2009 YEAR IN REVIEW
it’s all about the patient
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December 2009

Life in 2009 has been exciting, to say the least. We’ve battled hard and long to ensure the patient voice is heard on Capitol Hill. For health care reform to be truly meaningful for our country, it must be patient focused.

This is why the National Health Council (NHC) created the Five Health Care Principles:

- Cover Everyone
- Curb Costs Responsibly
- Abolish Exclusions for Pre-existing Conditions
- Eliminate Lifetime Caps on Health Insurance Benefits
- Ensure Access to Long-term and End-of-life Care

These Five Principles are at the core of our Campaign to Put Patients First.

We’re extremely proud of the National Health Council’s accomplishments this year. The NHC has become a more vocal and visible player in Washington, DC. We have been invited by Members of Congress and the Administration to present the views of the patient advocacy community on a broad range of issues. We have received an ever-growing number of invitations to discuss issues of importance to the patient community at influential meetings, including those held with ranking House and Senate committee members; new leadership at the Food and Drug Administration and National Institutes of Health; the Institute of Medicine; and before federal committees setting new national policies.

The 2009 accomplishments of the NHC are documented in the following pages. They are the collective results of an invigorated membership, an engaged Board of Directors, and the passion of the patient community we all serve.

As we move into a new year, we welcome your continued advice and input. It is only by combining our strengths and connecting with patients that we will be celebrating many more successes in 2010.

Sincerely,

Cindy Brownstein
NHC Chairperson
and
President & CEO
Spina Bifida Association

Myrl Weinberg, CAE
NHC President
Giving Patients a Voice

Campaign to Put Patients First

The Campaign to Put Patients First is dedicated to engaging people to help create and implement a modern health care system that meets the needs of patients. In 2009, the National Health Council (NHC) launched its new website, including a section devoted to the Campaign. These pages give patients with chronic diseases and disabilities and their family caregivers an opportunity to express their concerns to their elected officials, sign a petition in support of the NHC’s Five Health Care Principles, and share their personal stories.

Amalia from California wrote, “Managing a child with a chronic, congenital condition is full time. Managing and advocating through the maze of insurance is full time. It’s worth it, of course, but the ‘business’ of managing is wrong. Who suffers? Our patients. Please pass the [National Health Council’s] Five Health Care Principles.”

David from Texas stated, “I am a 45-year-old male who has hydrocephalus. I am also bipolar and have diabetes. My medication costs are beyond belief. Last year alone we spent $11,000 in out-of-pocket medical care. . . I didn’t ask for this. Who knows how long my demise will take, but I certainly don’t want to leave my wife in a financial bind. Make [health reform] a reality.”

Annette from Tennessee shared this: “I have an autoimmune disease called interstitial cystitis with intractable pain. I paid $1,172.00 each month for insurance and I’m unemployed. Now, I cannot even find a prescription drug plan that pays for my medicines. I am disabled and soon broke from paying for pricy medicines! What do I do? Please join me and ask for health care for seniors and disabled people.”

These are just a few of the many stories that were submitted by patients who visited the Campaign to Put Patients First website. They join the

- More than 4,600 people who have signed the NHC’s Petition for Health Care Change
- Nearly 14,000 people who have visited the Campaign web pages
- More than 2,700 people who have learned about contacting their elected officials
- More than 1,600 followers on Twitter, including several media sites
- Nearly 400 fans on Facebook

Social media was used to encourage patients to attend a congressional town hall meeting in their home district or talk with their members of Congress at public events about the need for health care reform.

As lawmakers prepared to return home for the August recess, the NHC launched its first ever Call on Congress using toll-free phone lines. Nearly 800 calls advocating for the NHC’s Five Health Care Principles were made in two weeks to elected officials.
Corporate Partnerships

In addition to giving patients a voice in the development and implementation of health care reform, the Campaign to Put Patients First is designed to engage employees in education and wellness programs that can improve their health, reduce their stress, and increase productivity, while providing employers with a way to demonstrate their concern. The program includes an NHC-branded web-based service in cooperation with Lotsa Helping Hands that allows individuals to create private, online communities to organize assistance during times of medical crisis, end-of-life caring, or family caregiver exhaustion.

