

International
Myeloma
Foundation

ADVOCACY AND YOU

IMF Advocacy Team



ROBIN ROLAND LEVY

SENIOR DIRECTOR PUBLIC POLICY AND ADVOCACY



KELLEY JONES

DIRECTOR PUBLIC POLICY AND ADVOCACY

- *STATE ADVOCACY*
- *GRASSROOTS ADVOCACY*



DANIELLE DOHENY

DIRECTOR PUBLIC POLICY AND ADVOCACY

- *FEDERAL ADVOCACY*



RAY WEZIK

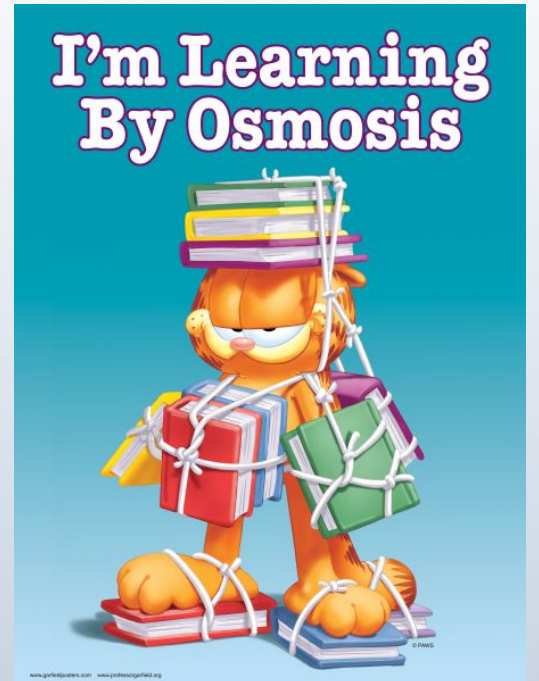
DIRECTOR PUBLIC POLICY AND ADVOCACY

- *LEGAL RESEARCH*
- *GRANT WRITING*



LEARNING OBJECTIVES

- WHAT IS ADVOCACY?
- WHAT IS MY ROLE?
- LEARN THE BASICS OF HOW GOVERNMENT WORKS;
INCLUDING HOW LAWS AND POLICY ARE MADE
- WHAT ARE THE IMF'S LEGISLATIVE PRIORITIES?
- HOW DOES ADVOCACY IMPACT THOSE LEGISLATIVE
PRIORITIES?
- DEVELOP BASIC SKILLS FOR EFFECTIVE ADVOCACY
- LEARN ABOUT THE IMPORTANCE OF DIVERSIFIED FUNDING
FOR A FREE AND UNBIASED VOICE



GOALS

- TO EXPOSE FUTURE ADVOCATES TO CURRENT LEGISLATIVE EFFORTS, ISSUES AND THE NEEDS OF THE MYELOMA COMMUNITY
- TO FOSTER AWARENESS ABOUT ADVOCACY AMONG IMF SUPPORT GROUP MEMBERS WHILE EMPOWERING THOSE MEMBERS TO BE ACTIVE ADVOCATES FOR THE MYELOMA COMMUNITY BOTH NOW AND IN THE FUTURE`



WHAT IS ADVOCACY?

- “ACT OF PLEADING FOR, SUPPORTING OR RECOMMENDING...”
– WEBSTER’S DICTIONARY
- PUBLIC SUPPORT FOR OR RECOMMENDATION OF A PARTICULAR CAUSE OR POLICY
- ANY ACTION THAT SPEAKS IN FAVOR OF, RECOMMENDS, ARGUES FOR A CAUSE, SUPPORTS OR DEFENDS OR PLEADS ON BEHALF OF OTHERS
- ADVOCACY IS A COORDINATED COMBINATION OF PROBLEM IDENTIFICATION, SOLUTION CREATION, STRATEGY DEVELOPMENT, AND ACTIONS TAKEN TO MAKE POSITIVE CHANGE.



