



# LEGISLATIVE TOOL KIT



DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION

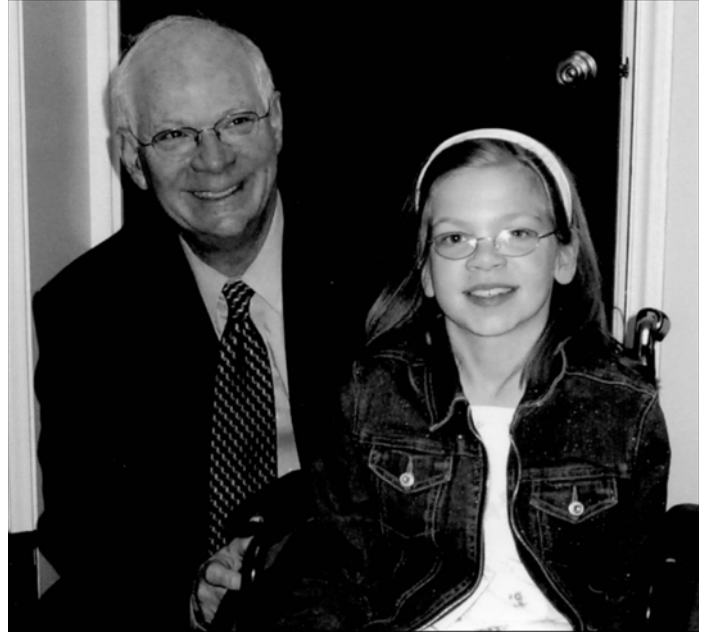
*celebrating 30 years of serving  
all dystonia-affected persons*

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## FIGHTING DYSTONIA THROUGH ADVOCACY – WORKING FOR THE FREEDOM TO MOVE

The Dystonia Medical Research Foundation (DMRF) is the leading patient advocacy organization dedicated to supporting research for the improvement of treatments and ultimately a cure for dystonia while raising awareness and educating the public about dystonia and supporting affected persons and their families.

Becoming a dystonia advocate is an important and empowering activity. By speaking out and actively supporting the Foundation’s legislative agenda, you will be educating legislators as to what dystonia is and how they can help the hundreds of thousands of Americans affected by this disease. You are joining a growing group of individuals who are fighting for the **basic right to move for everyone**.



Your story is important to raise awareness of how dystonia affects lives – your personal testimony is powerful and can make a big difference.

We thank you for your interest and stand ready to assist your efforts in any way we can.

As you know, government is divided into the federal, state and local levels. Each has an important role to play in our lives. The DMRF’s past advocacy efforts have been focused on the federal level, but state government is taking on an increasingly important role in the dystonia community.

This toolkit is designed to support your advocacy efforts by providing you with helpful information and hints that you will need in preparation for meetings with your legislators and in the follow-up work that is needed after meetings. In addition to the information contained in this toolkit, feel free to contact the DMRF national staff at 312.755.0198 or 1.800.377.3978 should you have any questions or require additional assistance.



***Governor of your State***

Mailing address  
Phone Number  
Fax Number  
Email address

District Office information

***State Senator***

Mailing address  
Phone Number  
Fax Number  
Email address

District Office information

***State Representative***

Mailing address  
Phone Number  
Fax Number  
Email address

District Office information

**SHARING DMRF INFORMATION – GETTING THE WORD OUT**

- Call the local offices of your federal and state officials.
- Introduce yourself and tell them about dystonia and the DMRF.
- Ask for the name of the health staff person in the local office and in the Washington, DC (state capitol office for state officials) office.
- Make a note of these persons. Share with them a brief summary of the mission of the DMRF and the programs you offer.

When calling:  
Be prepared.  
Be brief – concise  
Be comprehensive

- Put these elected officials and staff persons on your mailing list and email blast list.
- Send them a holiday card and notices of any events you may be hosting.
- Keep them informed of what you are doing. They want to know.

