



*grow your grassroots and
better influence public policy*

CASE STUDIES BY THE NATIONAL HEALTH COUNCIL

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executive summary

Patti Serna of Albuquerque, New Mexico, is not an expert in government relations or public policy. She doesn't know the difference between an authorization and an appropriation. And she has no idea what NIH, PDUFA, or CMS stand for.

Yet Serna is one of the National Alopecia Areata Foundation's most valuable advocates. By sharing her family's personal story with Representative Heather Wilson from New Mexico, she played a critical role in securing the introduction of legislation to improve Medicaid coverage for hair prostheses.

How many Patti Sernas are members of your organization?

Volunteers like Serna possess a tremendous amount of political power. They bring to life the personal, human side of a complex story for policy makers. Yet despite their incredible value, patients like Serna are not being widely used by voluntary health associations.

In 2007, a National Health Council report found that less than one percent of those affected by a chronic disease or disability are advocates on behalf of a patient advocacy organization. Such numbers effectively prevent most organizations, as well as the entire patient community, from creating the public support needed to improve health care for the more than 100 million people living with chronic conditions.

Most patient advocacy organizations acknowledge the value in organizing and motivating grassroots advocates like Patti Serna to take action. However, many would state that they need help in identifying, recruiting, training, and mobilizing these volunteers. Even those that have successfully mobilized their community believe they have only scratched the surface of this powerful resource.

In 2007, the National Health Council launched an innovative Grassroots Technical Assistance (GTA) program to address this challenge. By providing technical assistance – in the form of consulting services to selected members – the National Health Council sought to build a higher level of expertise in grassroots activism. It was able to do so through generous educational grants from Merck, Novartis, PhRMA, and Wyeth.

Over the course of a year, four organizations received consulting services to increase their ability to influence public policy. During this time, each organization created a task team of volunteers and staff, identified an objective on which to work, and then created and implemented a political campaign to achieve that objective.

During the development and implementation of these initiatives, and despite significant structural and organizational differences among the four participating groups, several common challenges and themes emerged, including

Breaking Down Walls – Involving volunteers and staff with varying areas of expertise greatly enhances the success of an organization's advocacy program. Rather than viewing advocacy as a stand-alone activity, each participating organization sought to incorporate it into their programmatic and fundraising activities. Not only did this gain buy-in from key stakeholders, it allowed each group to amplify its message and reach more people.

Aligning Resources and Objectives – Proclamations are easy to achieve, yet offer little tangible impact; requiring coverage for all Americans is highly meaningful, yet extremely difficult to accomplish. Each participating group spent many hours attempting to identify an objective that balanced maximum impact

with minimum difficulty based on the organizational resources – both financial and non-financial – at its disposal.

Maximizing Inclusion – Grassroots advocacy is largely about numbers and how much “noise” an organization can make. As a result, each participating organization attempted to create a campaign that enabled anyone concerned about his or her respective condition to participate and that would resonate with the patient community at large.

Staying Focused – Advocates, policy makers, and staff are overwhelmed with information. That's why building a consistent advocacy “brand” and staying focused and “on message” is critically important. Each participating organization struggled with the challenge of selecting “just one” issue on which to work.

On the following pages, we discuss each of these key findings and how each organization successfully addressed it. At the conclusion, we provide a simple strategic advocacy plan that can be adapted and utilized by any of the National Health Council patient advocacy group members.

breaking down walls

Epilepsy Foundation

Is there anything more closely linked to the mission of a voluntary health association than advocacy? From finding a cure and better treatments to ending discrimination, increasing public awareness and improving the lives of affected people, advocacy is one of the best ways to achieve an organization's mission.

So why is advocacy largely considered a stand-alone activity? Why is it often conducted far away from the national office, frequently in Washington, DC?

Too often, the relegation of advocacy as a separate activity results in its isolation within an organization. As a result, despite its importance to the mission, many staff and volunteers are not actively involved as advocates while others do not appreciate the important role advocacy can play.

Breaking down those walls and actively involving a wide range of staff and volunteers with varying areas of expertise is crucial to the success of an organization's advocacy efforts. That's because such individuals can – through the activities on which they are working – help disseminate messages to the community at-large and create the "noise" needed for an advocacy campaign to succeed.

