

2014 Annual Report

National Health Council

Championing the Needs of Patients

December 2014



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From the Chairperson and the Chief Executive Officer

In 2014, the National Health Council (NHC) continued to gain influence and recognition as the champion for people with chronic diseases and disabilities and their family caregivers. Our unique ability to bring together all the stakeholders in the health community to provide a united patient voice on systemic health issues helped propel major policy advancements in a number of areas.

This annual report highlights the NHC's many initiatives in 2014 to help people with chronic conditions live longer and feel better and to strengthen the community of patient advocacy organizations that represent them.

- More than a dozen of the NHC's recommendations were included in the proposed rule issued by the Department of Health and Human Services (HHS) for the 2016 health insurance exchanges.
- The NHC's Putting Patients First[®] website has helped thousands of people better understand their insurance plan options within the newly formed health insurance exchanges. The website and its cost calculator are visible elements in our multi-pronged strategy to improve access to care.
- The NHC's groundbreaking legislation – the MODDERN Cures Act – a bill designed to speed the development of new and better treatments and diagnostics for people with unmet medical needs, advanced in several significant ways. Two major provisions of the legislation were passed by Congress and signed into law by the President. In addition, the House Energy and Commerce Committee's bipartisan 21st Century Cures draft discussion paper included the MODDERN Cures provision creating a new drug category called dormant therapies.
- The NHC continued its work to define what it means to “engage patients.” In 2014, staff appeared before numerous stakeholder groups to shape perceptions about the importance of involving people with chronic conditions in a meaningful way throughout the drug development and regulatory approval continuum. In 2015, the NHC will convene a high-level group of health policy experts as a first step toward identifying solutions to ensure the patient voice is part of these processes.
- The NHC secured an exclusion for patient advocacy organizations from the reporting requirements of the Physician Payment Sunshine Act if they maintain full discretion over the allocation of funds received from pharmaceutical companies.

This has been an extraordinarily busy year for the National Health Council and our committed membership of more than 100 patient advocacy organizations, nonprofit organizations with an interest in health, provider organizations, and business and industry representatives. We hope you will read this report to learn more about our work and our successes.

As we prepare for 2015, we invite all stakeholders in the health community to join with us as we continue to advance the needs and aspirations of people with chronic diseases and disabilities and their family caregivers.



Nancy Brown
Chair, 2014 NHC Board of Directors and
Chief Executive Officer
American Heart Association



Myrl Weinberg, FASAE, CAE
Chief Executive Officer
National Health Council

National Health Council CEO Departing in 2015

National Health Council (NHC) Chief Executive Officer Myrl Weinberg (right) announced in June 2014 her decision to leave her position at the end of February 2015. Under Weinberg’s leadership, the NHC has become an effective, united, and powerful voice for the interests of people with chronic diseases and disabilities and their family caregivers. In her announcement, Weinberg said, “I am confident that the National Health Council will continue on its current, upward trajectory.”



Since becoming CEO, Weinberg has helped the NHC create a framework for building consensus among member patient advocacy organizations which empowers them to speak with a united voice on public policy initiatives resulting in legislation and regulations on a vast array of issues, including health care reform, comparative effectiveness research, and patient-focused drug development.

The Board of Directors followed a defined process for selecting Weinberg’s successor, and a Transition and Search Committee was named to manage the search for a new CEO. The committee was chaired by Larry Hausner, former Chief Executive Officer of the American Diabetes Association.

Uniting the Patient Voice in Public Policy

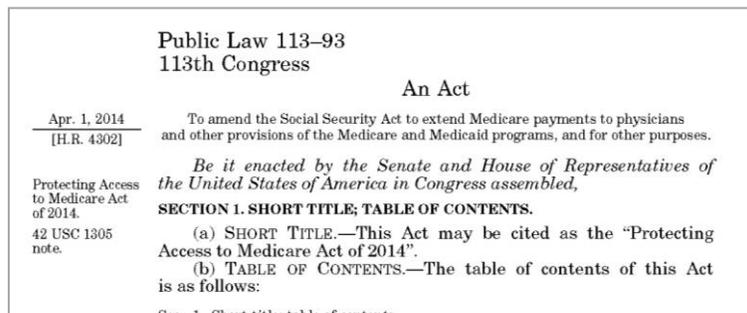
MODDERN Cures Act: Diagnostic Provisions Signed into Law

On April 1, President Barack Obama signed into law the [Protecting Access to Medicare Act](#), which temporarily delayed cuts to Medicare physician payments. The legislation also included the first major overhaul to diagnostic reimbursement since 1984 through inclusion of two provisions from the NHC’s [MODDERN Cures Act](#) –

adoption of a temporary Healthcare Common Procedure Coding System (HCPCS) billing code and the establishment of an advisory panel to offer input to the Centers for Medicare and Medicaid Services (CMS) on advanced diagnostic reimbursement.