**HOW TO ADDRESS YOUR LEGISLATORS**

When writing elected officials, address them in the following manner:

*Writing a Member of the US Senate:*

The Honorable (name)  
Dear Senator (name)  
United States Senate  
Washington, DC Zip Code

*Writing a Member of the US House of Representatives*

The Honorable (name)

Dear Congressman or Congresswoman (name)

US House of Representatives

Washington, DC Zip Code

*Writing a Governor*

The Honorable (name)

Governor, State of (State)

State Capital, State Zip Code

*Writing a State Senator or State Representative*

The Honorable (name)

Governor, State of (State)

State Capital, State Zip Code

## **WRITING ELECTED OFFICIALS**

Communications to elected officials make a difference. Federal and state legislators rely on letters from constituents to let them know how people in their districts feel on matters. The number of responses an official receives on an issue can actually determine how they vote on that issue.

The following are tips for you to use when writing to your officials.

- When writing to a legislator, make the letter personal – try not to use a form letter.
- E-mail correspondence is also effective but again, when time permits, send a personal communication.
- State that you are a constituent.
- If you are responding to an alert and do not have the time to personalize the letter or email, feel free to use the template provided.
- Mention the number of the bill or legislation you are writing about early in your letter or email.
- Be concise – try to say it all in one page – never more than two.
- Be respectful – even if you are writing to express your disappointment in a recent voice or position the legislator took, you should be polite and select your words carefully. You are building a relationship.
- Send a copy of your letter to the DMRF National Office, c/o Jennifer Molski. We like to track the number of letters sent on issues.

It is important to register your opinion on important issues. See the Appendix for a sample letter.

## **ALERTS – A CALL TO ACTION**

From time to time, the Foundation will issue a Legislative Alert – calling on you to voice your opinion on an important issue that affects the dystonia community. These alerts will be issued only at critical times. We ask that you respond promptly in writing, calling or e-mailing your legislators on the issue identified.

- Respond quickly
- Be concise
- Establish an Alert Tree – of families and friends who are willing to receive alerts and act quickly – this can be a huge boost to our legislative efforts.

## **MEETING WITH ELECTED OFFICIALS**

Personal meetings, with an elected official or member of their staff, are a very effective way to raise awareness of the legislative needs of the dystonia community and the DMRF. These meetings should be coordinated among your group – especially if you are meeting with an official in their home district office. The following are tips to help you have a successful meeting.

- Confirm your meeting in advance by phone – this particularly is important if you scheduled the meeting in the home district.
- Be on time – you may have to wait but you never want to keep them waiting for you.
- Be prepared – know what you are going to say, know your facts, and know what you want from the official.
- Go in a group for greater impact. Select a spokesperson and meet beforehand to coordinate who is going to say what.
- Lead with a personal story – the spokesperson should tell their story – personal testimonies are memorable and help the legislator or their staff person better understand the scope of dystonia.
- If you are a constituent, say so.
- Be concise and respectful of their time – stay focused.
- If you do not know the answer to a question – tell them you will get them the requested information. Do not make up an answer.
- Everyone should turn off cellular phones and pagers. You do not want to create distractions from the brief time you have for the meeting.
- Leave them with materials on dystonia and printed materials that support the request you have just made of them.
- Do not be disappointed if you are meeting with a staff person and not the official. Often times, especially with federal legislators, meeting with a staff person can be more helpful as they have more time for your meeting and to ask questions. Staff is critically important to the smooth running of an official’s operations.
- Send a thank you letter following your meeting. See appendix for an example.
- Ask the legislator or their representative for a firm commitment.

*Additional Tips:*

- Meeting with a federal legislator may be easier to do when they are home in their district offices – they are often more relaxed and have more time.
- Keep an eye on your local newspapers to learn when they may be in the area.
- Because you have introduced yourself and the DMRF to the staff in local offices, you can contact them, preferably in writing – a fax or an e-mail, to schedule an appointment for when the legislator will be next in the office and available.
- If you are meeting with a federal legislator in a home office, let the DMRF Director of Network Services know of your meeting. This will allow for you to receive the most updated information on an issue before your meeting so you will not be embarrassed. For example, if the legislator just signed on to sponsor the bill you are meeting with them to request their support, you will want to know this in advance.

### **PHONE CALLS TO OFFICIALS**

Calling an elected officials office can also be an effective means of registering your view on an issue. If you are responding to an alert – calling may be the only timely way to get your position to the legislator before a vote.