Like many patient advocacy organizations, the Epilepsy Foundation has a long track record of government relations success. Yet it also realized that a stronger connection with its members was needed to build upon these achievements.

Like other grassroots technical assistance recipients, the Foundation created a task team comprised of staff and volunteers with varying levels of expertise. Because of the important role they play within the organization, affiliate executives were asked to participate. Rounding out the group were fundraising, interactive communications, affiliate relations, and public relations experts.

The task team did not have difficulty identifying an issue on which to focus. When chosen as a GTA recipient, the Foundation had been working diligently to restore the protections of the Americans with Disabilities Act (ADA) and enact legislation to create Epilepsy Centers of Excellence within the Department of Veterans Affairs (VA) medical care system.

Up to that point, the Foundation had largely relied on mobilizing advocates to ask their elected officials in Washington to cosponsor both pieces of legislation. But with fewer than 7,500 advocates, the



Advocate Profile: Laurie Kelly

Laurie Kelly was frustrated. She'd written her congressman, Representative Bob Goodlatte from Virginia, several times. Her request was simple: Cosponsor a bill to protect people with epilepsy from discrimination. As the mother of a child with epilepsy, she knew people with the condition faced workplace discrimination on a daily basis.

But despite her best efforts, Kelly couldn't persuade him. But she didn't think of giving up. "Anyone who knows me knows how passionate I am about this," she said. If her single voice wasn't enough, she'd simply get more voices.

Kelly started collecting signatures on a petition urging Goodlatte to cosponsor the bill. She collected 13 signatures at a school social studies fair and then linked up with other families affected by epilepsy. Within two weeks, they had collected more than 200 signatures.

Kelly mailed the signatures to Representative Goodlatte and even met with him in Washington, DC. No dice. But she persisted and didn't give up hope. Her perseverance was rewarded when the House of Representatives passed the bill. Goodlatte had voted in favor of the bill and Kelly was ecstatic.

"This is one great day!" she said.

Foundation knew it needed to expand this effort and involve more people in the campaign. The challenge was identifying how to do it.

Communications and public relations were key components of this effort. While the communications and advocacy departments in the national office had worked collaboratively in the past, greater emphasis was placed on incorporating advocacy messages into existing communications channels.

For example, the February 2008 edition of *Epilepsy USA* magazine profiled an advocate, as well as the Foundation's VA and ADA campaigns. Messages were sent to eNewsletter subscribers, and staff media experts participated in the Foundation's *Kids Speak Up!* event in Washington, DC. As a result, significant local media coverage was generated about the event and the organization's two key legislative priorities.

The Foundation also sought to integrate advocacy with fundraising initiatives. Staff worked to persuade National Epilepsy Walk participants to visit Capitol Hill during the *Kids Speak Up!* event. *Kids Speak Up!* advocates were also encouraged to get involved with local activities when they returned home; one hosted a fundraiser shortly afterwards that netted the Foundation more than \$10,000.

Towards the conclusion of the grassroots technical assistance initiative, the Foundation began to develop plans for an organization-wide petition drive. The petition drive would serve as the first-ever opportunity for the national office and affiliates to work collaboratively on a national advocacy campaign.

Through the petition drive, the Foundation aims to create a greater sense of common purpose and demonstrate that the public supports its advocacy objectives. It also hopes to significantly increase the number of advocates willing to take action on behalf of the Foundation. One month after its launch, the petition drive had increased by 40 percent the number of national epilepsy advocates.

While advocacy is breaking down walls among staff and volunteers at the Foundation, the Grassroots Technical Assistance Program also helped generate significant support for the VA and ADA legislation supported by the Foundation. During the campaign, the number of congressional cosponsors continued to grow, and both bills were enacted into law in September 2008.

aligning resources and objectives

Huntington's Disease Society of America

There is an indirect relationship between the impact of an advocacy objective and the probability of achieving its enactment. Often, the easier it is to achieve a specific advocacy objective, the less impact it will have. The more difficult it is to achieve, the greater the impact it will have on a community. Finding an appropriate balance between the two is critically important to any successful campaign.