To support the Campaign, the National Health Council began enlisting partners from the health care community and corporate America to raise funds for employee health education efforts and awareness programs, and to support national and community events, which collectively allow the NHC to leverage its investment in improving the health and productivity of Americans.

Advertising and Collateral

To demonstrate to members of Congress and their staff that the greater patient advocacy community is united behind the NHC’s Five Health Care Principles, CEOs of NHC’s 48 member patient advocacy organizations all signed the Petition for Health Care Change. An advertisement of the petition listing the supporting organizations appeared in Politico, a DC newspaper widely read by members of Congress and political activists.

With the support of PhRMA, the NHC also placed advertisements in the Washington Post, USA Today, Wall Street Journal, Roll Call, and Politico urging Congress to address rising out-of-pocket health care costs.

The NHC also developed a Campaign mark that reinforces the well-known NHC logo for use on Campaign materials.
Influencing Public Policy

Meaningful Health Care Reform

The 111th Congress was sworn in on January 6 and immediately began work on an economic stimulus package that contained several items related to health care. The final bill included funding for health information technology. Funding for Medicaid as well as COBRA subsidies were included in order to help cover recently laid off workers. Comparative effectiveness research was funded in this package at $1.1 billion dollars.

In its continuing effort to provide a united voice for patients in the health care reform debate, the NHC held numerous meetings with members of the House and Senate and their staff, and submitted written comments to Congress, which are posted on the NHC website. All of the NHC’s Five Health Care Principles were addressed in the health care reform legislation voted on in the House and bill under consideration in the Senate in early December.

In particular, the NHC addressed how to create a value-based health care delivery system that meets the needs of people with chronic diseases and disabilities. NHC staff created a pictorial diagram that incorporates the various delivery elements and used it in presentations to Members of Congress, their staff, and to health policy leaders.

The NHC’s comments strongly encouraged Congress to also address long-term support and services, and described how patient care could be advanced by expanding care management options and eliminating or reducing out-of-pocket expenses for people with chronic conditions. The NHC, as part of a national initiative, supported the study of 12 value-based plan models that documents how their integrated approach to care is reducing or eliminating patient out-of-pocket expenses and improving health outcomes while lowering overall health care costs.

NHC President Myrl Weinberg and Executive Vice President and Chief Operating Officer Marc Boutin met with the Obama transition team to discuss the future of the National Institutes of Health (NIH). Weinberg also gave a presentation to the Obama transition team regarding the Food and Drug Administration and participated on an Institute of Medicine (IOM) committee which produced a report proposing changes to the structure of the Department of Health and Human Services. In addition, she was a member of the FasterCures task force that called for a new mission and focus for the Intramural Research Program at the NIH.
Intellectual Property and Biosimilars

The NHC enlisted the help of a consultant to conduct a literature review on intellectual property law and biosimilars, focusing on how both issues could affect patients. The consultant also analyzed legislation on both topics to assist the NHC in its work to direct research into disease areas that have seen little progress, such as neurologic and autoimmune diseases. The NHC also developed a set of values used to screen bills on intellectual property law and biosimilars as they were introduced in Congress.

In early spring 2009, another consultant conducted primary research on behalf of the NHC, which included focus groups, in-depth interviews, and message development/testing on the broad area of innovation, addressing pharmaceuticals, biologics, and devices. These reports helped the NHC to direct, inform, and design its policy initiatives on intellectual property and biosimilars.

Using information from these various sources, NHC representatives met with the staff of key House and Senate members who introduced legislation on intellectual property and biosimilars and suggested changes to two major biosimilars bills. The bills were rolled into the major health care reform legislation before the House and Senate.

