

2010 Year End Review

National Health Council

The Advent of Health Care Reform

December 2010



Table of Contents

Overview from the Chairperson and the President	3
Putting Patients First®	
Health Care Reform	4
Delivery System Reform	4
Essential Health Benefits.....	5
Comparative Effectiveness Research	5
Reauthorization of PDUFA	6
New Treatments and Cures	6
Appropriations.....	7
NHC/WebMD A Patient Voice Exchange.....	8
Supporting the Patient Advocacy Community	
Impact of the Economy on VHAs	9
Standards of Excellence™ Certification Program	9
Voluntary Health Leadership Conference	10
HealthResearchFunding.Org.....	10
Chief Scientific/Medical Officers and Research Directors Meeting.....	11
Chief Financial Officers Meetings	11
Washington Representatives Retreat.....	12
Member Communications Staff Meeting	12
2010 Management Compensation Survey	12
2009 VHA Revenue Report	12
<i>Health Groups in Washington</i> Directory	13
Member Job Bank	13
BoardSource Partnership.....	13
Strengthening Partnerships	
International Alliance of Patients' Organizations.....	14
Presentations	15
NHC in the News	16
New Members.....	16

Overview from the Chairperson and the President

December 2010

We all heard the cry of patients in 2010. The people with chronic conditions that we all serve and the patient advocacy community faced numerous challenges – political, economical, and even emotional.

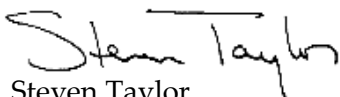
- **Christina from North Carolina:** I was born with a genetic condition compromising the integrity of my aorta. I have needed many surgical interventions and depend on medicine to survive. I am alive with a decent quality of life thanks to good doctors and good insurance. I urge you to Put Patients First in health care and continue all efforts to improve our nation's health care delivery system. Millions of us depend on health care excellence for life.
- **Margaret from Florida:** As a COPD caregiver, I am faced with numerous challenges....concern that my husband's oxygen needs may no longer be covered by Medicare, plus research money is limited for COPD and must be increased!
- **Jay from Pennsylvania:** I am now on permanent disability. I just about afford my medicines, co-pays, and hospital bills I owe. Psychologically I now bear the awkwardness of stares due to a deformity caused by surgeries on my head. I have worked hard all my life and always paid my taxes. There are more surgeries to come. I hope this letter and you can help.

This past year was a watershed for health care reform, and through it all, the National Health Council served a vital role of uniting us to fight for pragmatic solutions to better the lives of people with chronic diseases and disabilities and their family caregivers.

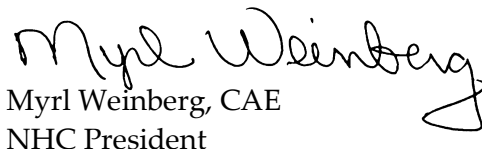
We can proudly say we have made a significant difference in moving our country toward implementing a more effective, efficient, and comprehensive health care delivery system that is truly patient-focused.

But this is just the beginning. Much is still left to do. We welcome your continued support and input in 2011 as we move forward with health care reform implementation.