The task team formed by the Huntington's Disease Society of America (HDSA) at the start of the Grassroots Technical Assistance Program soon realized that it would be difficult to decide on which public policy issue to focus. While the organization had been involved in government relations and advocacy in the past, typically as part of a coalition, this would be the first campaign fully initiated by the HDSA to address an issue relating specifically to Huntington's Disease (HD).

The task team realized that there are many issues affecting people with HD, a fatal neurodegenerative disease: access to appropriate medical care; medical research to find a cure and better treatments; an inability to obtain Social Security disability benefits; a lack of FDA-approved medicines to treat the disease; an inability to access long-term care; genetic non-discrimination; and many more.

Given the pressing needs of its constituents, the task team realized that focusing on just one of these issues could be very difficult. There was

also the issue of where the organization should focus its attention. With its headquarters in New York, could the Society have an impact on Washington, DC, and federal policies? With nearly 50 chapters and aligned medical institutions, did it make more sense to focus on state policies?

The task team initially narrowed its focus to three priority areas: improving the Social Security disability benefits application process; ending the two-year waiting period to receive Medicare benefits following a determination of disability; and securing funds from state legislatures for HD Centers of Excellence medical facilities.



Advocate Profile: Allan Rappoport

Allan Rappoport knew little to nothing about Huntington's Disease. Then he attended an HDSA event in San Diego and saw a video about the disease.

"I was blown away to learn about the devastation HD can wreak in families," he said. Despite no strong connection to HD, Rappoport decided to become an advocate for the 30,000 Americans affected by the disease.

The NHC Grassroots Technical Assistance program provided him with a great opportunity. Rappoport served as a member of the task team that implemented the program, and he excelled at organizing local advocates to secure a congressional sponsor of legislation.

He and a group of volunteers formed an advocacy committee and over a three-month period, organized meetings between constituents and each U.S. representative in the San Diego area. As a result of their hard work, Representative Bob Filner introduced HR 6259, the Huntington's Disease Parity Act of 2008, in 2007.

Rappoport gives San Diego chapter volunteers full credit for this success. "This was a team effort and couldn't have done this without the leadership of Sharon Schaefer, Misty Oto, James Saint Onge, and many others," he said.

Rappoport also credits the NHC Grassroots Technical Assistance program with energizing the HD community to take action. His next idea? Working with other HD chapters in the Western United States to build similar programs to influence HD policy.

Although each of these issues was of keen interest to the community, it seemed unlikely that HDSA could work on them simultaneously. Despite its highly motivated membership, compelling public message, and successful track record, the organization simply did not have the capacity to tackle all three issues.

So the task team, working with staff, discussed which among the three objectives offered the greatest potential return and likelihood of success. After much discussion, the task team abandoned the idea of securing funding from state legislatures for HD Centers of Excellence.

The group did decide, however, to seek the enactment of federal legislation to both improve access to Social Security disability benefits and end the two-year waiting period to receive Medicare benefits. While certainly an aggressive goal – elimination of the two year waiting period has been under assault for years – the task team felt it was something the organization could achieve given its existing resources.

Objective secured, the Society developed model legislation and sought to persuade a member of Congress to introduce the bill. Society members nationwide contacted their elected officials in the effort to secure a sponsor, but it was ultimately task team member Allan Rappoport and volunteers in San Diego that hit pay dirt. After numerous conversations with advocates, Representative Bob Filner from California agreed to become the bill's sponsor.

Since introduction, advocates have peppered members of Congress and staff with requests to cosponsor HR 6259, the Huntington's Disease Parity Act of 2008. By the end of the congressional session, eight representatives had agreed to cosponsor the bill. This was short of the group's goal, but a "remarkable" achievement nonetheless, according to HDSA task team member Deb Lovecky.

The Society is now working to ensure that the bill is reintroduced in the next session of Congress. Once introduced, HDSA will continue to recruit, educate, and mobilize advocates until the legislation is enacted into law.

"We have made significant strides in expanding our grassroots advocacy base while tackling one of the most frustrating barriers to care and services faced by our family members."

*Barbara Boyle, CEO
Huntington's Disease
Society of America*

maximizing inclusion

National Alopecia Areata Foundation

There are two strategies for achieving public policy success on Capitol Hill and in state capitols. One relies heavily on access to staff and policy makers. This is the world most people envision when they think of how things get done in Washington DC.