A separate case study report was developed using people with chronic diseases to illustrate how proposed legislation to address biosimilars may affect patients. The impact of intellectual property rules covering pharmaceuticals and the resulting impact on people with chronic conditions was discussed with the chief medical officers and researchers from member patient advocacy organizations. This discussion evolved into an examination of how the NHC could spur the creation of new treatments.

Doubling the Pipeline for New Treatments and Cures

Patients with chronic conditions have particularly strong interests in increasing their access to and fostering research on a full array of treatments to enhance their quality of life. A primary focus of many patient organizations includes supporting policies that ensure that new treatments are continually developed in the hope that each innovation will improve health and bring patients one step closer to prevention, early diagnosis, and cure.

To that end, the NHC retained a firm to provide an analysis of various laws and proposals that affect the development of new treatments in both the public and private sectors, and to help the NHC formulate recommendations and develop new legislation that promotes such research.

The NHC also retained another firm to conduct qualitative research, including focus groups and in-depth interviews, to better understand the views of people with chronic conditions about government incentives to encourage the development of new treatments by the private sector. While many patients have concerns about government-sponsored incentives to industry and prefer a more altruistic motivation to alleviate pain and suffering, all saw government as playing a necessary role in developing better treatments faster.

The NHC proposal speaks to the lack of incentives for developing unpatentable drugs or drugs whose development processes may exceed potential patent life. There is also ambiguity over the regulatory approval pathways and evidentiary standards for molecular diagnostic tests. A third area addressed in the NHC policy proposal looks at the widening gap between basic research and its application in clinical practice. This last item has been extensively researched by the
Parkinson’s Action Network, a member organization that greatly influenced the NHC’s thinking on the issue.

NHC President Myrl Weinberg, Executive Vice President and COO Marc Boutin, and Assistant Vice President for Government Affairs and Programs Kevin Cain met on September 2 with the new Food and Drug Administration (FDA) Commissioner Margaret Hamburg and the new Deputy Commissioner Joshua Sharfstein at FDA headquarters near Washington, D.C.

During the meeting, the group discussed ways that the NHC and the FDA can work together to create incentives to develop new treatments and improve the discovery pipeline, and ways to ensure the FDA has adequate resources to meet its mission, as the country moves toward more personalized medicine.

NHC leadership followed up with a second meeting with key FDA staff to discuss ways to advance the interests of the patient community in innovative new therapies for unmet needs, in cooperation with the FDA.

**Comparative Effectiveness Research**

To provide true value in health care, there must be a confluence of health research and a patient’s personal circumstances. A major legislative focus for the NHC in 2009 was comparative effectiveness research (CER) and how it can be appropriately used to enhance the delivery of health care.

NHC consultants conducted an analysis of current legislation and of bills introduced in Congress on this issue, as well as proposals for legislative changes.

By using this information and a set of values developed by the NHC’s Comparative Effectiveness Research Subcommittee, the NHC was able to craft and submit several letters and propose legislative language to the relevant congressional committees.

In addition, the NHC worked with its consultants to develop legislative language proposing guidelines on the usefulness of CER in clinical decision-making as well as a mechanism to appraise CER against such guidance. This legislative language would ensure that CER results are analyzed based on the extent to which findings are immediately relevant at the point of care before they are broadly disseminated and incorporated into practice and policy.

In March, NHC President Myrl Weinberg testified before the IOM committee charged with establishing priority research areas for CER and in April she testified before the Federal Coordinating Council for CER, emphasizing that the individual needs of patients and delivery system reform must be taken into consideration as part of the overall comparative effectiveness research process.

NHC was asked by the director of the Agency for Healthcare Research and Quality, Carolyn Clancy, to meet on CER and arranged a high level discussion with her and CEOs of member patient advocacy organizations at the NHC offices on April 20.

The NHC also arranged for a similar meeting with officials at NIH. The meeting included Dr. Lana R. Skirboll, acting director of the NIH Division of Program Coordination, Planning, and Strategic Initiatives, and Dr. Richard Hodes, co-chair of the NIH CER Coordinating Committee and director of the National Institute on Aging.
During the August congressional recess, NHC staff members conducted several meetings with congressional staff on CER. These included meetings with staff of the Senate Finance Committee and House Energy and Commerce Committee members, and with House Blue Dog Democrats.