Sincerely,



Steven Taylor
NHC Chairperson and
President & CEO
Sjögren's Syndrome Foundation



Myrl Weinberg, CAE
NHC President

Putting Patients First®

Health Care Reform

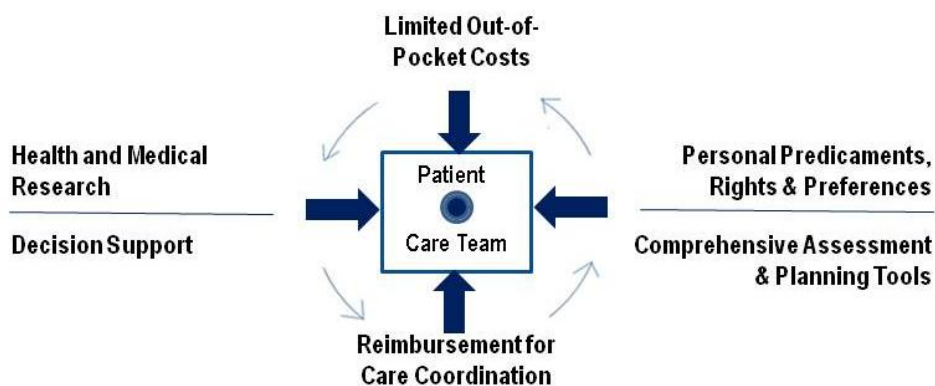
After more than two years of Congressional debate, President Obama signed into law in March 2010 the Patient Protection and Affordable Care Act (ACA), the most comprehensive legislation tackling this nation's health care system since the enactment of Medicare. Guided by its Five Principles for Putting Patients First®, the National Health Council (NHC) was intensely involved in the process to influence the legislation. The NHC is proud to say that all five of the Principles were addressed by the ACA, and much of NHC's proposed language was included in the law.

In mid-2010, the legislation started down the long road of regulatory rule-making. This will be a very challenging process for all NHC members. The NHC has moved into this phase with a focus on three priority areas of implementation: (1) delivery and reimbursement system reform; (2) the design of the essential health benefits package that all insurers must cover for the insured; and (3) comparative effectiveness research (CER).

Delivery System Reform

The passage of ACA was only the first step in health care reform. In the second half of 2010, the focus shifted to implementation of the new law.

To help explain what a patient-focused health care system should be, the NHC created a pictorial diagram that incorporates the various delivery elements and used it in presentations to Members of Congress, their staff, the Administration, and to health policy leaders.



From the patient's perspective, the NHC views true value in health care (as represented by the center dot in the illustration above) as the incorporation of both health research and the patient's personal circumstances, which include the individual's genetic, ethnic, religious, and social-economic status at the point of care. This scenario is balancing sound science (left side of the illustration) with patient-focused application (right side). The best care coordination, as the NHC describes it, combines medical research, clinical

expertise, and patient preference within a delivery system that pays for integrated care (bottom of illustration) and rewards compliance and adherence with limited or no out-of-pocket expenses (top).

The NHC has also created a tool to evaluate emerging health care delivery system models to determine whether or not they meet the needs of patients with chronic conditions. This analytic tool, in conjunction with the NHC's Five Principles for Putting Patients First®, will continue to guide the NHC in its efforts to advocate for health care delivery system reform.

Essential Health Benefits

In 2010, the NHC also worked with its consultants to draft a white paper on how the Secretary of Health and Human Services (HHS) could define “essential benefits” as required under ACA. The white paper was shared with NHC members as part of the NHC's initiative to create regulatory language to ensure essential health benefits are comprehensive enough to cover the needs of people with chronic diseases and disabilities.

In November, the NHC held a special meeting of VHA members to discuss how the definition of essential health benefits by the federal government may impact specific disease and disability communities that have already established state mandates to cover their condition. The NHC also submitted comments to HHS, the Institute of Medicine (IOM), and the National Committee for Quality Assurance (NCQA) for their work on defining essential health benefits.

Comparative Effectiveness Research

During the debate over health care reform legislation, the NHC made comparative effectiveness research (CER) a major focus. This initiative is an effort to ensure people with chronic conditions receive care that is based on evidence, yet recognizes the need for flexible decision-making by health care professionals in order to address a patient's unique circumstances and needs.

The NHC's CER Subcommittee developed a set of values to analyze CER legislation and the NHC advocated for language in the health care bill that would require that a newly created CER entity determine whether generated research would be useful at the point of care. This entity, the Patient-Centered Outcomes Research Institute (PCORI), was developed as a non-profit institution and, consistent with NHC's recommendation, was placed outside of any government agency. At the NHC's urging, the PCORI Board of Governors includes three seats dedicated to patient/consumer representatives.

The NHC played an active role in the nomination process for the PCORI Board of Governors. The NHC nominated five individuals to serve on the Board. On September 23, the Government Accountability Office released the names of the 19 members of the inaugural Board of Governors. Representatives from two NHC members, the Friends of Cancer Research and Pfizer Inc, were named to the Board.