Passage of these provisions marks the first time original legislation proposed by the NHC has been enacted. Together, both provisions will promote the development of advanced diagnostics that truly personalize care for patients.

The NHC will continue to advocate for passage of the remaining provisions of the MODDERN Cures Act. The House version of the legislation had 95 cosponsors, split nearly equally between both political parties and included the chairs of both the Democratic and Republican Congressional Campaign Committees. In addition, Senators Orrin Hatch (R-UT) and Michael Bennett (D-CO) introduced the [Dormant Therapies Act](#), which includes core provisions from the MODDERN Cures Act.



NHC Proposals Included in Congressional 21st Century Cures Initiative

The 21st Century Cures initiative is a bipartisan effort of the House Energy and Commerce Committee aimed at passing federal legislation to increase the development of new and meaningful medical

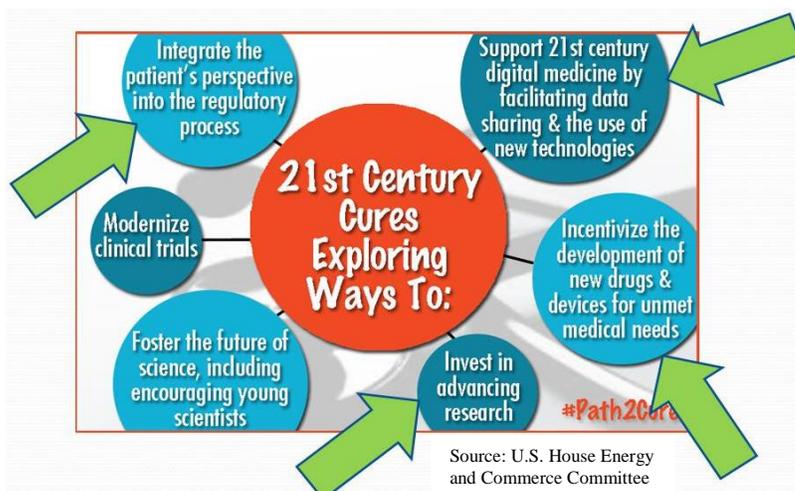


treatments and cures. Spearheaded by Chairman Fred Upton (R-MI) and committee member Diana DeGette (D-CO), the committee held a series of public hearings and released a series of white papers for reaction from the stakeholder community.

NHC Executive Vice President and Chief Operating Officer Marc Boutin (left) testified at a July congressional hearing on the 21st Century Cures initiative and explained how the NHC-crafted MODDERN Cures Act would address barriers created by the current U.S. patent system and promote needed medical innovation for new treatments and cures.

The NHC asked for the inclusion of four proposals in the 21st Century Cures initiative, all of which were received favorably by the committee. The top priority is inclusion of provisions from the MODDERN Cures Act creating a new drug category called dormant therapies.

The NHC also supplied language that creates a safe harbor for industry to engage with patients in order to better inform the research and development processes to ensure that the products that are produced best meet the needs of patients. In addition, the NHC submitted draft legislative language that would make it easier for patients to share their health information for research purposes. The NHC also advocated for the removal of administrative burdens in multi-site clinical research by streamlining the institutional review board (IRB) approval process, which will lead to more effective and efficient drug development.



Helping Patients Find the Right Health Insurance Plan

In January 2014, the NHC launched PuttingPatientsFirst.net, a website that provides tools for people with chronic conditions to help them understand how the health insurance marketplace (also known as the exchanges) works and how to choose the right plan that meets their budget and health needs. The website includes an out-of-pocket cost calculator that allows people to input their actual provider visits, hospitalizations, and medications to learn how their health needs will impact their total out-of-pocket costs for the year, depending on what type of health insurance plan they choose. The website also has a library of resources created by the NHC and its member organizations, such as overviews of the marketplace and condition-specific insurance information.

