WOMEN’S CHRONIC CONDITIONS: PREVALENCE AND POLICY
PRECONFERENCE
NCSL CAPITOL FORUM 2019

December 10, 2019
Phoenix, Arizona

Sponsored by Amgen
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AGENDA

- Overview and Introductions
- Legislative Overview of Women’s Chronic Conditions
- National Panel on Women’s Chronic Conditions
- State Actions to Improve Women’s Health
- Legislative Discussion
- Lunch and Wrap Up
NCSL APP AND SOCIAL MEDIA

- #NCSL
- @NCSLorg
Bipartisan membership organization
- All 50 states and the territories
  - 7,383 state legislators
  - All state legislative staff (30,000+)

Goals:
- To improve the quality & effectiveness of state legislatures
- To promote policy innovation and communication among state legislatures
- To ensure states a strong, cohesive voice in the federal system

Research, education, technical assistance
Voice of the states
INTRODUCTIONS

- Name
- State
- What you hope to learn today
- Fun Fact
OVERVIEW OF WOMEN’S CHRONIC HEALTH ISSUES: LEGISLATION AND STATE ACTIVITIES

- Prevalence
- Sex and gender disparities in medical research and care
- Recent legislative examples from around the country
- State programs
Sex and Gender Disparities in Medical Research and Care

- Fewer women participate in clinical research than men\(^1\).
- Women’s pain treated less aggressively than men’s\(^2\).
- Research often not separated by sex, even when disparities in outcomes and severity exist\(^3\).

Arkansas House Resolution 1010
(Adopted 2019)
- Recognizes National Wear Red Day.
- “Cardiovascular disease kills 1 in 3 women in the United States, yet up to 80 percent of cardiovascular disease can be prevented.”
California Senate Resolution 65
(Adopted 2019)

“Women have a higher prevalence than men of syndromes and diseases associated with chronic pain.”

“Women more frequently report pain to a health care provider, but are more likely to have their pain reports discounted.”
Illinois Senate Bill 162
(Enacted 2019)

- Mandates health insurance coverage for mammograms.
- Health plans cannot impose a deductible, coinsurance, copayment or any other cost sharing requirements.
Georgia House Bill 186
(Enacted 2019)

Requires the Office of Women’s Health to submit a report to the Office of Health Strategy and Coordination on the state of women’s health in Georgia.
Vermont: You First Program

- Administered through the Vermont Department of Health.
- Provides screenings for heart health, breast cancer, cervical cancer and heart healthy lifestyle programs.
Texas: Breast and Cervical Cancer Services Program

- Administered by the Texas Department of Health and Human Services.
- Provides screening services, diagnostic services, options for management and treatment and assistance to apply for Medicaid services.
THANK YOU!

Erik Skinner, MPH
Policy Associate, NCSL Health Program
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Panelists

- Nim Lalvani, Director, American Migraine Foundation
- Cathy Peters, Senior State and Local Campaigns Manager, American Cancer Society Cancer Action Network.
- Anna Hyde, Vice President, Arthritis Foundation
- Martha Gulati, MD, MS, FACC, FAHA, Division Chief, Cardiology, University of Arizona College of Medicine
- Liz Thompson, CEO, National Osteoporosis Foundation
The American Migraine Foundation is the premier organization dedicated to public awareness, education, support, advocacy, and research in migraine and other headache disorders. The mission of the American Migraine Foundation (AMF) is to mobilize a community for patient support and advocacy, as well as drive and support impactful research that translates into treatment advances for patients with migraine and other disabling diseases that cause severe head pain. AMF is committed to raising awareness of migraine as a disabling disease to help the community of more than 37 million Americans and the 1 billion individuals worldwide living with migraine.
Organizational Priorities

Education
Continue to be the recognized authority and lead driver of expertly curated educational content and resources for those living with migraine and other headache disorders.

Awareness/Support
Increase awareness and understanding of migraine as a disabling disease and offer hope and support for those impacted by migraine and other headache disorders.

Advocacy
Create tools and resources that empower, motivate and activate those living with migraine to mobilize a migraine movement.

Research
Become the lead driver of advancing migraine research through the American and International Registries for migraine research. (ARMR&IRMR)
The American Migraine Foundation Executive Team

David W. Dodick, MD, FAAN, FAHS
Chair, The American Migraine Foundation
Mayo Clinic Arizona

Lawrence C. Newman, MD, FAAN, FAHS
Vice Chair, The American Migraine Foundation
NYU Langone Medical Center

Nim Lalvani, MPH
Executive Director
The American Migraine Foundation
MIGRAINE IMPACT

1 BILLION WORLDWIDE
37 MILLION IN THE UNITED STATES

Women.
Men.
Children.
THE FACTS OF MIGRAINE

Migraine affects 1 in 7 people globally.

Migraine affects 1 in 11 children.

Migraine affects 1 in 5 women and 1 in 16 men.
THE FACTS OF MIGRAINE

148 Million

148 million people in the world are estimated to suffer from chronic migraine at least every other day.

Migraine is the 3rd most common disease in the world.

90%

Migraine interferes with education, career, and social activities for more than 90% of those living with migraine.
THE FACTS OF MIGRAINE

Migraine is one of the leading causes of outpatient and emergency department visits with 1,094,000 in 2016.

The direct and indirect costs of migraine totaled $36 billion in 2016.

157 million work days are lost each year in the United States due to migraine.
Move Against Migraine Campaign
The *Move Against Migraine* Campaign was one of the major outcomes of a multi-stakeholder brainstorm spearheaded by the leadership of the American Migraine Foundation, experts from the American Headache Society, patients and patient advocates.