NHC staff and member representatives were also invited to a collective meeting with staff members of the Senate Finance Committee and Senate Health, Education, Labor and Pensions (HELP) Committee. At this meeting, the NHC discussed policy positions on the governing entity for CER, as well as the proposal for usefulness guidelines as a part of a methodology committee. The NHC has continued to support a transparent and open CER governing process with strong patient and consumer representation.

Electronic Health Records

As the largest segment of consumers of health care, patients with chronic diseases and disabilities are logically the most likely candidates to benefit from electronic health records (EHRs). Almost half of those with chronic conditions have multiple medical co-morbidities, which means the use of EHRs becomes even more important and timely.

The NHC and eHealth Initiative embarked on a collaborative project to explore care coordination model programs powered by health information technology and the use of comprehensive patient assessment tools. The goal is to provide real examples where health care delivery was improved and cost savings were realized. Considerable research is being focused on how best to configure the EHR system for the provider, but the interest of the patient must not be lost and must be a driving force in the development of electronic health records.

The NHC submitted comments to the Office of the National Coordinator for Health Information Technology regarding the Health IT Policy Committee’s recommended timeline of requirements for meaningful use, as it relates to EHRs. The NHC commended the Policy Committee for focusing on improved quality, patient engagement, and coordination of care. However, the NHC letter also pointed out that significant transformation of the nation’s current health care system is not possible without incorporating comprehensive assessments and evaluations as a part of care coordination for those with chronic diseases and disabilities.

The NHC recommended that comprehensive assessments and evaluations be incorporated in the 2011 objectives and measures to improve care coordination. These assessments and evaluations can then be conducted and shared electronically among multi-specialty provider groups, patient, and family caregivers. These tools can also be expanded in the future to assess a patient’s interest or willingness to participate in clinical research.

Better Health Care by Design

The NHC and its members spent much of 2009 working on various elements of health care reform. Taking a step back, the NHC helped spearhead a new initiative called Better Health Care by Design that examines the growing burden of out-of-pocket medical costs and their impact on patients.

As part of the initiative, a free, weekly newsletter was created by Wyeth and the NHC to provide readers a timely snapshot of media reporting and analysis on the issues surrounding the impact of out-of-pocket costs on people with chronic diseases and disabilities and their family caregivers, providers, and employers.
This e-publication, *Better Health Care by Design*, helps NHC members and others concerned about the cost of health care stay abreast of the latest news on the economics of health care. To subscribe to *Better Health Care by Design*, go to [http://www.smartbrief.com/bhc bd](http://www.smartbrief.com/bhc bd).

**Appropriations**

The NHC worked with various stakeholders to present a united community in support of long-term, sustained increases in federal health research budgets. The NHC joined a new coalition called United for Medical Research (UMR) and worked with it and others to present statements of support for increased health appropriations for Fiscal Year 2010, including additional funds for NIH, Centers for Disease Control, and the FDA.

In August, NHC President Myrl Weinberg met with Rob Nabors, Deputy Director of the Office of Management and Budget, to discuss funding for NIH in FY 2011 and beyond. Also participating in the meeting were Darrell Kirch, president of the Association of American Medical Colleges; Mark Lively, president of the Federation of American Societies for Experimental Biology; and Howard Garrison, deputy executive director of public affairs of the Federation of American Societies for Experimental Biology.