In addition, PuttingPatientsFirst.net includes a section called Share My Story where patients can share their experiences with enrolling in marketplace plans and describe any difficulty they have affording their coverage or accessing their needed health services.



November marked the beginning of the 2015 open enrollment period for health insurance exchanges across the country, and the PuttingPatientsFirst.net cost estimator was enhanced for the new enrollment season. The updated website now factors in premium and out-of-pocket subsidies for low income purchasers, includes more insurance plans in the data set, and has an improved system for reporting coverage of prescription drugs.

Strengthening the Health Insurance Marketplace

To better understand the patient experience in the health insurance exchanges, the NHC conducted a series of nationwide focus groups in the fall of 2014 that involved people diagnosed with chronic diseases and disabilities who are covered by marketplace plans. A nationwide survey was also conducted with people with chronic conditions to learn what changes they would want made to improve the exchanges.

On November 6, the NHC sent a [letter to the Secretary of Health and Human Services \(HHS\), Sylvia Burwell](#), urging the department to adopt proposed regulatory language that the NHC crafted to ensure marketplace plans offer greater patient protections. The language calls for the elimination of discriminatory plan designs, improvements in provider network adequacy standards, increased plan transparency, more plan uniformity, and improved continuity of care.

HHS issued its proposed rule outlining the parameters for the 2016 insurance marketplace in late November, and the rule [touched on all of the NHC's concerns](#). In December, the NHC submitted its formal [comment letter applauding HHS](#) for working with the patient community to improve patient protections for people who are served through the exchanges. The letter outlined the NHC's support for provisions in the proposed rule and discussed additional changes to help ensure that patients have access to health coverage that addresses their medical needs at the most affordable price in 2016. A final rule for the 2016 marketplace is expected in early 2015.

Finalizing a Patient Risk-Benefit Information Collection Tool

After many rounds of constructive feedback, the NHC finalized its [patient information collection tool](#) to aid in the development of treatments for people with chronic conditions. This tool is intended for use by the FDA and patient advocacy organizations to help capture and organize information gathered from people with chronic diseases and disabilities and their family caregivers about their views on specific conditions and available treatment options.

This tool was used by the narcolepsy community in preparation for their Patient-Focused Drug Development (PFDD) meeting with the FDA. They used the NHC tool to create a patient survey, and the result was a much higher participation rate, despite narcolepsy's relatively small patient population, than data sources produced for previous PFDD meetings focusing on other conditions. Representatives of the narcolepsy community were pleased with the results of their survey and have cited the NHC's work as a reason for its success.

The NHC also finalized a guide on how to best utilize the tool, depending on a particular organization's resources.

Physician Payment Sunshine Act and the Impact on VHAs

One lesser known section of the Affordable Care Act is a requirement for pharmaceutical manufacturers to disclose any contributions made to physicians. While the general intent of the Physician Payment Sunshine Act was to create more transparent relationships between industry and treating physicians, it is also impacting the research portfolios of patient organizations. The Centers for Medicare and Medicaid Services (CMS) interpreted the legislation in a way that is causing pharmaceutical companies to require voluntary health agencies (VHAs) to report the names of any physicians participating in activities funded in part by the companies.

The NHC and staff from member patient advocacy organizations held a meeting in February with representatives of CMS to explain that the reporting requirements are not applicable to funds provided to patient organizations because the VHAs retain sole control over the allocation of the money. The NHC shared with CMS proposed clarifying language that the agency could incorporate into a Frequently Asked Questions document explaining the reason VHAs did not need to disclose.

In September 2014, approximately 70 patient organizations added their names to an [NHC sign-on letter](#) to CMS urging the creation of an exclusion from the Open Payments Program “that would exempt reporting for indirect payments to VHAs in cases when an applicable manufacturer grants full and independent discretion to VHAs in selecting recipients for funding.”

In December, the NHC followed up with a letter to CMS, again expressing concern with the agency’s interpretation and informing them that patient organizations have stringent processes to independently evaluate and award grants, regardless of the funder, and that revenue from a particular grant or sponsorship is indistinguishable from other sources. CMS responded to the NHC’s letter stating that unrestricted corporate donations to a VHA to use at the patient organization’s discretion would not be subject to the Sunshine Act reporting requirements. The NHC is in discussions with its VHA members on ways to educate both the patient community and corporate funders about this issue.

