long as all candidates running for the same office have a chance to participate.
- Must notify the IRS of the intent to lobby by filing [Form 5768](#)
-
- Must abide by any additional state laws regarding lobbying.

501(c)3 non-profits must keep the amount of [time or money spent on lobbying activities below a certain amount](#). Limits exist for both direct lobbying and grassroots lobbying (influencing the public on an issue), though the thresholds are different. The [details](#) regarding time, money, and activities are complicated, and 501c3s are urged to err on the side of caution

In Summary, What is the Difference Between Advocacy and Lobbying

- Although most people use the words interchangeably, there is a distinction between advocacy and lobbying
- When nonprofits advocate on their own behalf, they seek to affect some aspect of society, whether they appeal to individuals about their behavior, employers about their rules, or government about its laws
- Lobbying refers specifically to advocacy efforts that attempt to influence legislation



What can Advocacy Do ?

- Change or amend existing rules/laws
- Start new programs by allocating funds needed to design, start, and implement a program or service
- Successful advocacy efforts can create new laws

-Advocacy can ensure access to potentially life enhancing/ life saving treatments by guaranteeing equal access and fair insurance reimbursement.

-Advocating for change is imperative if we are to improve the lives of those living with GBS/CIDP and their loved ones.

-HIPAA (patient privacy act) has and will continue to frustrate you while, at the same time, offering you privacy

What is effective Advocacy ?

- Advocacy is most effective when it is a part of a structured, coordinated and unified effort .
- We must be a “collective voice” and targeted to the appropriate audience
- The audience may be one person or a group of people

Remember, as a former patient or someone who is experiencing or has experienced the diagnosis and treatment of GBS or CIDP with loved ones has a unique view of how policies and procedures impact this community. This carries enormous weight and influence.

Why Should we Advocate ?

- Although it is necessary, it is often not sufficient to just raise awareness of a cause to make lasting change.
- We have to shape Public Policy in a way that will sustain change.



For example, that means not only rolling up your sleeves to volunteer for your chapter or Foundation HQ, but also making a point to get and keep informed about GBS / CIDP issues which may include calling , writing, or visiting your elected /appointed local and state officials.

Organizing Grassroots Advocacy

Whether you know it or not, The Foundation has been active and has been successfully engaging critical advocacy issues at the Federal level, less so at the state level but that will change in 2010 !

- There have been several states that have issued Proclamations citing GBS / CIDP Awareness thanks to excellent chapter efforts*
- The PPTA (Plasma Protein Therapeutics Association) Legislative staff have met with key Congressional members and staff to address concerns over existing or pending legislation that pose a threat to market access, fair product and service reimbursement, lifetime caps on medical coverage, and quality of care issues*
- And then of course, we are intimately involved in health care reform*

cont...

Organizing Grassroots Advocacy

- Joining PPTA and working along side them are the 5 leading manufacturers of IVIG.....
Baxter, CSL, Grifols, Octapharma , and Talecris
- Working with and along side a strong , existing coalition of Patient Advocacy groups including.....
The Alpha 1 Association, GBS/CIDP Foundation International, the IDF Foundation, Committee of Ten Thousand, National Organization for Rare Diseases, the Jeffrey Modell Foundation, the World Federation of Hemophilia, and the National Hemophilia Foundation, and the Hemophilia Federation of America to name a few!

OK, How Do you Organize/Engage an Advocacy Event ?

- Can you Identify the issue and how would it benefit from a coordinated effort of support and advocacy?
- What is currently going on at the Federal , State, County, City, and/or community around this issue?
- What is our position and what other organizations or individuals **support** our position ? Are we/they passive or otherwise?
- What organizations or individuals **oppose** our or the coalition's position on this issue ? Why ?
- What is our organizations capacity (staff, resources, funding, etc .) to engage the issue ?
- What national organizations can provide any manpower or financial support?
- Who is the congressional/organizational target audience ?

Contacting Elected/Appointed Officials

(Consult/clear with the Foundation's Communication Committee before hand)

- Write a letter
- Foundation's website
- Email
- Phone call
- Visit face-to-face
- Invite them to visit your organization
- Hold a press conference (**only with headquarter approval**)
- Host a rally (**only with headquarter approval**)
- Provide testimony at public hearing
- Hold an "Awareness " event

When Meeting with Elected/Appointed Officials

the DO's

- Deal with reality , not ideology (what you think is best)
 - Know your facts, articulate them clearly
 - Keep it simple
 - Choose real results over confrontation
 - Be cordial, be prompt, be patient
 - Convince the undecided
 - Make specific and reasonable requests
 - Use the media, carefully
 - Repeat your message , until you get the right person's attention
- cont....