But there's a less visible, and less understood, strategy for achieving public policy success. It relies on the active involvement of "regular people." Letter writing, town hall meetings, rallies, and advocacy days in Washington, DC, or state capitols, characterize this model of social action.

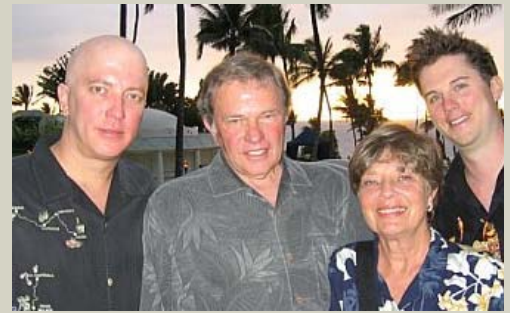
The National Alopecia Areata Foundation realized that it needed to tap into the potential strength of its membership. Alopecia areata is a rare autoimmune disorder that results, in its most severe forms, in the complete loss of body hair. The organization counted among its members many parents of affected children who were willing to get involved.

Coming to agreement on an objective was easy as the need to improve insurance coverage was high on every task team member's list of priorities. Though relatively new to public policy, the Foundation had achieved significant success in this area: several state laws had been enacted to require private insurance plans to cover the hair prostheses needed by people with the most severe forms of the condition.

Because of this success, the task team discussed working to enact similar laws in states around the country. But the team soon realized that such an effort would leave thousands of advocates unable to participate. Because a 50-state strategy was not possible given the organization's resources and capacity, there would be no activity on which to work for thousands of potential advocates in non-targeted states.

The task team agreed that while such an effort could lead to the enactment of state laws, the long-term costs could be significant. Instead, the task team opted to develop an all-inclusive initiative, one in which everyone affected by alopecia areata could participate. By doing so, the Foundation believed it would begin to create a culture of advocacy that could be tapped in the future.

But how to create such an initiative? The organization's task team of volunteers and staff discussed ways in which the overarching



Advocate Profile: Tom and Matt Kelley

Imagine waking up and finding all your hair gone. That's what happened to 38-year old Matt Kelley in 2006.

Since being diagnosed with alopecia areata *universalis*, Kelley has become a superstar advocate for the National Alopecia Areata Foundation. In addition to volunteering his time at the Foundation's headquarters, Kelley has made advocacy a high personal priority.

The grassroots technical assistance grant enabled Matt, and his father Tom, to play a leading role in the Foundation's advocacy efforts. Knowing the Foundation needed a bill sponsor in Congress, Matt asked his father to approach Representative Anna Eshoo from California.

"I've known Anna since the 1980s when I was a school board member and she was a county supervisor," Tom said. "I felt uncomfortable using my friendship," he said, "but when something like this hits close to home, it makes it more real." Thanks to Tom and Matt's involvement, Representative Eshoo agreed to introduce HR 5936, the Alopecia Areata Medicaid Parity Act.

According to Matt, HR 5936 has galvanized the alopecia areata community. "It's validated the condition [and] a lot of people are rallying around the bill, trying to get their representatives to support it," he said. "This is a big deal for our community."

policy objective (improving insurance coverage) could be revised and made more inclusive. They ultimately decided to seek enactment of a federal law to improve Medicaid coverage for hair prostheses.

At first, the decision to focus on Medicaid may seem strange. Medicare covers many more people than Medicaid, but few children, a challenge for an organization in which parents play an active role. A federal insurance mandate, requiring coverage by all private insurance carriers, was ideal but likely unachievable given the political climate and Foundation's capacity to affect policy.

Focusing on Medicaid had its advantages. Improving coverage would be relatively inexpensive as approximately 5,000 people with the most severe forms of alopecia areata (*universalis* or *totalis*) rely on Medicaid for coverage. And because many private insurance plans use Medicaid (and Medicare) as a guide for making coverage decisions, improving Medicaid coverage would impact private coverage nationwide.

