

# 2012 Advocacy Priorities & Health Care Reform Implementation

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## 3 Things to Keep in Mind:

- **Your voice is important!**
  - “Ten people who speak, make more noise than ten thousand who are silent.”  
- *Napoleon Bonaparte*
- **Ignoring the pain, disability and cost of arthritis is unacceptable. We need to raise awareness!**
- **Arthritis research, prevention and access to care are important.**



## Why are you here?

- To learn to tell your story so your elected officials will hear you, know what is important to you
- 50 million Americans, 21 million who are limited in some way by arthritis
- Most common cause of disability, impact on work
- Costly: \$128 billion, high personal cost
- 2/3 of Americans diagnosed with arthritis are *under* the age of 65
- **YOU ARE THE EXPERT!**



- 300,000 children (1 in 250 kids) have juvenile arthritis
- 10 states do not have a single pediatric rheumatologist, and 7 have only one; less than 250 pediatric rheumatologists in the country
- RA patients have a higher risk of certain cancers, heart disease
- Spending on arthritis medications more than doubled between 1998 and 2004, years when the average income did not increase.



**Congress/State houses need to know  
these facts and know it doesn't have  
to be this way.**



- Your Members were elected to represent the people...WE are the people.
- You are here today to learn how to be an effective advocate....you will follow-up back home... and you won't be going away.



## Current Environment


- Challenging ... budget cutting is real and choices must be made.
- However, cutting research and prevention is a mistake and will do more harm than good. This must be a priority!
- Where are we?
  - Continuing Resolution (through March 2013)
- Sequestration
  - What is it?
  - What is the AF doing?
  - How could it impact arthritis programs and research?




**69% of Americans believe it is unacceptable to cut spending on research and development of new cures for diseases**


*GarinHartYang, Feb 2011, polling data*







FEDERAL SPENDING	<b>\$3.7 TRILLION</b>
HEALTH ENTITLEMENT SPENDING (MEDICARE, MEDICAID, CHIP)	\$797 BILLION
DEFENSE DISCRETIONARY	\$715 BILLION
SOCIAL SECURITY SPENDING	\$701 BILLION
NON-DEFENSE DISCRETIONARY	\$549 BILLION
HEALTH DISCRETIONARY SPENDING	\$58 BILLION (F.550)








# Arthritis Foundation 2012 Advocacy Priorities





## New AF Strategic Plan

**One of 5 Strategic Objectives: *Influence* public policy to benefit people with arthritis.**

We are focusing on four key areas in 2012:

- Access
- Research
- Prevention
- Awareness

The AF's legislative priorities address these areas ...



## ACCESS TO CARE

**•ISSUE: Access to arthritis medications**

- ASK:** Ask your Member of Congress to become a co-sponsor of H.R. 4209 *The Patients' Access to Treatments Act* and help end discrimination against specialty tier medications.
- We are seeking an original sponsor in the Senate.
- The Arthritis Foundation is working in a larger coalition to achieve this goal.



## ACCESS TO CARE

- **ISSUE:** Access to pediatric rheumatologists
- **ASK:** Ask Members of Congress to support including \$5 million in funding for the **Pediatric Subspecialty Loan Repayment Program.**



## ARTHRITIS RESEARCH

- **ISSUE:** Sustained research investment necessary to reduce arthritis burden and build on years of discovery.
- **ASK:** Support arthritis research at the National Institutes of Health (NIH) and National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)



## ARTHRITIS RESEARCH

- **ISSUE:** Support arthritis research at the Department of Defense (DOD).
- **ASK:** Urge Congressional support for the inclusion of “**post traumatic osteoarthritis**” and “**rheumatoid arthritis**” in the **Congressionally Directed Medical Research Program (CDMRP)** for the Peer Reviewed Research Program in the Defense Appropriations bill for Fiscal Year 2013.
  - WIN: Senate language included “**post traumatic osteoarthritis**” and “**rheumatoid arthritis.**”



## PREVENTION

- **ISSUE:** Need to Support Arthritis Prevention at the Centers for Disease Control (CDC).
- **ASK:** Ask Congress to increase CDC arthritis prevention funding and oppose consolidation of chronic disease programs.