When Meeting With Elected/Appointed Officials

The DO's

- Keep the meeting short (10 to 15 minutes max)
- When the meeting is finished, thank the member and staff for their time, offer yourself as a resource, and provide them with the appropriate contact information

Meeting With Elected/Appointed Officials

The DON'Ts

- **Don't** inundate the member or staffer with voluminous materials
- **Don't** assume that your audience understands your specific problem or your jargon
- **Don't** assume meetings with staffers are not productive
- **Don't** be afraid to say “ I don't know”.
- **Don't** make vague requests
- **Don't** be intimidated



And in Conclusion we need.....

-A Key relationship strategy with specific outcomes

-We need to broaden our grassroots capabilities through education, newsletter, issues letters , alerts, and well defined well executed outreach programs

We need an Issues Management model that includes a “First Response” Team. Do you have one ?

Key Web Resources

- House of Representatives <http://www.house.gov>
This site provides information about your Representatives, the committees they serve on, and current legislation under consideration by the House
- The U.S. Senate <http://www.senate.gov>
This site provides information about your two senators, the Committees they serve on , and any current legislation under consideration by the Senate
- The White House <http://www.whitehouse.gov>
You can obtain information about the president and vice president, read White House press releases, look through White House historical documents. get information about White House tours, and browse the White House library at the White House homepage

cont.....

Key Web Resources

- Thomas World Wide Web System <http://thomas.loc.gov>

Acting under the directive of the leadership of the 104th Congress to make federal legislative information freely available to the public, a Library of Congress team brought the THOMAS World Wide Web system (named for Thomas Jefferson) online in January 1995. It includes coverage of the floor activities of both the House and Senate, information on any bill dating back from the 104th Congress to the current session, and access to the Congressional record

- Plasma Protein Therapeutics Association <http://www.pptaglobal.org>

As the global representative for the plasma collection and therapeutics industry, PPTA works cooperatively with patient groups, policymakers, regulatory agencies and other stakeholders to address critical issues that impact the industry and patients who depend on plasma protein therapeutics. PPTA's strength lies in its membership. The Association's global and regional steering committees bring together industry experts to focus on important issues relating to the quality, safety and efficacy of plasma therapeutics.

Key Web Resources

- http://www.welcometousa.gov/Healthcare_families/Health_insurance.htm

The links in this section provide important information about how to find low-cost healthcare and other federal and state healthcare programs for newly arrived immigrants

- <http://www.fda.gov/oca/sthealth.htm>

Your main contact point for an alphabetical listing of U.S. State Health Department contact information

- <http://www.cms.hhs.gov/>

US federal agency which administers Medicare, Medicaid, and the State Children's Health Insurance Program. Provides information for health professionals and consumers of health care services

Key Web Resources

- www.uneedpsi.org
PSI is the "ground breaking" 501(c)(3) non-profit, charitable organization of its kind. For nearly two decades, PSI has helped people who live with certain chronic illnesses or conditions locate suitable health insurance coverage and access ways to satisfy expensive co-payments. PSI **provides assistance** with the cost of health insurance **premiums** associated with COBRAs, State High Risk Pools, Open enrollment, Guaranteed Issue policies, HIPAA conversion policies; and **prescriptions co-payments** associated with private insurance as well as with Medicare Parts B and D.
- <http://www.patientadvocate.org/resources.php>
Patient Advocate Foundation seeks to empower patients to take control of their health care. Case managers work with patients to discover local, state, and federal programs that provide assistance for their individual needs. If you or someone you know needs assistance with their insurer, employer and/or creditor regarding insurance, job retention and/or debt crisis matters relative to their diagnosis of life threatening or debilitating diseases, please call us at 1-800-532-5274 or [email us](#).

Patient Support Networks

The Big Chapter Question !

How do we connect to newly diagnosed patients or those in immediate need ?

BROADEN ADVOCACY OUTREACH by conferring with...

- Major Health Insurance Providers (disease management)
- Major Pharmacy Benefit Managers
- State Insurance Commissioner
- State Medical Director/ State Department of Health



We will be exploring all of these options , we need your help !

Excellent Links

- “A Foundation’s Guide to ADVOCACY”, Council on Foundations-2121 Crystal Drive , Suite 700 Arlington, Va 22202 www.cof.org
- “ADVOCACY Handbook “, NAFSA-Association of International Educators-1307 New York Avenue NW, Suite 800, Washington D.C. 20005 www.nafsa.org
- “ ADVOCACY 101 “ , New York City HABITAT for Humanity, 111 John Street, 23rd floor, New York, NY 10038 www.habitatnyc.org

Dear members, thank you for your time and your special efforts !

"Confidence is what you have before you understand the problem."

"Eternity is a very long time, especially towards the end."

Thank you Woody Allen !