Building a Usability Framework for CER

The Patient-Centered Outcomes Research Institute (PCORI) has developed what it calls “[usefulness criteria](#),” which are based on the NHC’s publicly released work on the creation of a comparative effectiveness research (CER) usability framework to help patients make better decisions at the point of care.

This is a huge win for the patient community because a core function of usability is ensuring the needs of patients are the focus at each stage of CER. PCORI’s work to establish usefulness criteria was conducted in part by the Patient Engagement Advisory Panel, which included NHC Executive Vice President and Chief Operating Officer Marc Boutin and was chaired by Charlotte Collins of the Asthma and Allergy Foundation of America, an NHC member.

Strengthening the Patient Advocacy Community

NHC Launches Ethics and Accountability Initiative

There is a wealth of information circulating in the mainstream media about how donors should evaluate charities. Numerous charity watchdog groups with varying methodologies – from simple financial ratios to well-thought-out accreditation systems – add to the din. Meanwhile, recent research indicates that donors are unaware of or confused about how to identify a worthy recipient of their charitable donations.

The upshot: The charitable sector needs a more consistent and focused approach to communicating with donors about ethics and accountability. To that end, the NHC brought together a group of leading organizations within the sector to develop a strategy to promote a common framework for discussing ethics and accountability – one that recognizes the full scope of charitable operations and impact.

Partnering with the NHC on its Ethics and Accountability Initiative are:

- BBB Wise Giving Alliance
- Independent Sector
- Community Health Charities
- National Human Services Assembly

In addition, the NHC asked two members organizations – American Cancer Society and American Kidney Fund – to help guide the initiative.

This group will guide the development of a message platform and communications plan to help the partner organizations align messaging and begin to educate donors about what makes a well-run and effective charity.

If the initiative is successful, donors will get clear, simple advice on how to evaluate a charity's trustworthiness and impact in meeting its mission. And that would be good news for the members of the partner organizations, as well as the NHC's member patient advocacy organizations, which already meet high standards for organizational management and governance through their participation in the NHC Standards of Excellence Certification Program®.

Standards of Excellence Certification Program®

The NHC's [Standards of Excellence Certification Program®](#) demonstrates that member patient advocacy organizations (also known as voluntary health agencies or VHAs) are committed to the highest standards of transparency, accountability, and public stewardship.

In 2014, the Standards of Excellence initial certification was awarded to the following five organizations:

- Colon Cancer Alliance
- The Leukemia & Lymphoma Society
- National Kidney Foundation
- Prevent Cancer Foundation
- WomenHeart: The National Coalition for Women with Heart Disease



In 2014, the NHC revised [Standard 8](#) on Board of Directors meetings to allow for the use of video technology to replace face-to-face meetings.

27th Annual Voluntary Health Leadership Conference

Each February, the NHC brings together the chief executive officers and their lead volunteers from member patient advocacy organizations to learn about the latest in medical research and health care policy and to share best practices for meeting their organizational goals to serve people with chronic diseases and disabilities.

The largest ever gathering of representatives from NHC patient organizations met for the 27th Annual Voluntary Health Leadership Conference from February 12-14 in Tucson, Arizona.

Nearly 80 senior staff and volunteer leaders from 32 organizations heard from speakers on topics such as creating a culture of innovation, organizational transformation, and finding new ways to generate revenue. In addition, attendees heard from Dr. Christopher Austin, Director of the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health, and Dr. Tracy Gaudet, Director of the Office of Patient Centered Care and Cultural Transformation at the Veterans Health Administration. Copies of the presenters' slides, supplemental materials, and links to videos are available on the [NHC website](#).

NHC Affinity Groups and Professional Development Opportunities

The NHC is the only organization that harnesses the collective power of the patient community to address systemic health care issues that affect all patients, regardless of disease or disability, and to provide professional development opportunities to help member organizations meet their respective missions. In the past year, the following NHC groups met to discuss cutting-edge issues and share best practices:

Chief Development Officers Affinity Group

- Mike Tringale, Senior Vice President of External Affairs, Asthma, and Allergy Foundation of America, *Chair*

Chief Financial Officers Affinity Group

(This group is made up of the chief financial officers from the NHC's member VHAs and from member organizations of the National Human Services Assembly.)

