



CML ADVOCACY - LEARN, SHARE, GROW
12TH INTERNATIONAL CONFERENCE FOR
ORGANIZATIONS REPRESENTING PEOPLE
WITH CML



BELGRADE
SERBIA
2-4 MAY 2014

Presenting the Regions
**CML Advocacy in
North America**
Challenges - Priorities - Initiatives

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THE NATIONAL
CML SOCIETY



Challenges:

- Access
 - High cost of treatment
 - Oral cancer treatments not covered by insurance plans as their IV counterparts
 - Varying coverage/co-insurance amounts leave patients with excessive out-of-pocket expenses
 - Many under or uninsured individuals fall outside the parameters of drug company assistance programs
- Adherence, Testing/Monitoring, Disease Education, Research Input
 - Inadequate understanding of importance of adherence
 - Newly Dx – role of adherence in future treatment cessation
 - Intolerance and side effect management
 - Access/drug coverage issues
 - Insufficient knowledge of monitoring/testing
 - QoL and strategies for living with a chronic illness
 - Few opportunities for patient engagement at a research level

Priorities:

- Drug Parity, Access to Treatment Act*, and Part D Beneficiary Appeals Fairness Act*
 - Support of parity legislation at the state/provincial/national level
 - Calls for oral cancer treatments to be covered under insurance plans „no less favorably“ that their IV counterparts
 - Support for HR460, the Access to Treatment Act (United States)
 - require insurance plans to limit cost-sharing requirements for specialty drug tiers to the level of cost sharing required for non- preferred brand drug tiers.
 - Support for the Part D Beneficiary Appeals Fairness Act (S1365 / HR2827)
 - Ensures that seniors can access the medications they need that are currently inaccessible due to restrictive „specialty tiers“ drug designations.
- Adherence, Testing/Monitoring, Disease Education, Research Input
 - Adherence Guide and What is MY PCR? Materials distribution/training
 - Provide ongoing opportunities to learn more about living with CML
 - Opportunities to learn more about treatment cessation programs/trials
 - Explore strategies for developing inroads into the research development process

Initiatives:

- Drug Parity & Access to Treatment Act (HR460)*, Part D Beneficiary Appeals Act*
 - Provide access to and education on parity and access issues
 - Provide and promote action opportunities in each state/province
- Adherence, Testing/Monitoring, Disease Education
 - Provide access to educational opportunities
 - Teleconferences/Webinars
 - Educational events
 - Adherence Guide distribution (NCMLS/Patient Resource Publishing)
 - What is My PCR?/Where Am I On The IS? Campaigns
 - Connection to leading CML physicians and researchers
 - Other opportunities

*US



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Thank you

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Leukemia & Lymphoma Society

The Max Foundation

and

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