Voting + Advocacy = Power!

Know your candidates' views on crucial issues, and use your power as an advocate and a voter

by Nancy West

Did you know that people with disabilities are 10 percent less likely to be registered to vote, and 20 percent less likely to actually go to the polls and vote in an election?

Yet, the votes of people with disabilities are critical to ensuring that the voice of the disability community is heard loud and clear in Washington D.C., state capitals and municipalities nationwide. Battles for passage of crucial legislation affecting accessibility, health care, caregiving and funding for medical research have been won in the past because people with disabilities advocated for these issues and voted for candidates who would support them.

In this election year, the issues we face are no less critical. In particular, people with neuromuscular diseases should be aware that proposed funding for next year's National Institutes of Health (NIH) budget — the lifeblood of medical research — is level. Despite the fact that the 2011 fiscal year budget funded only one in six NIH grant applications — the lowest rate on record — no budget increase is being planned for the 2013 fiscal year.

'Sequestration' threat to NIH budget

As this article goes to press, the NIH budget also is threatened by the prospect of automatic spending cuts, or *sequestration*, scheduled to take effect in January 2013 under the Budget Control Act of 2011. Unless Congress takes action, the plan will lead to across-the-board cuts to all nondefense discretionary federal spending, including an estimated cut of around 7.8 percent at NIH, according to the Congressional Budget Office.

In May 2012, the House passed Rep. Paul Ryan's (R-Wis.) budget plan aimed at protecting defense spending from automatic spending cuts by instead making cuts to social services and the health reform law. House Democrats offered alternative legislation that would have eliminated subsidies to large oil firms and agricultural interests, and imposed the "Buffett Rule" (a minimum tax on millionaires). However, this alternative proposal was defeated in the House Budget Committee on a party-line vote. (For more details on sequestration's impact on federal research funding, visit researchamerica.org/sequestrationreport.)

"We are in danger of putting medical research on hold just at a time when we're on the cusp of advances that could make all the difference in the quality of life for many individuals with diseases and disabilities," states Mary Woolley, president of Research!America, a nonprofit alliance of academia, business, patient organizations and scientific societies dedicated to making medical research a higher national priority. "People just assume that everything possible is being done scientifically to assure better health and quality of life. But the truth is we are not doing everything possible, and research is not moving quickly enough."

Advocacy makes a difference

Although the U.S. Food and Drug Administration's (FDA) mandate is to provide safe, speedy and predictable oversight and regulation of clinical trials, the agency faces serious challenges in its efforts, particularly lack of adequate resources. Members of the MDA community have the potential to change this and speed the research process by advocating for the resources and policies to support it.

"History tells us that advocates make the difference when policymakers get stymied or distracted by other important issues," says Woolley.

For example, during a recession economy in 1995, explicit plans were on the table to cut the NIH budget by 5 percent per year for five years. Through the power of advocacy, that decrease was not only overturned, but became a 7 percent increase the first year, followed by a successful effort to double the NIH budget within five years — a 15 percent increase each year!

In a similar economic climate in 2011, the U.S. Senate Appropriations Committee proposed a significant cut to NIH funding. However, the House Appropriations Committee proposed a $1 billion increase. Why? Because Rep. Dennis Rehberg (R-Mont.), chair of the House Labor, Health and Human Services Appropriations Subcommittee, heard directly and consistently from his constituents that research was really important to them. Ultimately, the House and Senate compromised with a net $250 million increase in funding for the NIH. Advocacy was the catalyst.

Know your candidates' views

To ensure faster progress in medical research and other issues so vital to health and quality of life, more people with disabilities need to advocate and exercise their right to vote.

Before you vote, know where the candidates stand on the issues, not just for national offices, but for state and local elections as well. State officials decide many budgetary issues related to health care, and officials at all levels influence decisions about health and human services. Make an appointment to meet with your elected officials in person if possible, or send an email with specific requests for action.

"Make the most of any contact you have with elected officials by making a very specific and concrete request such as, 'We want you to help pass a $32 million budget for the NIH this year,'" urges Woolley. (For more tips on meeting with members of Congress, visit researchamerica.org/uploads/PortersPrinciplesAdvocacyMessagesFINAL.pdf)

"By making an impact on your congressional representatives, you have a chance to change the national conversation on issues important to people with disabilities," says Christopher Rosa, City University of New York's University Assistant Dean for Student Affairs, a member of MDA's Board of Directors, and a published disability studies scholar and advocate.

MDA's advocacy program is "uniquely positioned to make sure the community we serve is organized and actively involved in all aspects of the democratic process," notes Rosa, who has **Becker muscular dystrophy**.