In December, Weinberg and a select group of representatives from the UMR coalition held a high-level discussion with representatives from the President’s Office of Science and Technology Policy (OSTP) about the importance of establishing a long-term commitment to medical research, if the nation is to solve its health care, jobs, and economic challenges. The group approached the Administration about creating a signature Presidential initiative to highlight the importance of medical research. Other attendees at the meeting were Jim Kohlenberg, chief of staff, OSTP; Michale Stebbins, assistant director for biotechnology, OSTP; Jennifer Gera with the Health Division, Office of Management and Budget; Jeff Crowley, director, Office of National AIDS Policy and a senior advisor on disability policy; Clyde Yancy, MD, president, American Heart Association; Steve Fluharty, associate vice provost for research, University of Pennsylvania; Pat White, vice president for federal relations, Association of American Universities; Janet Lambert, vice president for government relations, Life Technologies Corporation; and Melanie Nathanson, managing director, The Glover Park Group.
Supporting the Patient Advocacy Community

Impact of the Economy on VHAs

The National Health Council began tracking the impact of the nation’s economic downturn on member voluntary health agencies (VHA) in January 2009. A survey report, The Impact of Today’s Economy on Voluntary Health Agencies, was presented at the NHC’s Annual Voluntary Health Leadership Conference.

Seventy percent of respondents to the survey of VHA CEOs said the economy was having a negative impact on their ability to achieve their mission. Expectations were that the downward trend in revenue generation would get worse during 2009.

In fact, by the time the survey results were discussed at the VHA Committee meeting in February, most CEOs were saying that the impact was turning out to be considerably worse than indicated by the survey. Many VHAs had cut travel and administrative expenses and imposed hiring freezes or staff lay-offs.

The survey was repeated in July 2009, with higher participation by the VHAs. The July survey results showed the impact of the economy on VHAs was broader and deeper than originally reported. Seventy-seven percent of the survey participants had eliminated or reduced salary increases, 50 percent had instituted a hiring freeze, and 46 percent had laid off staff. On a positive note, 47 percent of the VHA respondents expect the trend in revenue generation to get better in 2010, and 37 percent expect it to say the same.

Under NHC policy, every three years there is an automatic dues increase based on the cost of living index. Because of the impact of the economic downturn, the NHC Membership Committee recommended and the Board of Directors concurred moving forward only with the dues increase for the Business and Industry membership category. The dues increase for the other membership categories will be postponed until 2011.

Guidance on Research Grant Overhead

Many of the member patient advocacy organizations allocate significant portions of their budget to fund scientific research to find treatments and cures for devastating chronic diseases. These research grants often include charges to cover overhead expenses at the academic institutions where the researchers are housed. The fees can vary widely.

At the request of a group of voluntary health agency CEOs who attended the Voluntary Health Leadership Conference in February 2009, the NHC undertook an examination of the issues surrounding research grant overhead with an eye to developing best practice guidance to inform VHA negotiations with research institutions.

A survey of NHC member VHAs was conducted in April, and additional data was gathered from the Health Research Alliance. The results were analyzed and a draft guidance paper was circulated to all VHA CEOs and other selected members for comment.
The final guidance document and a summary of the comments were presented at the June meetings for approval by the Membership Committee, the VHA Committee, and the Board of Directors.

**HealthResearchFunding.Org**

The number of NIH grants that are deemed significant and of scientific and technical merit far exceeds the number that can be funded within the NIH budget. The NHC is partnering with the NIH Office of Extramural Programs in developing a database that would make information on unfunded but worthwhile NIH research proposals available to the NHC’s members and other potential funders of health research.

Once underway, this database will facilitate the exchange of information between potential funders and investigators. Health research funding sources can avoid duplication of effort and more efficiently identify valuable research projects to fund. In addition, investigators and their respective research institutions can spend less time, effort, and resources looking for funding, and more time conducting research.

The NHC is working with an experienced health IT firm to develop an NHC-branded website for the database project. NHC staff will begin testing the site with the group of scientific officers and research directors from NHC member organizations. Once testing is complete, NIH will notify all non-funded applicants deemed significant and of scientific and technical merit of the availability of the database. The plan is to fully launch the database to NHC members in early 2010.

**Member Job Bank**

The NHC launched a special page on its website in 2009 for member organizations to post job openings. The idea of the Job Bank is to foster the unique talent pool among member health organizations. The Job Bank helps patient advocacy groups connect with talented and experienced people – and vice versa. From its launch last summer through October, more than ten organizations had posted job openings, and the Job Bank registered as one of the top landing pages for the NHC website.

