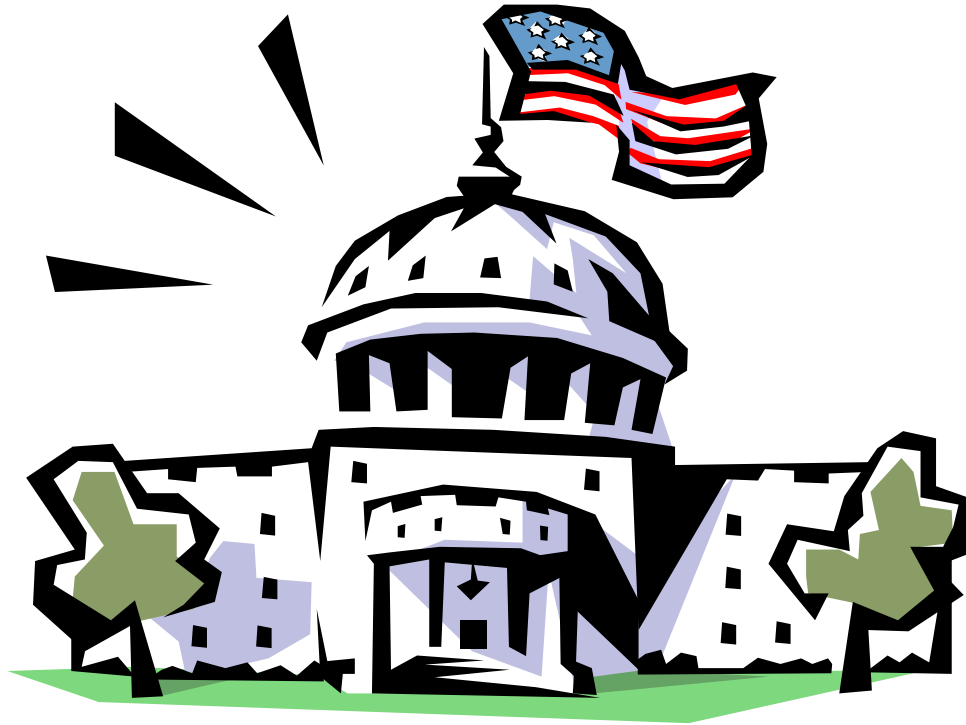


# Grass Roots Advocacy: Making Your Voice Heard



Patrick Collins  
Sr. Manager, Public Affairs

# Why is Advocacy Important?

- Myositis is a rare condition
- Need to educate government officials about Myositis
  - Research Funding
  - Medicare/Medicaid coverage
- Access to therapies
- Access to physicians
- Everybody else is advocating
  - By not doing so, you get lost in the shuffle
- **Advocacy + Effort = Results**

# Why Should You Believe Me?

- New York State Senate
- NYC Mayor Rudy Giuliani
- Director of Government Affairs,  
National Hemophilia Foundation
- Sr. Manager, Public Affairs  
CSL Behring



- CSL Behring – manufacturer of immune globulin
  - Collaborates with patient advocacy organizations

# The Power of Grass Roots Advocacy

- Convinces elected officials to act on your behalf



Respiratory and Allergic Disease Foundation Lobbying Day – May 11, 2007.

Group shot with Rep. Bobby Rush

# The Power of Grass Roots Advocacy

- Elected Officials react to group advocacy



Volunteers from the Hemophilia Foundation of Illinois with State Senator Kathleen Ryg.

# Grassroots Advocacy and Outreach\*

- Advocacy
  - Leveraging your resources and contacts to help advance initiatives of The Myositis Association
- Outreach
  - Engaging the public in a dialogue about the work and activities of The Myositis Association surrounding major initiatives
- Combine grassroots advocacy and outreach to increase awareness about Myositis to build public support

\* Modified from definition from Grassroots Solutions, Inc.