THE THREE “A’S” OF ADVOCACY

- **AWARENESS**

- YOUR OWN, FRIENDS, FAMILY, COLLEAGUES, & LEGISLATORS

- **ADVANCEMENT**

- BY GETTING INVOLVED, YOU CAN HELP ADVANCE A MOVEMENT OR EFFECT POLICY CHANGE

- **ACTION**

- MAKE CONTACTS, WRITE LETTERS, CALL OR VISIT YOUR ELECTED OFFICIALS, & SUPPORT AN ORGANIZATION



WHAT IS LOBBYING?

A KIND OF ADVOCACY THAT ATTEMPTS TO INFLUENCE SPECIFIC LEGISLATION THROUGH INTERACTION WITH THE PEOPLE IT AFFECTS (GRASSROOTS) AND/OR THE PEOPLE WRITING THE LEGISLATION (DIRECT).



ADVOCATE VS. LOBBYIST

- WHEN NONPROFIT ORGANIZATIONS ADVOCATE ON THEIR OWN BEHALF, THEY SEEK TO AFFECT SOME ASPECT OF SOCIETY, WHETHER THEY APPEAL TO INDIVIDUALS ABOUT THEIR BEHAVIOR, EMPLOYERS ABOUT THEIR RULES, OR THE GOVERNMENT ABOUT ITS LAWS.
- LOBBYING REFERS SPECIFICALLY TO ADVOCACY EFFORTS THAT ATTEMPT TO INFLUENCE LEGISLATION
- THIS DISTINCTION IS HELPFUL TO KEEP IN MIND BECAUSE IT MEANS THAT LAWS LIMITING THE LOBBYING DONE BY NONPROFIT ORGANIZATIONS DO NOT GOVERN OTHER ADVOCACY ACTIVITIES.

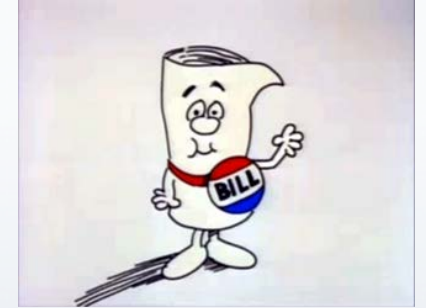


WHAT CAN ADVOCACY DO?



- CHANGE A LAW

- PASS A LAW



- IMPACT REGULATIONS

- RAISE AWARENESS OF AND ISSUE

- GIVE PEOPLE A VOICE

Impact!



WHY SHOULD YOU BE AN ADVOCATE?