- Debbie Johnson, Chief Financial Officer, American Diabetes Association, *Chair*

Chief Legal Officers Affinity Group

- Rhonda Lees, Vice President of Legal Affairs, American Diabetes Association, *Chair*

Chief Scientific/Medical Officers and Research Directors Affinity Group

- Timothy Coetzee, Chief Advocacy, Services, and Research Officer, National Multiple Sclerosis Society, *Chair*

Communications Affinity Group

- Steve Weiss, Senior Director, Communications and Media Advocacy, American Cancer Society Cancer Action Network, *Chair*

Government Relations Affinity Group

- Lauren Chiarello, Director, Federal Affairs, National Multiple Sclerosis Society, *Chair*
- John Madigan, Vice President, Public Policy, American Foundation for Suicide Prevention, *Vice Chair*

Grassroots Team

- Steve Gibson, Chief Public Policy Officer, The ALS Association, *Chair*

Appropriations Issue Team

- Lisa Cox, Associate Director of Federal Government Affairs, American Diabetes Association, *Chair*

FDA Issue Team

- Jennifer Sheridan, Director of Policy Development, Parkinson's Action Network, *Chair*

Health Care Reform/Comparative Effectiveness Research Issue Team

- Marko Mijic, Government Relations Manager, American Heart Association, *Chair*

All meetings are posted on the NHC [web calendar](#).

2013 VHA Revenue Survey

To help NHC member VHAs benchmark their revenue streams against those of their peers, the NHC produced the 2013 VHA Revenue Survey in June 2014.

Forty-one member organizations took part in the annual survey, which covered revenues for fiscal years 2011, 2012, and 2013. As a member benefit, all VHA members received a generic report detailing aggregate revenue data. Participants in the survey also were given a confidential, customized report comparing their organization's results against their peer group (small, medium, large, and extra-large organizations) and against all survey participants.

2014 Management Compensation Report

The annual *Management Compensation Report for National Voluntary Health and Human Service Organizations* was updated with the latest information on more than 80 staff positions, from entry level to the executive office. This crucial report is produced annually as a joint project of the members of the NHC and the National Human Services Assembly.

This is the only report of its kind specifically for national health and human service non-profit organizations, ranging in size from fewer than 10 employees to more than 120 staff.

The *Management Compensation Report* covers salary management practices, total cash compensation, base salary and salary ranges, retirement benefits, dental benefits, life insurance benefits, sick leave and disability benefits, paid time-off practices, variable pay, and other benefits, such as flex spending accounts and tuition assistance. The compensation information is broken down by broad geographic location, organizational budget, and total number of employees.

Good governance guidelines are increasingly stressing compensation and benefits surveys as a basis for analyzing the propriety of chief executive and senior staff compensation. The federal IRS Form 990 specifically asks whether an organization uses a tool of this sort.

NHC participants receive a free copy of the final report, and others may purchase the report by visiting the NHC [publications page on the web](#).

Extending Our Reach

New Members in 2014

The strength of the NHC comes from the fact that it provides a dynamic forum in which all stakeholders can meet for reasoned discussion, collaboration, and advocacy. The NHC is honored to have the following organizations and businesses join in this past year and become part of the NHC's collective effort.

Voluntary Health Agency

- Colon Cancer Alliance
- The Leukemia & Lymphoma Society
- National Kidney Foundation
- Prevent Cancer Foundation

Professional and Membership Associations

- Consortium of Multiple Sclerosis Centers
- Medical Imaging & Technology Alliance
- National Alliance for Caregiving

Business and Industry

- Biogen Idec

Measuring the Value of Member Programs and Services

To help assess the value that members place on NHC services, the council tracks member participation in its various NHC activities. Based on the most recent data, the overall participation level remains high with 93 percent of all VHA members and a solid two-thirds of other member organizations participating in multiple activities throughout the year.

New National Health Council Website Launched

Work started early in 2014 to redesign and restructure www.nationalhealthcouncil.org to improve its usability and help visitors to the website more easily find information about the NHC, its policy initiatives, members, and member tools. The website, which was launched in December, is an important outreach tool for the NHC, and it registered nearly 103,000 unique visits in 2014.

