

Grassroots Advocacy National MPS Society

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Goals

- Encourage members of the National MPS Society to meet with their federal lawmakers
- Provide information and tools to make it easy and comfortable
- Advance the policy agenda of the Society

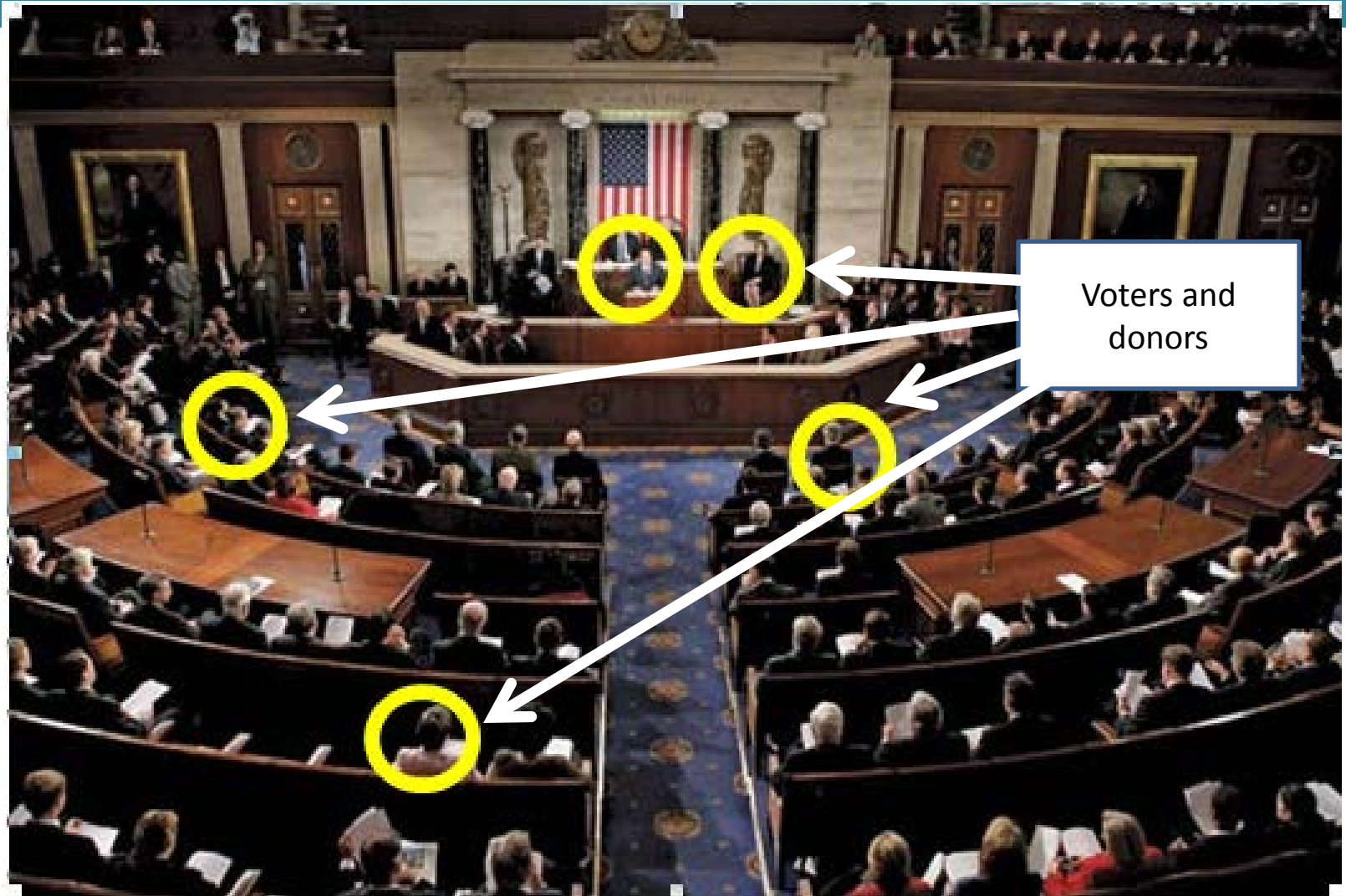
The Society's federal policy goals

- Appropriations – money for MPS research
- Legislation to create accelerated approval pathway for new treatments
- Resolution for National MPS Awareness Day

How do policies get passed?