# Would I be effective lobbying?

- Elected Officials are:
  - Lawyers
  - Businessmen
  - Government affairs staff
  - Military
- Farmers/ranchers
- How many have myositis?
- How many know more than you about myositis?
- **YOU ARE THE EXPERT**

# Are They Interested in What I have to say?

- Local District Office and Staff
  - Live in same community as you
- Issue Specific Staff
  - Health staffer for instance
- State agencies have legislative liaisons
- Positive result from office
- Interest in local community
- Most elected officials want to assist
  - Stereotype of politicians not valid

# What can we do to ensure consideration for Myositis in public policy?

- Educate ourselves about the issues
- Build a Grassroots Advocacy and Outreach program to educate the Governor, legislators, the media and community leaders
- Become active in policy issues
- Elected officials will react if you become involved
- Get involved in 2008 elections

# Grassroots Advocacy and Outreach Prerequisites

- Message: How are people with myositis different from other patient populations and why should policy makers support such efforts
- Objectives:
  - Identify and describe the issues
  - Provide supporting facts
  - Explain impact on a person with myositis, his/her family, the community
    - Personal stories are very important
  - Create awareness
  - Impact behavior
  - Motivate action
  - Influence policy

# How do I contact my legislator?

- Best way – in person
  - District office for individual case issue
    - Individual insurance matter
  - Legislative office for policy changes
    - Ensure that Medicare covers IVIG for treatment of Myositis
- Secondary methods
  - Telephone
  - Letter
  - E-mail



# UNITED STATES HOUSE OF REPRESENTATIVES

109<sup>th</sup> Congress, 1<sup>st</sup> Session



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Various links to information related to the legislative process.

## Search House Sites

# How do I contact my legislator?

- Group advocacy days
  - NHF Washington Day
  - HFA congressional lobbying day
- Benefits associated with being part of a larger group
  - BDAST lobbying day in Albany?
  - New York State Hospital Association
  - NY chapter/organization day in Albany
- As an individual or family

# What do I say that will make an impact?

- Tell your story – make it personal
- How does myositis affect your life?
  - Immobility
  - Swelling of muscles
  - Cost associated with treatment
- State how the issue affects you and others like you
  - Out of pocket costs
  - Finding a new insurer after reaching lifetime cap
- Educate staff about myositis

# Build a Relationship with Your Elected Officials

- Speak with them at town hall meetings
- Develop the relationship with staff
- Become a resource to them on myositis and its complications
- Let them rely on your experiences
- Become active locally
  - Local political organizations
  - Chamber of commerce
  - Unions
  - Elks club/lions club/rotary club/VFW or Legion post, etc.

# Does your elected official know?

- IVIG is a biologic, not a drug?
- That no two brands are alike
- That no two providers are alike
  - Homecare vs. infusion suite vs. pharmacy
- Physical Reaction to IVIG
  - Potential adverse events
  - Allergic reactions based on product formulation

# Case Study - Hemophilia

- People with hemophilia used contaminated blood clotting factor throughout the 1980's
- Contracted HIV
- Many passed away...but not all
- Devastated families
  
- What could individuals and families do in order to obtain compensation?
- **ORGANIZE AND ADVOCATE**

# Case Study - Hemophilia

- Hemophilia Population organized
- Created the Ricky Ray Hemophilia Relief Act
- Convinced Rep. Porter Goss and Senator Mike DeWine to introduce legislation
- 7 year effort – bill finally considered
- Passed unanimously
- Congress funded for \$655 million
- Individuals and families received \$100K each
- Recognition from federal government