NHC Voice Before Health Community Stakeholders

In 2014, the NHC presented the patient perspective on cutting-edge health issues before influential health care and research entities. NHC staff presented at events organized by numerous organizations and businesses, including the following:

- Democratic Governors Association
- Republican Governors Association
- Republican Lieutenant Governors
- Democratic Attorneys General Association
- Republican Legislative Campaign Committee Club 100
- Women in Government
- AcademyHealth
- AdvaMedDx

- The ALS Association
- American Cancer Society
- American Foundation for Suicide Prevention
- American Heart Association
- Association for Vascular Access
- Biogen Idec
- Biotechnology Industry Organization (BIO)
- Brookings Institution
- Cancer Support Community
- Drug Information Association
- Epilepsy Foundation
- eyeforpharma
- FasterCures Benefit
- Food and Drug Administration
- GlaxoSmithKline
- Health Technology Assessment International
- International Alliance of Patients' Organizations (IAPO)
- International Federation of Pharmaceutical Manufacturers and Associations
- March of Dimes Foundation
- Patient Advocacy Across the Life Sciences
- Patient-Centered Outcomes Research Institute (PCORI)
- Pfizer
- Pharmacy Quality Alliance
- PhRMA
- PKD Foundation
- Public Relations Society of America Health Academy

NHC in the News

Because of its influential policy work, the NHC was frequently called upon to provide comment and insight on important health care issues in 2014. Here are just a few of the media outlets in which the NHC presented the united voice of the patient community:

- American Journal of Pharmacy Benefits
- BioCentury
- BioCentury TV
- CBS News
- Charleston (West Virginia) Daily Mail
- Chicago Tribune
- CNNMoney.com
- Comcast Newsmakers
- Consumer Eagle
- EP Vantage
- Forbes
- Government Health IT
- Health News Colorado
- HeraldOnline.com
- Huffington Post
- Inside Health Policy
- Kaiser Health News
- Kent (Washington) Reporter
- KSNV/News3 (Nevada)
- Modern Healthcare
- Money magazine
- PhRMA Conversations blog
- Portland (Oregon) Business Journal
- Stateline
- Talkline (West Virginia Radio)
- The Pink Sheet
- Wall Street Journal
- Washington Post

A Different Normal – An NHC/WebMD Blog

The NHC has been a proud partner with WebMD, the largest web-based source of patient information, in presenting [A Different Normal](#). This blog has provided a link between member patient organizations and the millions of visitors to the WebMD website.

WebMD launched a new design for the blog that includes better search optimization for people seeking information about living with chronic conditions, better readability on mobile devices, and better



promotion of the site across the WebMD platform under a new name *Second Opinion: Chronic Conditions – When you're living a different normal.*

The NHC thanks the following member organizations that participated in the blog in 2014:

- Alpha-1 Foundation
- American Foundation for Suicide Prevention
- Foundation for Ichthyosis & Related Skin Types (FIRST)
- The Marfan Foundation
- National Eczema Association
- National Psoriasis Foundation
- Prevent Blindness

Some organizations have asked their annual patient volunteer award winners to write about their experiences living with a chronic condition or serving as a family caregiver. Other organizations utilize the blog as an opportunity to write about new patient education tools or service programs with links back to their website.

International Alliance of Patients' Organizations CEO Announces Resignation

The [International Alliance of Patients' Organizations](#) (IAPO) is a unique global alliance representing patients of all nationalities across all disease areas. NHC was instrumental in its creation and operations, and NHC Executive Vice President and Chief Operating Officer Marc Boutin serves on the Governing Board as Treasurer.



The CEO of the International Alliance of Patients' Organizations (IAPO), Jo Groves, announced in October her decision [to leave the organization](#) at the end of 2014. Groves was with IAPO for ten years, and during that time the organization grew from 100 to more than 250 organizations and forged relationships with the World Health Organization and the United Nations Economic and Social Council.

The IAPO Governing Board is conducting a global search for a new CEO.

Financials

The NHC posts its IRS 990 form on the [About the NHC](#) page of the NHC website. The audited financial statements for fiscal year 2014 will be posted as part of the *National Health Council Annual Report* in the spring of 2015.



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