**Standards of Excellence™ Certification Program**

The National Health Council’s Standards of Excellence demonstrate that member VHAs are committed to the highest standards of transparency, accountability, and public stewardship.

Progress toward 100 percent compliance continued in 2009 with three additional VHAs gaining recognition for having fully met the standards: the American Liver Foundation, National Hemophilia Foundation, and Spondylitis Association. In addition, at year’s end, eight VHAs were undergoing their three-year compliance recertification reviews. About two-thirds of member VHAs had completed revisions to their corporate relations policies to bring them into compliance with the NHC’s revised standard on corporate relationships.

During 2009, the NHC undertook an examination of VHA practices regarding payment of overhead charges in research grants. The resulting guidance document included recommendations that maximize the percentage of funds used for the direct costs of research, balancing donor expectations with the needs of the research institutions receiving the grants.
To ensure a voice in the self-governance debate beyond the voluntary health sector, NHC President Myrl Weinberg continued serving on Independent Sector’s Ethics and Accountability Committee and was selected to serve on the Better Business Bureau’s Wise Giving Alliance Panel on Charity Effectiveness.

**Voluntary Health Leadership Conference**

Twenty-eight of the patient advocacy organization members of the National Health Council participated in the 22nd Annual Voluntary Health Leadership Conference in February 2009.

This unique event offered organization CEOs and their volunteer leaders unprecedented access to high-level national health care thought leaders to discuss the top issues of the day – from health care reform to health research. The conference also provided an unparalleled opportunity for peer-to-peer networking, sharing of best practices, and volunteer development.

The meeting touched on the broad range of NHC initiatives, including an update on the Campaign to Put Patients First. Guest speakers included:

- Mark McClellan, MD, former administrator for the Centers for Medicare and Medicaid Services and former commissioner of the Food and Drug Administration;
- Harvey Fineberg, MD, president of the Institute of Medicine;
- Mark Fendrick, MD, the co-editor in chief of the *American Journal of Managed Care* and co-director of the Center for Value-based Insurance Design.

**Chief Scientific/Medical Officers and Research Directors Meeting**

The annual meeting of the chief scientific/medical officers and research directors from VHA member organizations was held in October. Discussion focused around the lack of incentives for developing unpatentable drugs or drugs whose development processes may exceed potential patent life, overcoming the abyss between laboratory research and clinical practice, the NHC document on Guidance on Research Grant Overhead, and the cooperative database project with the NIH.

**Chief Financial Officers Meetings**

Top finance executives from the NHC’s member VHAs gathered twice in 2009 to hear presentations on timely issues impacting nonprofit business, human resources, and administration. The first meeting was held in May in Alexandria, Virginia, and attendees were presented with the results of the NHC’s survey, The Impact of Today’s Economy on Voluntary Health Agencies. The resulting conversation covered such issues as how organizations are dealing with the current economic crunch, including the options of cutting costs, conserving resources, maximizing investment options, and diversifying income streams. Courtesy of the Alpha-1 Foundation, each attendee was provided a copy of the book *Zone of Insolvency*.

The second meeting of the CFOs was held in October in Washington, DC. NHC provided an update on the economic impact study, which was repeated in the summer. Richard Larkin, CPA, technical director for not-for-profit accounting at the Institute for Nonprofit Excellence, gave a presentation on accounting and auditing. Kenneth Euwema, vice president of membership.
accountability at United Way Worldwide, discussed operating reserves as an imperative for financial stability.

**Washington Representatives Retreat**

The 2009 Washington Representative Retreat is scheduled for December 3 and 4 at the Inn at Perry Cabin in St. Michaels, Maryland. At that time, government affairs representatives from member patient advocacy organizations will examine the current status of various issues, including health care reform, the FDA’s work on innovation and comparative effectiveness research. Guest speaker for the retreat is Rachel Behrman, associate commissioner for clinical programs and the director of the Office of Critical Path Programs at the FDA.