In addition, NHC President Myrl Weinberg served as a member of the HHS National Advisory Council for Healthcare Research and Quality. NHC Executive Vice President and Chief Operating Officer Marc Boutin was selected to serve on the the Agency for Healthcare Research and Quality (AHRQ) Effective Health Care Program Stakeholders Group, which provides input on the AHRQ Effective Health Care Program (EHCP). EHCP funds individual researchers, research centers, and academic organizations to work together with AHRQ to produce effectiveness and comparative effectiveness research for clinicians, consumers, and policymakers.

Reauthorization of PDUFA

Beginning in the summer of 2010, the Food and Drug Administration (FDA) started to lay the groundwork for the next reauthorization of the Prescription Drug User Fee Act (PDUFA). The FDA held monthly meetings where stakeholders could discuss provisions that should be included in reauthorization. The NHC has been an active participant in these meetings.

Before the first meeting, the NHC developed a set of priorities to use throughout the discussion process. One main focus for the patient advocacy community is adjusting the benefit-risk evaluation to be stratified for different therapies. The stratification would be based on a variety of factors, including the severity of the condition the therapy treats and the existence of competing treatments. Based on previous research involving people with chronic conditions, the NHC believes that a patient with a debilitating or life threatening disease with few treatment options will have a higher tolerance for risk than a generally healthy health care consumer.

Another focus of the patient advocacy community in the reauthorization process has been updating regulatory science at the FDA through the use of emerging technology. The NHC is promoting adaptive clinical trial designs that use biomarkers as a surrogate endpoint.

At the September stakeholder meeting, the FDA released a set of 17 potential PDUFA enhancements. These were 17 proposed policy options that the FDA may decide to insert into the PDUFA agreement. The NHC was pleased to see that both regulatory science and adjusting the benefit-risk equation were addressed within these proposals.

New Treatments and Cures

People living with chronic conditions have a particularly strong interest in increasing their access to and fostering research on a full array of treatments to enhance their quality of life. Many patient advocacy organizations focus on supporting policies that ensure 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.

In 2007, the chief scientific/medical officers and research directors of the NHC's member patient advocacy organizations (also known as voluntary health agencies or VHAs) asked the NHC to

develop policy solutions that would dramatically increase the number of cures and treatments available to patients. The NHC responded by creating proposed legislative language in 2010 that has been named the Modernizing Our Drug and Diagnostic Evaluation and Regulatory Networks (MODDERN) Cures Solution.

The MODDERN Cures Solution addresses the lack of incentives for developing unpatentable drugs or drugs whose development processes may exceed potential patent life. The proposed legislation also seeks to eliminate ambiguity over the regulatory approval pathways and evidentiary standards for molecular diagnostic tests.

With the help of consultants, the NHC spent much of the year modifying the legislative text based on robust input from NHC members, other members of the health care community, staff from Congressional offices, and the FDA. The NHC believes that the proposed legislative language will greatly benefit patients and will not warrant opposition from any stakeholder group, including the pharmaceutical, biotechnology, and device industries as well as generic drug makers.

The NHC has met with Congressional staff from both parties in both the Senate and the House of Representatives, attempting to gauge interest in the legislation, seek input, and ultimately find a bipartisan group of Members of Congress to introduce the bill. The NHC has also met with senior staff from the FDA, National Institutes of Health (NIH), and the White House and received substantive feedback which was used to modify the draft language.

Appropriations

Much of the health research community was united around a request to increase funding for the NIH by seven percent in fiscal year 2011 (Oct. 2010-Sept. 2011), which would result in an NIH budget of \$35 billion. The NHC supported this increase and also urged the patient advocacy community to support this level as well. As a member of United for Medical Research (UMR), NHC also helped prepare a letter signed by more than 20 governors in support of a funding increase at least equal to the President's budget request, which was a 3.1 percent increase. This letter was bipartisan and was one of the first efforts to involve the governors in requesting continued support for NIH.

The NHC also supported increased health appropriations for fiscal year 2011, including additional funds for NIH, Centers for Disease Control, FDA, and the Agency for Healthcare Research and Quality.