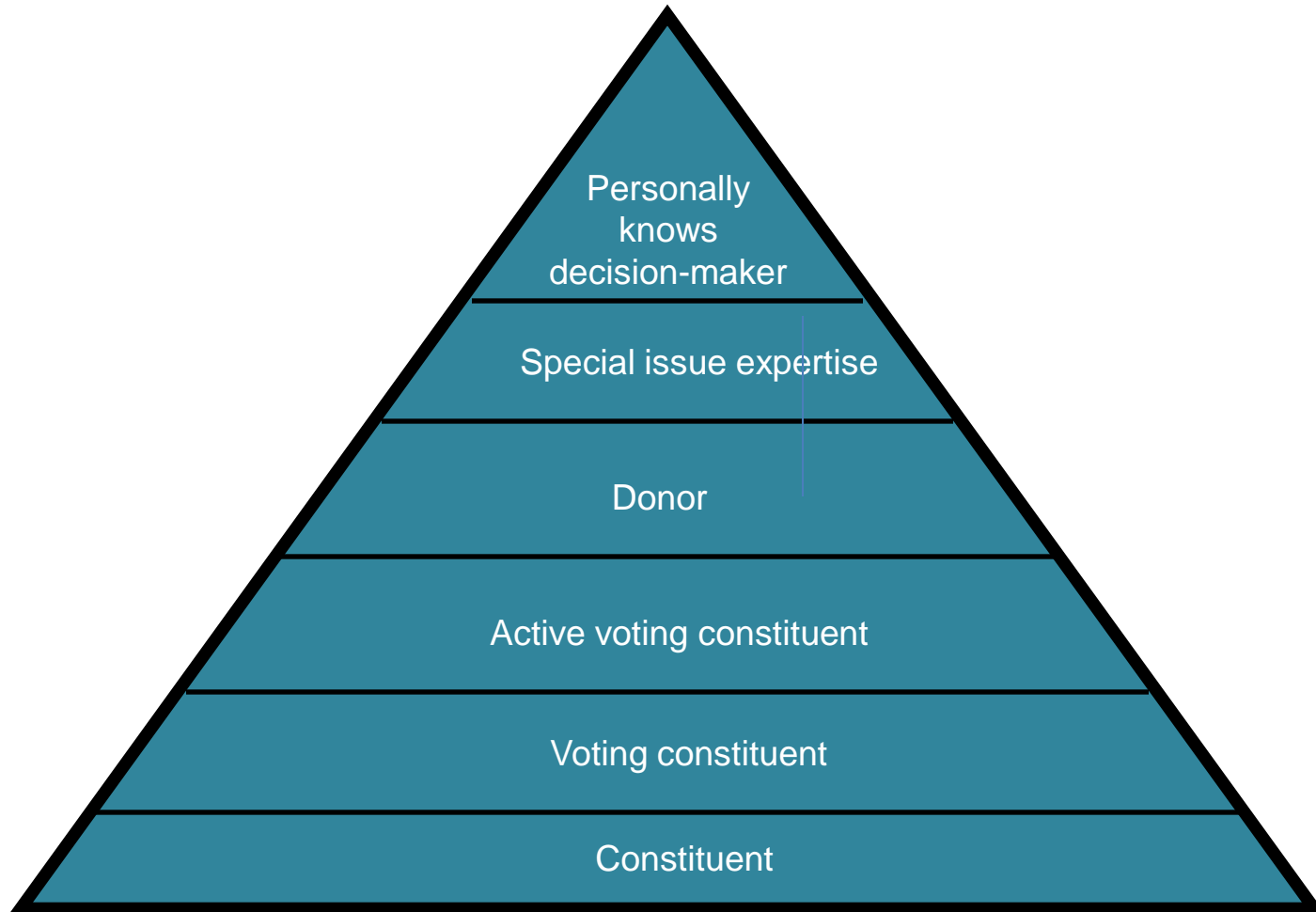
Who makes it happen?



What is advocacy?

Advocacy is the application of pressure and influence on the people and institutions that have the **power** to give you what you want.

Where is your power?



Key considerations

- What do you want?
- Why do you want it?
- What person or institution has the **POWER** to give it to you?
- How will you build credibility with and get access to those **POWER** brokers in order to influence their decision-making?