The MDA Advocacy Web pages (mda.org/advocacy) provide tools to support grassroots national, local and virtual communities in advocating for legislation. These include:

- **Achieving a Better Life Experience (ABLE) Act of 2011:** Bills currently in the Senate and House provide for the establishment of "ABLE accounts" for the care of family members with disabilities.
- Rare disease inclusion in the latest draft of the **Prescription Drug User Fee Act (PDUFA):** Thanks to advocacy by MDA and other organizations, the House and Senate each passed reauthorization bills that included "accelerated approval" provisions designed to spur the development of potentially lifesaving therapies for individuals living with rare neuromuscular diseases.
- **Faster Access to Specialized Treatments (FAST) Act** (House bill) and **Transforming the Regulatory Environment to Accelerate Access to Treatments (TREAT) Act** (Senate bill): Both acts will speed the approval of therapy and cures to patients facing serious and life-threatening conditions, including neuromuscular disease.
- **Fairness in Medicare Bidding Act:** House bill to repeal Medicare's competitive bidding program for durable medical equipment services and supplies.

Another way to know your candidates' views is to visit Research!America's Your Candidates, Your Health Web page (yourcandidatesyourhealth.org). All 2012 presidential and congressional candidates have been invited to state their views on medical research on this site. If yours have not responded, send an email via the Research!America website to request a response.

"If candidates get enough requests from enough constituents, they will respond," says Woolley. "People who don't talk about medical research before they are elected are very unlikely to become champions afterward. It's important to engage them on this issue before they're elected."

Get out the vote!

If you think that your one vote won't make much difference, think again.

"If people with disabilities voted at the same rate as people without disabilities, 10 million more voters would have participated in the last presidential election," says Rosa. "That in itself would be enough to tip the balance of any election."

Why don't more people with disabilities vote? Some cite inaccessibility of voter registration, polling places and the voting machines themselves. But thanks to legislation such as the *Americans with Disabilities Act (ADA)*, the *Help America Vote Act (HAVA)* of 2002 and the *National Voter Registration Act*, many improvements have been implemented that make voting more accessible than ever.

Citizens have the option to register to vote by mail or in person at an expanding list of accessible public venues. The laws also require that polling places have clearly marked accessible parking spaces, entrances with ramps, and voting equipment that provides equal access and participation, including privacy and independence for individuals with disabilities and other voters.

If your polling place is not accessible on Election Day, ask for immediate assistance from poll workers on site. "Don't take no for an answer — it's your right," emphasizes Rosa. If you don't get the help you need, contact the Board of Elections in your area immediately.

Voting by absentee ballot

People with disabilities always have had the opportunity to vote via absentee ballot.

Rosa contends that, while this is a valid way to vote, it is not as satisfying as full participation in the voting process. "Going to your polling place and voting with other citizens in your community is a qualitatively different experience than casting an absentee ballot by yourself at home," he states.

Rosa urges individuals to make sure their polling places are accessible so that an absentee ballot isn't the only option. If you opt to vote by absentee ballot, be sure to apply for and mail it in plenty of time to arrive by the deadline, usually by the time the polls close on Election Day. You also can drop off your absentee ballot at the polling place on Election Day.

Some states offer a permanent absentee ballot list. Once a voter asks to be added to the list, he/she will automatically receive an absentee ballot for all future elections.

Accessible voting technology

The Help America Vote Act spawned the development of new accessible voting machines with features such as a sip-and-puff system for voters who have difficulty using their hands and a system of pedals for those who can use their feet but have problems with manual dexterity.

In 2011, the U.S. Election Assistance Commission (EAC) provided funding to a Clemson University research team for a three-year, $4.5 million project to increase the accessibility of new, exist-

More Online

Go to quest.mda.org and click on July-September 2012 Quest for more information on the power of voting. See a checklist of things to do before election day; learn about curbside voting in some states; and make note of several valuable resource sites for voters. For a personal perspective on voting, check out Emily Munson's blog "Policy Shift: Get Involved!" at the MDA Transitions Center (transitions.mda.org). Emily, 27, is an Indianapolis attorney who has **spinal muscular atrophy**.

ing and emerging technology in the design of voting systems. The team is led by Juan Gilbert, professor and chairman of the Human-Centered Computing Division in Clemson's School of Computing.

Gilbert also is the developer of Prime III, an electronic voting system with many accessible features. With Prime III, voters can choose to follow written or spoken instructions, and they can record their votes by touching a screen or speaking into a microphone. Even when using the voice-activated ballot, voters' privacy is protected because a series of voice prompts leads voters to say words such as "next" or "vote" rather than the candidates' names.

Prime III is being used for the first time in 2012 state and federal elections at some locations. Clemson's team is continuing to develop voting technology that further enhances accessibility.

Become a poll worker

On Election Day, poll workers play a crucial role in providing accommodations to voters who need them. Rosa urges people with disabilities to consider serving as poll workers.

"We have a national shortage of poll workers and people with disabilities are in a position to really make an impact. They can lend important insight into the accommodation needs of voters with disabilities that your typical poll worker wouldn't have," he says.

Exercise your right to vote

Rosa observes that members of the MDA community have fought long and hard for full participation in all aspects of American life and full citizenship.

"The core of full citizenship is voting," Rosa emphasizes. "As a community, we need to educate our colleagues and peers about how they can give rise to the change they hope to achieve by participating actively in the voting process and by advocating for the right to fully participate without barriers. By exercising our right to vote, we have the power to elect policymakers whose actions will reflect the needs and interests of our community." ❑

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