The primary goal was to develop a comprehensive Migraine Awareness Campaign that includes unified messaging that can be used consistently by all stakeholders.

The primary goals of the campaign are to:

- Generate awareness that migraine is a serious neurological disease.
- Empower patients with migraine to seek treatment and locate appropriate medical care.
- Provide patient education and support through the American Migraine Foundation’s website and social channels to activate a community of patients to take action.
Two UK sites are planned in next phase of the expansion plan

King's College Hospital
London
Investigator
Peter Goadsby

The Walton Centre
Liverpool
Investigator
Nicholas Silver

Two Australian sites have been established

Alfred Hospital
Melbourne
Investigator
Elspeth Hutton

Prince of Wales Hospital
Sydney
Investigator
Alessandro Zagami

Potential expansion

St. Vincent's Hospital
Melbourne
Investigator
Christina Sun-Edelstein

King's College Hospital
London
Investigator
Peter Goadsby

The Walton Centre
Liverpool
Investigator
Nicholas Silver
Chaired by AMF Chair Dr. David Dodick, IHS-GPAC is the premier global organization consisting of premiere neurology, pain, and headache societies worldwide, patients, patient advocacy organizations, payers, regulators, pharmaceutical and biotechnology industry, clinicians, and researchers. IHS-GPAC working alongside its partners (AMF, included) is focused on engaging global employers to create a better quality of life in the workplace for those living with migraine.

The only global organization focused on unifying the approach to putting patients first, especially in the drug development process. PFMD is a global organization consisting of patients, patient advocacy organizations, payers, regulators, pharmaceutical partners, clinicians, and researchers.
Understanding that migraine is a disabling neurological disease and impacts individuals during their most productive years.

Understanding that migraine impacts any gender at any age, but migraine affects women 3 times more often than men.

Collaboration with patient, providers, and key stakeholders will help those living with migraine get access to the resources and care that they need.
Thank You

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State Policies to Reduce Breast Cancer Mortality
Key Breast Cancer Data

- Most commonly diagnosed cancer in women
- Second only to lung cancer in cancer deaths
- One in 8 women diagnosed in their lifetime
- Breast cancer death rate has decreased 40% since 1989
- 3.8 million breast cancer survivors
Breast Cancer Disparities

- Incidence rates highest among white women
- Death rates are 40% higher among black women
- Black women more likely to be diagnosed with metastatic and triple negative breast cancer
Breast Cancer Policy Priorities: State Funding for Screening

- Adequate funding for state breast and cervical cancer early detection programs serving uninsured women
- Find more breast cancers at early stages when they are more successfully treated and less costly
Breast Cancer Policy Priorities:
Ensure Access to Care

- Ensure women diagnosed with breast cancer have access to quality, affordable treatment
- Preserve patient protections in health care laws
- Curb non-comprehensive health plans
Breast Cancer Policy Priorities: Funding for Research

– Increase funding for cancer research at state and federal level
– More people benefit from research discoveries that go from bench to bedside
Catherine Peters
Senior State & Local Campaigns Manager
American Cancer Society Cancer Action Network
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Arthritis Overview

Anna Hyde
Vice President, Advocacy and Access
Arthritis Foundation
Common Arthritis Misconceptions

It is an old person’s disease

Kids don’t get arthritis

Exercise will just make it worse

Arthritis is just mild aches and pains

There’s nothing you can do to help your arthritis

If you don’t look sick, you must be fine
Quick Facts

• There are over 100 forms of arthritis impacting more than 54 million Americans

• Osteoarthritis (OA) is the most common form, impacting more than 27 million Americans

• Arthritis is the leading cause of disability in the US

• Arthritis costs more than $304 billion annually in direct and indirect health costs

• Despite its prevalence and impact, there is no disease-modifying treatment for OA

• Women are disproportionately impacted
What Patients Tell Us About Their Symptoms

• Pain is the number one challenge and causes many other challenges
• Stiffness and fatigue are also extremely common
• This all leads to mobility issues and difficulty doing simple tasks
• They often have co-morbidities, including hypertension, diabetes, and anxiety
• It impacts their ability to fully participate in the workforce

“If I could wave a magic wand, the first thing about my OA I would eliminate is the pain.”
What Patients Tell Us They Need

• Peer-to-peer support
• Coverage for alternative pain treatments
• Better options for pain treatments
• Better care coordination
• Quicker diagnoses
• Access to self-management programs
• Practical lifestyle tips
• More research for a cure
What We Know Helps

- Lifestyle changes
  - Weight loss
  - Exercise
- Care coordination
  - Medication management
  - Digital tools
- Peer support
  - Online community
  - Support groups
What the AF Does to Support People with Arthritis

- Online community
- In-person connect groups
- Data collection
- Helpline
- Arthritis Today magazine
- Online tools
- Your Exercise Solution

Toolkits
- Breaking the Pain Chain
- Better Living Toolkit
- Rx for Access
CHRONIC DISEASE PANEL Q&A
15 MINUTE BREAK
STATE ACTIONS TO IMPROVE WOMEN’S HEALTH

- Teresa Aseret-Manygoats, State Chronic Disease Director, Arizona Department of Health Services
Table Discussion

- Take a moment to reflect on the presentations
- Discuss your takeaways or insights with your table
- Send a representative to share with the group
Keep the conversations going with your colleagues

Share with NCSL staff: What do you want to see from NCSL in 2020 on women’s health issues?

- For example, more publications, webinars or meetings? On what topics?

Please turn in your feedback form- it is your ticket to leave 😊
THANK YOU!

If you have any questions or requests for information please don’t hesitate to contact us:

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