Unfortunately, instead of passing appropriations legislation for fiscal year 2011, Congress passed a continuing resolution that keeps the government operating at funding levels identical to fiscal year 2010.

NHC/WebMD A Patient Voice Exchange

In 2010, the NHC announced the launch of a new online community with a unique digital access, distribution, and multimedia approach to serve the more than 133 million Americans living with chronic diseases and disabilities. The social networking community – A Patient Voice – brings trusted experts together with the WebMD audience to freely share information in both public forums and private, invitation-only settings.

A Patient Voice was launched the first week in March, and is becoming increasingly more popular with more than 3,800 unique users.

In September, NHC President Myrl Weinberg served as the guest expert on A Patient Voice and provided updates on enactment of the Affordable Care Act. The Patient Voice community also provides opportunities for increased visibility for NHC's member organizations.

The NHC thanks the following individuals who served as guest experts in 2010: LaVarne Addison Burton, NHC Board of Directors member and President and Chief Executive Officer for the American Kidney Fund; Steven Taylor, NHC Board of Directors Chair and Sjögren's Syndrome Foundation Chief Executive Officer; Julie Block, President and Chief Executive Officer with the National Eczema Association; and Rick Seidan, Member of the Board of Trustees with the National Psoriasis Foundation. The NHC is currently in negotiations with five other member organizations to participate in late 2010 and 2011.

Supporting the Patient Advocacy Community

Impact of the Economy on VHAs

Since a severe economic downturn took hold in 2008, the NHC has periodically surveyed its VHA members to gauge the impact of current economic conditions on their ability to achieve their missions. The first two surveys, conducted in December 2008 and July 2009, revealed that the downturn was having a negative effect on approximately 70 percent of VHAs participating in the survey.

Significant declines were reported in most fundraising categories, and investments had been hard hit. The majority of VHAs were taking cost-cutting measures, such as reducing travel and administrative costs, imposing hiring freezes, and laying off staff. Worse still, many had been forced to cut back on program services and funding for medical research.

The NHC conducted another economic survey in July 2010. Compared to the first two surveys, fewer respondents (60 percent) said that current economic conditions were having a negative impact. Twenty-five VHAs provided revenue projections for 2010, with 40 percent of these organizations forecasting an average increase in revenue of 5.8 percent, while 36 percent expected income to remain flat. This is a significant turnaround from a year ago, when 70 percent of respondents forecast a decrease in revenue averaging 15 percent.

Moreover, 55 percent of VHAs foresaw continued growth for 2011, while about one-third of respondents expected conditions to stay the same. These responses mirror the optimistic view expressed by respondents to the July 2009 survey.

VHAs expressed a determination to closely monitor economic developments going forward. To that end, the NHC developed a crisis management response plan which will allow VHAs to quickly share information and strategies whenever leading economic indicators point to a potential economic recession.

In a further effort to be sensitive to the continuing financial challenges facing member organizations, the NHC Membership Committee recommended and the Board of Directors concurred with again postponing the automatic dues increase originally scheduled for 2010 for another year. The dues increase will now take effect in 2012.

Standards of Excellence™ Certification Program

The National Health Council's Standards of Excellence™ Certification Program demonstrates that member VHAs are committed to the highest standards of transparency, accountability, and public stewardship.

As of December 1, one new member VHA, the PKD Foundation, gained recognition for having fully met the standards. In addition, nine of 11 VHAs had successfully completed their three-year compliance recertification reviews.

In 2010, the Board of Directors approved a revision of the standard on diversity of revenue sources. The intent of the revised standard is to demonstrate that voluntary health agencies get their funding from a broad base of sources to ensure public accountability, promote financial stability, and avoid undue influence from any one contributor. The standard requires VHAs to maintain compliance with IRS regulations governing 501(c)(3) public charities, which require them to demonstrate a broad base of public support. It also requires VHAs to establish certain annual benchmarks related to funding sources and to measure performance against them.