The power of personal stories

- Make it real
- Make it local
- Make it personal
- Make it powerful
- ***Make them feel***

How to tell your story

- What are the impacts of MPS?
 - Daily and long-term
 - Not every detail, but specifics
 - Social, emotional, economic, educational
- What do you want them to feel?
- What do you want them to do?
- Feelings are more important than facts
- Pictures are worth a thousand words

Ways to illustrate your story

- Timeline of photos
- Artwork about MPS from your children
- Itemized hospital bill
- Stack of insurance claims
- # of days of missed work, missed school, medical appointments in 6 months
- Estimated list of out-of-pocket payments in a year

Meeting with members of Congress

- Where? – in your home state
- When? – this spring and summer
- Why? – to share your story, educate them about MPS, and begin to build a relationship
- How? – it's easy!

Step 1: Finding your members

- U.S. Senators: you have 2
http://www.senate.gov/general/contact_information/senators_cfm.cfm
- U.S. Representatives: (also called Congressmen/women) you have 1
<http://www.congressmerge.com/onlinedb/index.htm>

Step 2: Find their local offices

- Visit their websites to find out where they maintain offices in their home states
- Senators:
http://www.senate.gov/general/contact_information/senators_cfm.cfm
- Representatives:
<http://www.house.gov/representatives/>

Step 3: Request a meeting

- Find out when they are back home
- Request a meeting online

Dear [SENATOR or CONGRESSMAN/WOMAN] [LAST NAME]:

As a member of the National MPS Society, I am writing to request a meeting with you and your aides to discuss several issues that affect children with mucopolysaccharidoses, or MPS diseases, [or provide your specific disease] and their families.

I will be available to meet with you at your [LOCATION] office on [DATES YOU ARE AVAILABLE] and would welcome the opportunity to speak with you about these issues. I can be reached at the phone numbers listed below and will look forward to hearing from you regarding a time we can meet. Thank you for your consideration.

Respectfully,

[YOUR NAME]

[YOUR ADDRESS]

M: [YOUR MOBILE PHONE]

O: [YOUR OFFICE PHONE]

H: [YOUR HOME PHONE]

Step 4: Follow up to get it scheduled

- Be polite and persistent
- Be willing to meet with staff
- Confirm appointment

Step 5: Prepare for your meeting

- Toolkit materials:
 - Strategies for gathering information about lawmaker
 - Guide to sharing your personal story
 - MPS Diseases Fact Sheet (leave behind)
 - Legislative Policy Priorities (leave behind)
 - Talking points for legislative meetings
 - Simple strategies for building a relationship

Do a little research

- Before meeting with your lawmaker or their district staff, spend 15-30 minutes surfing the web to read their bio, see if they have been mentioned in the media recently, and to view recent photos
- If you know people in your state who may have met with the same lawmaker within past couple years, ask them for pointers

Learning about your lawmaker

What do they care about? What motivates them? What issues are top interests?

- Biographies
- Campaign websites
- Wikipedia
- Social media:
 - Facebook
 - Twitter
 - Blogs
- Donor history: www.opensecrets.org (under “Politicians and Elections”)

Step 6: Conduct your meeting

- Introductions
- Explain the National MPS Society's mission
- Briefly explain MPS
- Share your personal experience with MPS
- Briefly discuss the Society's legislative agenda
- Relationship building
- Thank you's

Building a relationship

- Punctuality, patience, flexibility
- Get to know staff
- Be brief and conversational
- Ask questions
- Share your personal story and experience
- Acknowledge differing opinions
- Respond honestly
- Be appreciative
- Follow up with requested information
- Offer to be a resource
- Check in consistently

Tips

- Do NOT feel that you need to cover everything!
- The only thing you need to be an expert on is your experience
- Less is almost always more
- Your number one job is to tell your story and begin a relationship

Final steps

- Tell us how it went – legislative meeting feedback form
- Send a thank you note
- Keep in touch with your lawmakers



Legislative Meeting Feedback Form

After you meet with your lawmaker, please fill out this form and return it to the National MPS Society:

Email: stephanie.bozarth@mppsociety.org

Mail: PO Box 14686, Durham, NC 27709-4686

Date of Meeting:	
Your name/email	
Name of U.S. Senator or Representative	
Congressional Office Location: (city/state)	
Legislator and/or Staff Members Present: (list all)	
Meeting Attendees: (list all constituents at the meeting)	
What did you learn about how the lawmaker communicates with constituents?	
Did the lawmaker have any advice for you/MPS?	
Did the lawmaker have any experience with MPS or other rare diseases?	
How did the	

Questions and Discussion

Thank you!

- Accessing the Legislative Toolkit
- Give us a shout if you have questions!

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