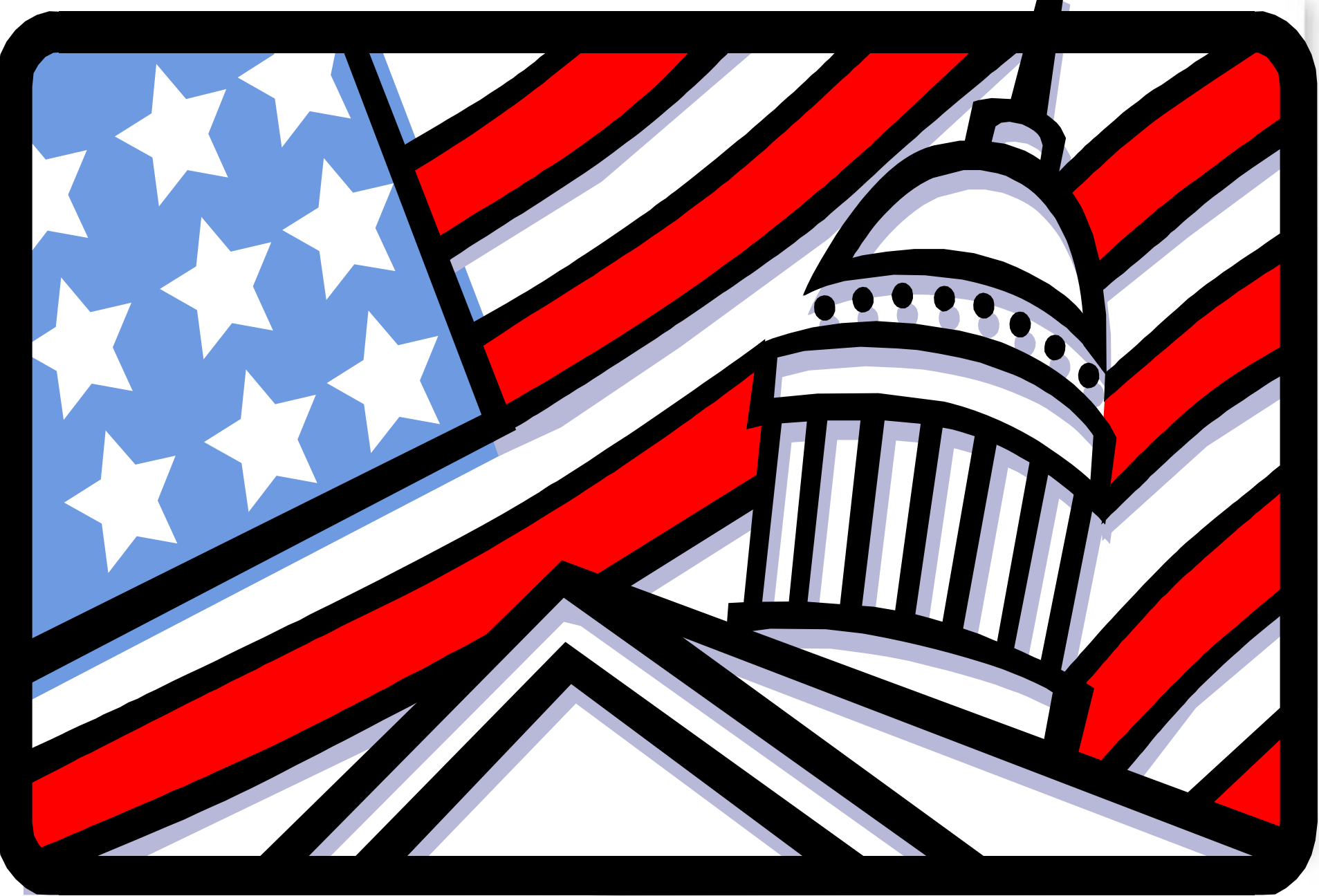
# Make Your Point

- Be specific in the assistance you are seeking.
- Bring supportive documentation if necessary/appropriate
- Follow up with staff
  - Ask what would be an appropriate period of time
- Share any results or communications from Medicaid/insurer with staff
- Let them know if you are satisfied
  - If yes, then thank them in writing

# The Squeaky Wheel

- The squeaky wheel gets the grease
  - Be persistent, but not annoying
  - Do not be bashful - ask for assistance

“If the squeaky wheel gets the grease, then lets start squeaking”



Biotherapies for Life™ **CSL Behring**