Most importantly, focusing on improved Medicaid coverage would enable everyone in the organization to get involved in the campaign. Once introduced, the organization would mobilize every advocate to contact his or her member of Congress to cosponsor the legislation. As the number of cosponsors grew, the Foundation would seek to have it attached to another bill or enacted as a stand-alone measure.

The benefits of the inclusive strategy emerged shortly after it was introduced to the community at large. Foundation members Patti Serna and Tom and Matt Kelley, none of whom had been particularly active in the Foundation's advocacy efforts, shared with legislators their personal stories of being parents of children with alopecia areata.

Those legislators, Representatives Heather Wilson from New Mexico and Anna Eshoo from California, eventually co-introduced HR 5936, the Alopecia Areata Medicaid Parity Act. As members of the Energy and Commerce Health Subcommittee, they were well positioned to advance the bill in Congress,

Through their grassroots efforts, 18 representatives agreed to cosponsor HR 5936 in the waning days of the last congressional session and the Foundation is prepared to build upon this success in 2009.

getting focused

Children and Adults with Attention Deficit Hyperactivity Disorder (CHADD)

What are you known for?

For some organizations in Washington, DC, that can sometimes be a tough question to answer. Are you known for your work on improving Medicaid, Medicare, or private insurance coverage? Do your efforts focus on increased funding for medical research at NIH or the Department of Defense? What about ending discrimination, improving Social Security benefits, or enacting state laws that benefit your constituents?

Or is it all of the above?

In our information saturated era, it is extremely difficult to deliver a consistent message to policy makers. Focusing on one key policy area, and marshalling the lion's share of your resources towards its achievement, is critically important and often an overlooked strategy. Doing so allows you to build a solid "brand" among policy makers and advocates.

For organizations just getting started in advocacy, developing a single-minded focus and creating a brand identity isn't terribly difficult. With little history in the advocacy arena, there are fewer turf battles and vested interests, making it easier to get everyone to focus on one key issue. However, it can be much more difficult for organizations with an existing advocacy program.

Children and Adults with Attention Deficit Hyperactivity Disorder (CHADD) has been active in public policy for many years. The organization has a long history of affecting change and a strong staff presence in Washington, DC. It also collaborates on many issues with other mental health organizations.

While CHADD has developed a presence in the nation's capital, it has engaged in relatively little advocacy at the state level. The group therefore made a strategic decision to utilize the NHC Grassroots Technical Assistance grant to build its capacity at the state level. With its year-long legislature and a strong volunteer presence, Pennsylvania would serve as the "testing group" for such an effort.

A diverse team of staff and volunteers was developed to create and implement the state effort. Given the large number of medical and educational issues affecting people with attention deficit/hyperactivity disorder (AD/HD), and the task team's diverse membership, the group wanted to focus on multiple issues



Advocate Profile: Natalie Knochenhauer

With four kids, all diagnosed with attention deficit/hyperactivity disorder, Natalie Knochenhauer doesn't have a lot of free time on her hands. But what little time she does have has been put to good use.

Since taking a lead role in CHADD's grassroots technical assistance efforts in Pennsylvania, Knochenhauer has helped get a bill introduced, secured 60 cosponsors, and appeared on a public affairs television program in Philadelphia.

An attorney by profession, Knochenhauer credits the simplicity of CHADD's objective and message as central to their success. "Improving coverage for part-time college students is easy to understand and explain," she said. "The truth is, you don't need to work on ten issues at a time to be an effective advocate."

Focusing on just one simple policy objective "has opened doors with teachers, principals, and the general public to discuss other issues affecting people with AD/HD," Knochenhauer said. "It has also allowed us to build our volunteer infrastructure and generate media coverage."

As a result of these efforts, Knochenhauer has become the "go-to" person in Pennsylvania on issues relating to AD/HD and public policy. Now she just needs to find some more free time.

simultaneously and devote the bulk of its efforts to providing advocacy training to volunteers in Pennsylvania.

Overcoming this natural desire to tackle all problems at once took time and many conversations among group members. Everyone on the task team seemed to have a different perspective on which direction to follow. But ultimately the group agreed to focus their energy on enacting a law to allow part-time college students to remain on their parents' health plans.

With a single policy objective in mind, the group could now get down to work. Draft legislation was created and a simple message platform was distributed to all members of the task team. Personal stories describing the human dimension of the problem were also collected and distributed to policy makers and volunteers.