Voluntary Health Leadership Conference

Though major snow storms across the country brought havoc to travelers in February 2010, 24 member patient advocacy organizations participated in the 23rd Annual Voluntary Health Leadership Conference.

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.

Guest speakers included

- Carolyn Clancy, MD, Director of the Agency for Healthcare Research and Quality
- The Honorable Tommy Thompson, former U.S. Secretary of Health and Human Services and former Governor of Wisconsin
- Jan Berger, MD, Founder of Health Intelligence Partners
- Jim Yunker, Vice Chair of the Giving USA Foundation and Chair of its Editorial Review Board
- Art Taylor, President and Chief Executive Officer of the Better Business Bureau's Wise Giving Alliance

HealthResearchFunding.Org

Each year, there are numerous research proposals for promising new treatments that make their way through a peer review process but do not receive funding. In 2010, the NHC, with input from NIH, finalized its work on the development of a web database designed to bring researchers together with patient advocacy organizations and other funding sources. It's called HealthResearchFunding.Org.

The goal of the database is to foster the funding of new research that will provide hope to patients with chronic conditions and their families.

By utilizing the HealthResearchFunding.Org database, researchers gain an organized and unvarying environment in which to exhibit their proposals alongside their peers. Their respective research institutions will spend less time, effort, and resources looking for financial support and more time conducting research to aid in the development of new treatments.

Chief scientific/medical officers and researcher directors from NHC member patient advocacy organizations and representatives from NIH concluded beta-testing on the website in July. HealthResearchFunding.Org was opened to all NHC member patient advocacy organizations in the fall of 2010. Members added their own requests for research proposals and encouraged outside investigators whose proposals were peer reviewed by VHAs but not funded to register on the site and add their abstracts.

The NHC and NIH are reaching out to the research community, utilizing a number of different communications vehicles.

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 November. Discussion focused on the affect of health care reform on research, technology transfer, HealthResearchFunding.org, and the NHC's initiative to bring new and more personalized treatments to patients with chronic conditions. The Chief Scientific/Medical Officers and Research Directors will meet again in the fall of 2011.

Chief Financial Officers Meetings

The chief financial officers (CFOs) from the NHC's member VHAs and member organizations of the National Human Services Assembly gathered twice in 2010 to hear presentations on timely issues impacting nonprofit business, human resources, and administration. The first meeting was held in May in Washington, DC, and the discussion focused on changes to the IRS Form 990 and its new reporting requirements, what employers should know about health care reform implementation, and trends in the association world due to the economy. The meeting included presentations by Greg Goller of KPMG LLP; Marc Boutin, NHC Executive Vice President and Chief Operating Officer; and Scott Briscoe, Editor-in-Chief, New & Social Media, for the American Society of Association Executives (ASAE).

The second meeting of the CFOs was held in October in Washington, DC. The attendees discussed succession planning, health care reform implementation, economic models, and various issues to consider when using unpaid interns. The meeting included presentations by John Graham, ASAE President and CEO; Richard Brewster, Executive Director, National Center on Nonprofit Enterprise; Florence Corsello, Senior Vice President and CFO, Girl Scouts of America; Nancy Hughes, NHC Assistant Vice President, Communications and Marketing; and Boutin.

Washington Representatives Retreat

The NHC's annual Washington Representatives Retreat was held December 2-3 in Annapolis, Maryland. At the meeting, attendees heard several speakers discuss current public policy topics, such as comparative effectiveness research, health care reform implementation, and legislation to develop new and better treatments for people with chronic conditions. Special guest presenters included Glenna Crooks from Health Policy Strategies and former Representative Tony Coelho. Representatives from NHC VHA members also discussed policy priorities for 2011, which include health care reform implementation, appropriations, and FDA issues such as the Prescription Drug User Fee Act and medical innovation for unmet needs.

Member Communications Staff Meeting

Communications staff from NHC member patient advocacy organizations, professional and membership associations, and nonprofit groups met on October 22, at the NHC Offices, for NHC's first ever Communications Group Meeting. Participants were invited to share information about their respective projects and initiatives, and to discuss ways the organizations can support each other in reaching out to various stakeholder groups. Participants also learned about current NHC projects in the works and various opportunities for members to engage with the NHC.