## AWARENESS

- **ISSUE:** Need to raise awareness on Capitol Hill of arthritis prevalence and impact
- **ASK:** Urge Members of Congress to join the bicameral, bipartisan **Congressional Arthritis Caucus** and unite in the fight against arthritis. (77 Members)



## Affordable Care Act (ACA)

### *Health Care Reform Implementation*

- Affordable Care Act was enacted into law in March 2010
- AF praised the Supreme Court's decision
- The Supreme Court upheld the constitutionality of the ACA in June 2012
  - Individual Mandate Stands
  - Subsidies stand
  - Federal grants to establish exchanges stand
  - Private market rules stand
  - Medicaid expansion



## Protections and Benefits

### These are in place NOW:

- Curbs on canceling policies
- Rapid Appeals
- Ban on Lifetime limits
- Annual dollars limits on their way out
- Free preventive care and annual checkups
- Premium rebates if insurers underspend on care
- Standard disclosure forms



## Protections and Benefits

### These are in place NOW:

- Young adults can stay on a parent's plan until age 26.
- Chipping away at pre-existing condition exclusions.
- Adults with pre-existing conditions
- Children under 19 with pre-existing conditions



## What's coming?

- Most Americans will be required to have health insurance in January 2014
- No more pre-existing conditions denials
- Online insurance marketplaces (State exchanges)
- Essential Health Benefits: Minimum level of coverage
- Medicaid Expansion

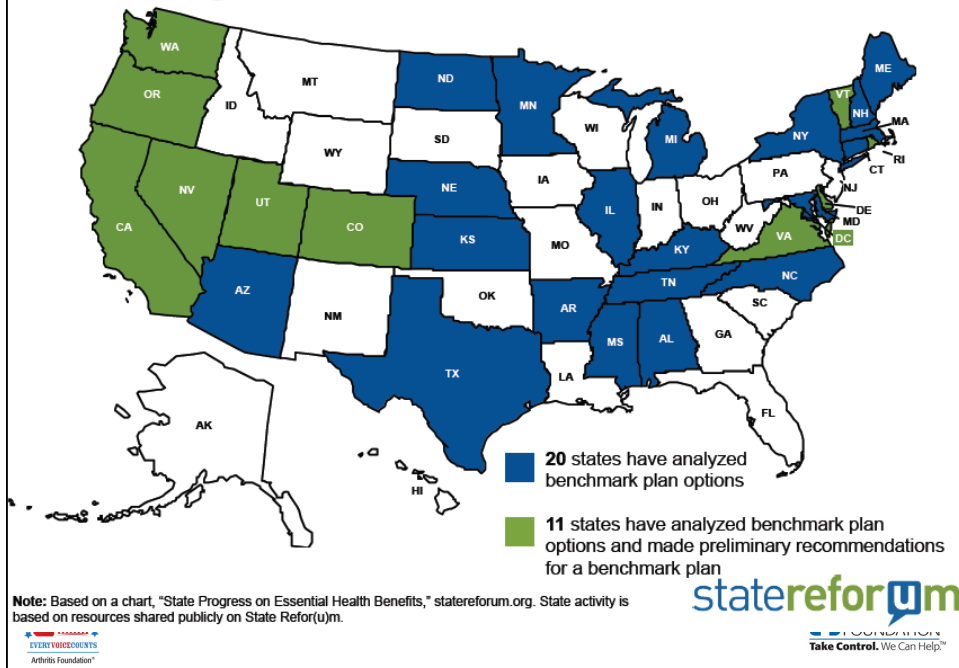


## Where are we?

- States are in the midst of a lot work; they have a lot of decision-making power and have tight deadlines.
- The states will decide:
  - Medicaid expansion: Governor's reactions
  - EHB Benchmark Plans
    - September 30<sup>th</sup> deadline for recommendations; otherwise default plan; will be open for public comment
  - State Exchange Blueprints
    - Due to HHS by November 16<sup>th</sup>, 2012



## State Progress Toward Essential Health Benefits



## New York's Progress

- On April 12, 2012, [Governor Cuomo issued Executive Order #42](#) to establish a statewide Health Exchange within the Department of Health.
- On July 9, 2012, Governor Cuomo submitted a [declaration letter](#) to the Centers for Medicare & Medicaid Services (CMS) confirming New York's intent to establish a State-based Health Benefit Exchange.

Donna Frescatore serves as the Executive Director of the New York Health Benefit Exchange.



## New York's Progress

- The establishment of the New York Health Benefit Exchange was included in the Governor's 2012-13 Executive Budget Proposal.
- The New York Health Benefit Exchange has established five Regional Advisory Committees to provide advice and make recommendations about the creation of the Exchange.
- New York has received implementation grants from federal government to help create the exchange.
- On June 23, 2012, the Assembly passed the Governor's Program Bill (A8514/S5849), which would create the New York Health Benefit Exchange. The Bill is awaiting action in the State Senate.



## New York's Progress

- New York has analyzed several benchmark plans (with outside, independent consultants) in anticipation of HHS deadline off 9/30.
- Recommendation has not been made yet to HHS
- Once made, opportunity for public comment
- Governor Cuomo plans to comply with Medicaid expansion



## **We need you!**

- It is critical you are involved in this process as the patient voice is essential!
- Many opportunities to provide input.
- We can't do it without you!
- **THANK YOU!**