**2009 Management Compensation Survey**

The newly designed federal form 990, which must be filed by non-profit organizations, asks whether an organization uses comparability data for determining the compensation of staff.

The National Health Council annually releases a benchmarking report of compensation practices across a spectrum of approximately 90 mid-level and executive positions. The report, a joint effort by the NHC and the National Human Services Assembly, includes data from both VHAs and human service organizations, such as the Salvation Army.

This year 53 national organizations located around the country participated in the survey, the highest participation of NHC members since the report’s inception. In keeping with past practice, one free copy of the *Management Compensation Report* was sent to all participating VHAs. For all others, the report is available at the member price of $100 ($125 for nonmembers) and by going to the NHC website at http://www.nationalhealthcouncil.org/pages/publications.php.

**2008 VHA Revenue Report**

To help patient advocacy groups benchmark their revenue streams against those of their peers, the NHC also produced the *2008 VHA Revenue Survey*. Forty-two member organizations took part in the annual study, which covered revenues for fiscal years 2006, 2007, and 2008. All VHA members received a generic report detailing aggregate revenue data as a member benefit. However, participants in the survey also were given a customized report comparing their results with their peer group (small, medium, large and extra-large organizations) — and all survey participants in general.

**Health Groups in Washington Directory**

Since its first printing in 1975, the NHC’s *Health Groups in Washington* directory has become recognized as the single, most useful resource for locating major, non-governmental health-related organizations in the Washington metropolitan area. The directory is published every other year and was updated in November 2009. Approximately 900 organizations and businesses are included in the most recent edition, which is available in both print and electronic format. Ordering information is available by going to the publications page on the NHC website at http://www.nationalhealthcouncil.org/pages/publications.php.
**BoardSource Partnership**

BoardSource membership provides nonprofit organizations with the tools they need to build a high-performing board. Members use its resources and services to find solutions, leadership tips, and governance knowledge about board-related issues.

Twenty-five National Health Council member organizations have enrolled their board members and key staff at the national and chapter levels using the special NHC offer.

**International Alliance of Patients’ Organizations**

The International Alliance of Patients’ Organizations (IAPO) continues to grow in influence within the worldwide health care community as the international voice for patient-centered care. In 2009 NHC President Myrl Weinberg completed her two-year term as chair of the IAPO Governing Board. She continues to serve on the Governing Board as immediate past chair.

In 2009, IAPO developed new and updated existing policies and procedures, many of them similar to those NHC requires its members to adopt in order to meet the NHC Standards of Excellence™. One of the newest IAPO policies supports the involvement of former Board members on external committees and their participation at external events.

In May, IAPO hosted a unique, influential gathering of representatives from patient organizations and the World Health Organization (WHO). The meeting in Geneva, Switzerland, was held just prior to the WHO World Health Assembly and offered WHO representatives an introduction on how patients can be powerful allies in setting public policy.

IAPO also created a Policy Statement on Patient Information that addresses the importance of presenting patient information in an appropriate format, according to health literacy principles that consider the individual’s condition, language, age, understanding, abilities, and culture. NHC staff was asked to review and supply comments on the draft policy.

In October, IAPO together with four regional patient organizations, held a regional workshop in Buenos Aires, Argentina, for patient groups in Latin America. Bringing together 27 patient groups from 11 Latin American countries, the workshop continued IAPO’s work to support patient groups. The IAPO Governing Board also met concurrently with the workshop, with Weinberg in attendance.

The NHC was honored to host IAPO’s Chief Executive Officer Joanna Groves for a day during her business trip to Washington, DC, in early August.
Providing a United Presence

NHC Website

One of the key vehicles used by nonprofit organizations for information dissemination is the World Wide Web. After months of planning and detailed work in 2008, the NHC launched its new website in January 2009.

![New NHC Website Screenshot]

The new site provided the NHC with greater flexibility in providing information to patients, members, and the general public. It allowed for quicker turn-around in posting important materials that document the NHC’s involvement in public policy.