The group plans to reconvene at least once each year.

2010 Management Compensation Report

The revised IRS Form 990, which must be filed by non-profit organizations, asks whether an organization uses comparability data for determining the compensation of staff. The NHC annually releases a benchmark report of compensation data across a spectrum of approximately 80 mid-level and executive positions. The *2010 Management Compensation Report*, a joint effort of the NHC and the National Human Services Assembly, includes information provided by both VHAs and human service organizations, such as the Salvation Army.

In 2010, 59 national organizations located around the country participated in the survey, including 35 VHA members, the highest participation by 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. Additional copies are available for sale by using the order form on the NHC website at www.nationalhealthcouncil.org/pages/publications.php.

2009 VHA Revenue Survey

To help patient advocacy groups benchmark their revenue streams against those of their peers, the NHC also produced the *2009 VHA Revenue Survey*. Forty-one member organizations took part in the annual survey, which covered revenues for fiscal years 2007, 2008, and 2009. As a member benefit, all VHA members received a generic report detailing aggregate revenue data.

Participants in the survey also were given a customized report comparing their results against their peer group (small, medium, large, and extra-large organizations) and against 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. Free copies of the directory were distributed to all Members of Congress in 2010. 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 on the publications page of the NHC website at www.nationalhealthcouncil.org/pages/publications.php. The publication was made possible with the support of UnitedHealth Group.

Health Groups in Washington is scheduled to be updated and printed again in 2011.

Member Job Bank

In 2009, the NHC launched a special page on its website 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 summer 2009 through November 2010, the webpage received more than 1200 page views and helped more than 13 organizations representing all NHC membership categories fill staff vacancies. The NHC Job Bank registered in both 2009 and 2010 as one of the top landing pages for the NHC website.

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. In 2010, 27 NHC member organizations enrolled their board members and key staff at the national and chapter levels in BoardSource, using a special NHC discount offer.

Strengthening Partnerships

International Alliance of Patients' Organizations

In 2010, the International Alliance of Patients' Organizations (IAPO) continued representing patients of all nationalities across all disease areas. The NHC was instrumental in IAPO's creation and operations.

IAPO's 4th Global Patients Congress was held February 23-25 in Istanbul, Turkey. The conference explored ways to strengthen health care systems globally and provided participants with programs and workshops where they developed their skills and shared best practices. IAPO also announced the launch of its Strategic Plan 2010-2014: Putting Patients at the Centre of Healthcare. NHC President Myrl Weinberg and NHC Executive Vice President and Chief Operating Officer Marc Boutin were presenters at the conference.

In April, IAPO Chief Executive Officer Joanna Groves presented an overview of the PROTECT Project at a European Federation of Pharmaceutical Industries and Associations patient think-tank meeting in Brussels, Belgium. The PROTECT Project is a consortium coordinated by the European Medicines Agency with an overall aim to strengthen the monitoring of the benefit-risk of medicines in Europe.

IAPO represented the patient voice at the World Health Organization Assembly (WHA) in Geneva, Switzerland, in late May. Before this assembly, IAPO provided numerous patients and patient organizations in membership the opportunity to not only attend the WHA, but also participate in a pre-meeting called the IAPO Patient Workshop: Working Effectively with the World Health Organization, which was also held in Geneva coinciding with the WHA. During the Assembly, IAPO also held a side event during the WHA event called Noncommunicable Diseases and the Development Agenda: The Voice of the Patient. During the meeting, patients and family members from around the world shared how chronic diseases, including diabetes and cancer, have affected their lives and led them to advocate on behalf of patients.

At the end of July 2010, three of the founders of IAPO – Weinberg; Virginia Ladd, Executive Director, American Autoimmune Related Diseases Association; and Albert van der Zeijden, Representative of the Council for the Chronically Ill and the Disabled in the Netherlands and Chairman of the Dutch National Council of the European Disability Forum – finished their terms on the IAPO Governing Board. All three helped to shape the way IAPO works today.