The following are tips on how to make an effective call to an official:

- Ask to speak to the legislator and don't be surprised if you actually get to speak with them.
- As with meetings – be prepared - know what you are going to say, know your facts, and know what you want from the official.
- State why you are calling – reference the bill number or issue and say what you want from the legislator.
- Say you a constituent, if you are.
- Be concise and respectful of their time – stay focused.
- If you do not know the answer to a question – tell them you will get them the requested information. Do not make up an answer.

*Additional tips:*

- If you are responding to a DMRF Legislative Alert – it is preferable that you call the Washington, DC office.
- Let the DMRF national office know the outcome of your call – send an e-mail to [advocacy@dystonia-foundation.org](mailto:advocacy@dystonia-foundation.org)
- Call the White House and register your view on important issues. You can reach the White House by calling 202.456-1111, between 9:00 am and 5:00 pm Eastern Time.

## **DMRF LEGISLATIVE ALERT CALL TO ACTION**

### **Urge the House of Representatives to Support Health and Education Funding In the Fiscal Year 2007 House Budget Resolution**

**Action Needed by April 5, 2006**

**Contact your Member of the House of Representatives Immediately!**

On Wednesday, April 5<sup>th</sup>, the House of Representatives will begin consideration of the Fiscal Year 2007 House Budget Resolution. During consideration on the floor, Congressman Michael Castle, (R-DE) is planning to offer an amendment that would add \$7 billion for discretionary health and education programs, as Senators Specter (R- PA) and Harkin (D-IA) were successful in accomplishing during consideration of the Senate Budget Resolution.

Contact your House member and urge him or her to support the Castle amendment to add \$7 billion to the Fiscal Year 2007 House Resolution.

To obtain contact information for your House member, please call the U.S. Capitol Switchboard at 202.225.3121 or visit [www.congress.org](http://www.congress.org).

If you prefer, see the sample correspondence. Given the time sensitivity, letters are best sent via fax or e-mail.

**Letter to Member of the U.S. House of Representatives**

April 3, 2006

The Honorable Tom Jones  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Congressman Jones:

As a constituent, I am writing to ask for your support of critical health care and education programs for the Fiscal Year 2007 House Budget Resolution.

I am disappointed that the President's fiscal year 2007 budget and the House Budget Resolution approved by the Budget Committee proposes significant cuts to important health care programs such as those at the National Institutes of Health and the Centers for Disease Control and Prevention. As a person who lives every day with dystonia – a neurological movement disorder that causes abnormal and painful muscle contractions. I believe more funding is needed for research. These agencies are making invaluable contributions to research, education, and public awareness. Now is not the time to decrease our investment in these important programs that hold such great promise for our nation's future, and for me and the 300,000 others who suffer from dystonia in this country.

As the House considers the Fiscal Year 2007 Budget Resolution, I am asking that you support Congressman Michael Castle's amendment to add \$7 billion for critical discretionary health and education programs.

Thank you for your consideration of my views. Please advise me of your actions regarding the budget at your earliest convenience.

Sincerely,

Mary Smith  
Member.  
DMRF Plainesville Support Group

May 3, 2006

The Honorable Mary Silver  
United States Senate  
Washington, D.C. 20515

Dear Senator Silver:

Thank you for meeting with me and the other members of the Dystonia Medical Research Foundation Plano Area Support Group yesterday. We very much appreciated the opportunity to talk with you about dystonia and its affect on our lives and what you can do to help the 300,000 Americans who struggle every day to meet the challenges of this painful and debilitating disorder.

Your support for increasing the amount appropriated for NIH funding in the 2007 budget is critical to our continuing the momentum of progress in unraveling the mysteries of dystonia and other devastating illnesses. Thank you for your commitment to increasing the amount for research. On behalf of me and the other members of our group, we thank you for your time and efforts.

Thank you also for all the work you do on behalf of the people of Texas.

Sincerely,

Susie Marks  
President  
DMRF Plano Support Group

## **DYSTONIA MEDICAL RESEARCH FOUNDATION PRIORITIES**

The mission of the Dystonia Medical Research Foundation is to advance research for more treatments and ultimately a cure for dystonia; to promote awareness and education; and to support the needs and well being of affected individuals and families. Until a cure is found, the Foundation will support scientific research on dystonia and more effective treatments, with fewer side effects.