The new site also gave staff opportunities for promoting NHC members and their work in a Resource Directory, on-line membership lists, and on the Campaign to Put Patients First web pages. NHC staff added rotating logos of member patient advocacy organizations to the Campaign site to bring greater visibility to their involvement in the initiative.

Staff has begun working with its web designer to create a new function on the NHC website to give patients the opportunity to support the NHC’s activities through donations.
Presentations

In 2009, the NHC saw a marked increase in the number of requests for staff to present before influential health care groups. In addition to testimony presented before federal bodies, NHC staff presentations were given in the past year before the following organizations and events:

- Drug Information Association Annual Conference for Contemporary Pharmacovigilance and Risk Management Strategies
- FDA Sentinel event co-sponsored by eHealth Initiative and the FDA and convened by the Engelberg Center for Health Care Reform
- Better Health Care by Design Initiative media event
- Aspen Health Stewardship media event
- Aspen Institute Health Forum Highlights event
- Direct-to-Consumer Genetic Testing panel discussion at the Roche Science and Ethics Advisory Group
- Panel discussion on health reform, hosted by GE and moderated by NBC White House Correspondent Chris Reid
- 2009 Patient Advocacy Leadership Summit
- 2009 PhRMA Annual Conference
- BIO briefing on biosimilars
- Faster Cures briefing on the Institute of Medicine HIPPA report
- National Youth Leadership Forum on Medicine
- National Pharmaceutical Council Symposium on CER and congressional staff briefing on CER
- 2009 RAND Conference Prescription for Healthier Patients: Real Solutions for Better Medication Adherence
- NIH Scientific Management Review Board Working Group on Deliberating Organizational Change and Effectiveness
- American College of Cardiology Medical Directors Institute
- Council for American Medical Innovation congressional staff briefing on incentives
- Oregon Rheumatology Alliance Summit on Advocacy
- Fall Conference of the Center for the Study of the Presidency and Congress
- Power of Partnering Regional Meetings in Suffern, New York, and Chicago, Illinois

In The News

Because of its work in the public policy area, the NHC was called upon to provide comment and insight on important health care issues of the day. Here are some of the publications where the NHC appeared in 2009.

- NHC commentaries in the American Journal of Pharmacy Benefits about biologics, health care delivery reform, individual care plans, and comparative effectiveness research
- NEHI Member Spotlight — New England Healthcare Institute
- Healthcare Reform at What Cost? — NonProfit Times
- Healthcare Reform: A Crash Course in Manufacturing Uncertainty, as published in the— American Chronicle
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- Influence Game: Biotech Drug Lobbying War — Associated Press
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• Congress and the Council for American Medical Innovation Begin the Debate Over Reforming the Nation's Health Care System— Washington Times
• Comparative Effectiveness: Its Origin, Evolution, and Influence on Health Care — Journal of Oncology Practice
• Prescription Savings Program Expands Eligibility Criteria, Responds to Challenging Economic Times— Medical News Today
• Council for American Medical Innovation Debuts Amid Calls for Focus on Economic Growth, Finding Cures— DigiTAL50
• President Hosts Forum to Work on Health-Care Changes — Arkansas Democrat-Gazette

**New Members in 2009**

The strength of the NHC comes from the fact that it provides a dynamic forum in which all stakeholders can meet for reasoned discussion, effective collaboration, and persuasive advocacy. We are honored to have the following organizations and businesses join in this past year in our collective effort to provide a united voice for people with chronic diseases and disabilities and their family caregivers.

Voluntary Health Agencies

• National Organization for Rare Disorders
• Parkinson’s Action Network

Professional and Membership Associations

• American Academy of Hospice and Palliative Medicine
• American Association on Health and Disability
• The Blue Cross Blue Shield Association
• Consumer Healthcare Products Association
• National Alliance for Hispanic Health
• WomenHeart: The National Coalition for Women with Heart Disease

Nonprofit Organizations with an Interest in Health

• Hospice Foundation of America

Business and Industry

• Forest Laboratories
• Takeda Pharmaceuticals North America, Inc.