In 2010, IAPO also began participation in the Patient Partner Advisory and Dissemination Committee, a project of the European Union Commission. Patient Partner is collating examples of best practices on patient organization involvement in clinical trials, as well as holding workshops on this theme. IAPO was asked to join the Advisory and Dissemination Committee to ensure that the results of the project reach all stakeholders.

Presentations

In 2010, 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 various federal bodies, NHC staff presented at the following events:

- Protecting Privacy in Health Research Critical Issues Workshop sponsored by the Center for Applied Cybersecurity Research at Indiana University
- Partnership to Improve Patient Care briefing on Delivering Patient-Centered Care
- Brookings Institution expert meeting on The Science of Communicating Medication Information to Consumers
- Brookings Institution Sentinel Project on Active Surveillance Implementation Council
- Society of Nuclear Medicine conference on Comparative Effectiveness in Molecular Engineering
- International Conference of Nurses
- National conference on Shaping Convergent Strategies for Comparative Effectiveness Research sponsored by the National Pharmaceutical Council, the Health Industry Forum, America's Health Insurance Plans (AHIP), and the Blue Cross Blue Shield Association
- Drug Information Association (DIA) Annual Meeting
- National Advisory Council for Healthcare Research and Quality
- New England Healthcare Institute Annual Meeting
- Briefing on PDUFA held by the Biotechnology Industry Organization and the Pharmaceutical Research and Manufacturers Association
- Biotechnology Industry Organization's Research Advocacy and Molecular Diagnostics Working Group
- International Federation of Pharmaceutical Manufacturers & Associations Assembly
- International Alliance of Patients' Organizations 4th Global Patients Congress
- 11th Annual Patient Assistance Programs Conference sponsored by the Center for Business Intelligence
- EuropaBio-BIO Workshop on Comparative Effectiveness and Health Technologies Assessment
- Bristol-Myers Squibb Town Hall meeting on Comparative Effectiveness in the U.S. – A Patient-Centered Perspective
- Pfizer Advocacy Summit on Implementation and Challenges of Health Care Reform
- 21st International Symposium on ALS/MND

The NHC also took part in the following meetings of its member organizations;

- Arthritis Foundation Leadership Forum
- The ALS Association Board of Trustees
- National Psoriasis Foundation webcast on Access to Healthcare

In The News

Because of its work in the health care reform process, 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 2010.

- *American Journal of Pharmacy Benefits* columns about molecular diagnostic tests, addressing the unmet needs of patients, translational research, development of and access to new treatments, and improving patient medication information
- *Medical Progress Today* article on Improving FDA's REMS
- *Canadian Medical Association Journal* article on the establishment of the Patient-Centered Outcomes Research Institute (PCORI) and international patient charters
- *The Journal of Gift Planning* article on the use of social networking strategies
- *Wall Street Journal* feature on clinical trials
- *BioCentury* article on the reauthorization of PDUFA
- *Health Affairs* article entitled A Proposal to Protect Privacy of Health Information While Accelerating Comparative Effectiveness Research
- *American Chronicle* on Do We Need National Health Standards?
- The Actively Fused Blog on Desperately Seeking a Patient-in-Chief?
- ASAE's magazine, *Associations Now*, column on Passionate Pragmatism for Advancing Social Change
- *FDA Week*, article on PDUFA Reauthorization

New Members in 2010

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 and become part of the collective effort to provide a united voice for people with chronic diseases and disabilities and their family caregivers.

Voluntary Health Agencies

PKD Foundation

Professional and Membership Associations

American Association for Cancer Research
Drug Information Association
National Business Coalition on Health
Personalized Medicine Coalition

Nonprofit Organizations with an Interest in Health

National Venture Capital Association

Business and Industry

Bayer HealthCare
Cephalon Pharmaceuticals
Talecris Biotherapeutics



NATIONAL HEALTH COUNCIL

1730 M Street NW, Suite 500, Washington DC 20036-4561

Phone: 202-785-3910 | Fax: 202-785-5923 | E-mail: info@nhcouncil.org | www.nationalhealthcouncil.org