### **Dystonia Research**

To continue to make advancements in dystonia research, Federal support is needed for the National Institutes of Health. The DMRF urges Congress to be vigilant in its funding for the NIH and its subordinate research institutes, and urges **Fiscal Year 2007 (FY07) Funding** levels of:

**NIH** (National Institutes of Health):

*\$30 billion, a 5% increase over FY06.*

**NINDS** (National Institute of Neurological Disorders & Stroke):

*\$1.61 billion, a 5% increase over FY06.*

**NICHD** (National Institute of Child Health and Human Development):

*\$1.33 billion, a 5% increase over FY06.*

**NIDCD** (National Institute of Deafness & Communication Disorders):

*\$412.7 million, a 5% increase over FY06.*

**NEI** (National Eye Institute):

*\$700.4 million, a 5% increase over FY06.*

### **Access to Dystonia Therapies**

DMRF urges Congress and the Centers for Medicare and Medicaid Services (CMS) to preserve access to necessary medications and therapies for dystonia patients. Such therapies allow Dystonia affected individuals to remain employed and fully engaged in society and their personal lives.

- The Medicare Modernization Act assured an **adequate reimbursement rate for therapeutic Botox injections** for calendar years 2004 and 2005, but the planned CMS competitive bidding proposal creates a great deal of uncertainty for future rates. DMRF is also concerned about the reimportation of injectable drugs, and *urges an exemption for the reimportation of injectable orphan drugs.*
- In addition, the DMRF urges the CMS National Coverage Policy to **provide inclusion of the electrical nerve stimulation procedure** (as it relates to deep brain stimulation provided by an implanted stimulator device) whenever it is deemed medically necessary. Currently, deep brain stimulation (DBS) provided via an implanted deep brain stimulator is subject to Medicare coverage at the discretion of the insurance company.

### **Genetic Non-discrimination Legislation**

The DMRF calls on Congress to pass the *Genetic Information Nondiscrimination Act* this session and send a bill to the President. The Senate has already unanimously passed S. 306, introduced by Senator Olympia Snowe in February, 2005. The House must now pass **H.R. 1227**, introduced by Representative Louise Slaughter (D-NY), the House companion bill to the Senate's genetic nondiscrimination legislation. Congressional action is essential to ensure that Americans will not be discriminated against because of their genetic information.

## DYSTONIA FACT SHEET

- Dystonia is a disorder that causes the muscles in the body to contract or spasm involuntarily. These muscle contractions force the body into twisting, repetitive movements and abnormal positions.
- Dystonia can affect a specific part of the body such as the legs, arms, neck, face, eyes, and vocal cords or affect all major muscle groups simultaneously.
- Symptoms are usually chronic but may also appear only during “attacks” or episodes.
- Dystonia may be inherited or caused by specific factors such as trauma, certain medications, and additional medical conditions. However, for most people who have dystonia the cause remains unknown.
- Dystonia is not usually fatal, but it is a chronic disorder that causes varying degrees of disability and pain, from mild to excruciating.
- There is no known cure for dystonia.
- Dystonia is the third most common movement disorder following essential tremor and Parkinson’s disease. It affects an estimated 300,000 men, women, and children in North America.
- Despite the prevalence of dystonia, awareness and proper diagnosis of this disorder is extremely limited. Many patients report that it took visits to numerous physicians over the course of *years* to achieve a correct diagnosis.
- There is no single treatment that is appropriate for all cases of dystonia or even a therapy that benefits a majority of patients. Medical treatment may include oral medications, botulinum toxin injections, and brain surgery. The results of brain surgery are particularly dramatic in some individuals.
- The inability to predict or control the movements of the legs, arms, neck, shoulders, face, eyes, jaw, tongue, and/or vocal cords has a profound affect on an individual’s existence. The disorder can interfere with nearly all aspects of a person’s life including daily functions such as walking, sitting, sleeping, eating, and talking.
- The appearance of awkward body postures and uncontrollable movements often make patients reluctant to go out in public or even withdraw from loved ones and friends for fear of being misunderstood or mistreated.