Within the course of a few weeks, the group had gone from possessing wildly divergent views to a single, clear, consistent message for policy makers and the public. In other words, a strong "brand." Without that alignment, it is unlikely that the group would have seen such great success in the program.

Shortly after it was created, state Senator Josh Shapiro agreed to introduce CHADD's legislation. As a senior member of the legislature's insurance committee, Shapiro was perfectly positioned to play a leadership role in securing its ultimate enactment.

Over the following weeks, CHADD members across the state were mobilized to take action and urge their elected officials to support the legislation. One volunteer in particular, Natalie Knochenhauer, spent countless hours building support for the legislation and generating significant media coverage.

While the legislation did not become law in 2008, legislators and advocates are poised to reintroduce the bill in 2009 with Shapiro's strong support. Because of their singular focus, CHADD is now known as the group in Pennsylvania fighting for this issue. Given their success to date, it only seems a matter of time before they will ultimately prevail.

"This is one of the most exciting developments in the seven and one half years I have been with CHADD."

*Clarke Ross, CEO
CHADD*

a roadmap to grassroots advocacy success

Strategic Advocacy Planning Blueprint

Do you want to initiate a grassroots campaign in your community? Do you want to enhance your current capacity to affect policy through the mobilization of constituents?

As part of the National Health Council's Grassroots Technical Assistance Program, each selected organization participated in a five-step strategic advocacy planning process. This process ensured the involvement of a diverse group of staff and volunteers, created consensus in the identification of an objective, and resulted in the creation of an advocacy campaign that the organization could launch to achieve its objective.

Below you will find the five steps included in the strategic advocacy planning process. By launching this process, you will be on your way to creating a successful campaign.

Phase 1 – Create a Working Group

Patient advocacy organizations launching a grassroots-based campaign are strongly urged to establish a working group to provide input and oversight into the project. Ideally such a committee will

- Include six to eight people, of which 50 percent are volunteers and 50 percent are staff.
- Have volunteers and staff with a range of experiences and responsibilities within the organization.
- Incorporate individuals with expertise in advocacy, income development, marketing, communications, and/or field activities.
- Meet four to six times annually by telephone or in person.
- Appoint as leader a staff member with responsibility for advocacy.

Phase 2 – Identify Your Objective

Once the working group is in place, it is vital to fully articulate what specific political/policy objective it seeks to achieve. During this phase, we worked each selected organization to:

- Create political objectives that address organizational/community challenges.
- Identify objectives on which you can have a demonstrable impact.
- Prioritize those objectives most likely to succeed given available resources.
- Differentiate among objectives, tactics, and strategies.
- Identify, solicit input, and secure support from key stakeholders.

Phase 3 – Develop a Campaign

Once an objective has been identified and internal support secured, a campaign must be developed. This should include both strategy and tactics. During this phase of the campaign, the National Health Council worked with each group to

- Develop a political strategy and relevant tactics.
- Organize a timeline of activities.
- Identify the roles and responsibilities of various stakeholders.
- Design political messages that best position the issue/organization.
- Identify potential campaign constituents, allies, and opponents.
- Construct short-, medium-, and long-term goals to measure success.
- Enumerate organizational resources that can help the campaign succeed.
- Ascertain ways in which the campaign can help build your organization.

Phase 4 – Secure Resources

Once developed, it will be important to identify and obtain the resources needed to achieve success. Campaign resources may include

- Grassroots advocates nationwide and in specific districts/states.
- Medical professionals with specific expertise.
- Individuals that have an existing relationship with a policy maker.
- Media and political spokespersons.
- Consultants with specific expertise (lobbyist, media relations).
- Political leaders.
- Financial supporters.
- Collateral materials (website, brochure, fact sheet, pins/buttons).
- Volunteers with specific expertise relevant to the campaign objectives.

Phase 5 – Implement Your Campaign

Once sufficient resources have been obtained, the campaign will be launched. Once launched, the task team will continue to assist in its implementation and provide oversight to the organization's leadership.

**To learn more about the campaign, please contact
Joseph LaMountain at jlamountain@nhcouncil.org or 202-288-5124.**



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