*YOU MAY “HATE” POLITICS, BUT YOU CAN’T IGNORE
THE CONSEQUENCES OF POLITICS.*

**MAKE SURE YOUR VOICE
IS HEARD!**



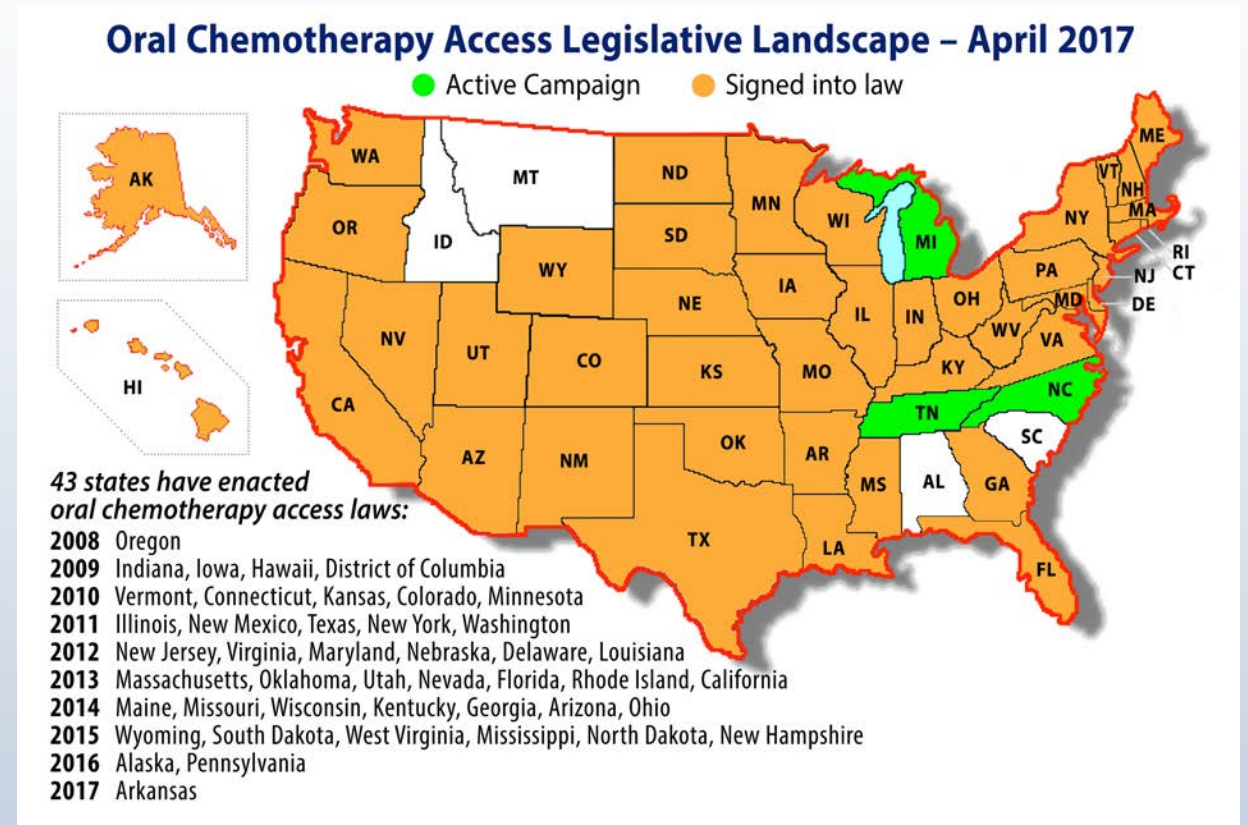
WHAT DO ADVOCATES DO?

- BUILD RELATIONSHIPS
- EDUCATE POLICYMAKERS
- RAISE AWARENESS
- SHARE YOUR STORIES; MAKE YOUR VOICE HEARD!



EXAMPLES OF SUCCESSFUL ADVOCACY

- STATE LEVEL ORAL PARITY
 - 43 STATES AND THE DISTRICT OF COLUMBIA
- INCREASED FUNDING FOR RESEARCH
- MARCH DESIGNATED MYELOMA ACTION MONTH



THE LEGISLATIVE PROCESS

HOW DOES A BILL BECOME A LAW?



THE LEGISLATIVE PROCESS

- **SLOW**
- VARIES FOR FEDERAL AND STATE
- KNOW WHEN YOUR VOICE WILL BE HEARD
 - PROPOSAL OF A BILL
 - PUBLIC HEARINGS ON THE ISSUE
 - LOBBYING INDIVIDUAL LEGISLATORS
- **AND INTERVENE**



HOW DOES ONE ADVOCATE FOR PUBLIC POLICY?

- FIND LEGISLATORS
- GET IN TOUCH
- DEVELOP YOUR MESSAGE
(IMF ADVOCACY CAN HELP!)
 - WHY SHOULD THE LEGISLATOR
CARE ABOUT THE IMF AND OUR ISSUES?
- POSITIVE IMPACT



IMF Federal Policy Priorities

- Health Care Reform
- Cancer Drug Coverage Parity
- Appropriations
 - National Institutes of Health Funding
 - National Cancer Institute Funding
 - Department of Defense (Congressionally Directed Medical Research Programs)
- Medicare Part D Donut Hole Closure
- Medicare Specialty Tiers



IMF State Priorities

- Cancer Drug Coverage Parity



- Implementation of Cancer Drug Coverage Parity



Questions?

Contact us!

Advocacy@myeloma.org

Follow us on Twitter

@IMFadvocacy



Like us on Facebook

@advocacyIMF

