

Advocate Handbook

MICHIGAN CANCER TREATMENT FAIRNESS COALITION

Dear Advocate,

Thank you for volunteering to meet with your state representative regarding life-saving legislation that will benefit thousands of Michigan residents. Your efforts represent the voices of cancer patients affiliated with more than 17 patient access organizations across the state.

Meetings held in your home district are crucial to the success of the bill. Your representatives need to know that many of their constituents will benefit from SB 625.

In the following pages, you will find resources that will better help you understand the issue and communicate your personal story. Our goal is to ensure that you have all the tools you need to conduct a successful legislator meeting. Remember, you do not need to be an expert on the issue. Your focus is to tell your story and build the foundation for a strong relationship with the office.

Thank you again for your efforts and please do not hesitate to contact me with any questions.

Sincerely,

A handwritten signature in black ink, appearing to read "Brian Sladek". The signature is fluid and cursive, with the first name "Brian" and last name "Sladek" clearly distinguishable.

Brian Sladek
Senior Manager, Advocacy
The Leukemia & Lymphoma Society
Brian.sladek@lls.org
Mobile: 727-366-1003

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CANCER TREATMENT FAIRNESS LAWS: GIVING CANCER PATIENTS HOPE

The way we treat cancer is changing, with oral anti-cancer medications playing an increasingly important role. These include targeted therapies available in pill form that directly attack cancer cells, and in some cases, can have fewer side effects.

As of January 2016, 40 states and the District of Columbia have passed legislation to limit patient out-of-pocket costs for oral anti-cancer medications. To see which states have passed these laws, visit www.speac.myeloma.org.

WHAT IS CANCER TREATMENT FAIRNESS?



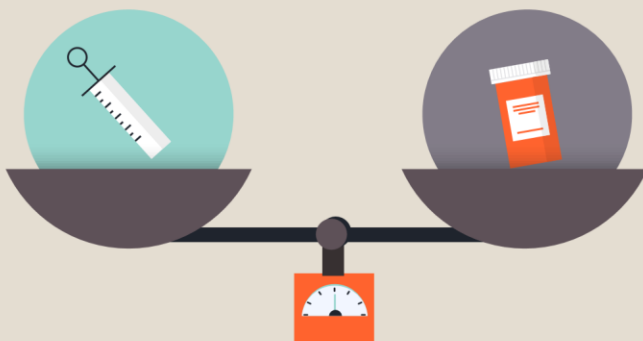
Traditionally anti-cancer medications were primarily administered intravenously and covered under a plan's medical benefit, sometimes requiring patients to pay a moderate co-pay, or in some cases, no cost at all for the medication.



Oral anti-cancer medications are usually part of the health plan's pharmacy benefit, often resulting in high, burdensome out-of-pocket costs through coinsurance, which requires patients to pay a percentage of the overall cost.

HOW CAN MY STATE ACHIEVE CANCER TREATMENT FAIRNESS?

Lawmakers in your state should join the ranks of 40 other states and pass legislation in 2016 that gives cancer patients access to the most effective treatments.



Cancer treatment fairness laws are intended to address the problem of inequitable coverage between oral and IV anti-cancer medications by requiring health plans to ensure that a patient does not pay more for an oral therapy than they would for an IV.

The laws do not mandate coverage of oral therapies, but simply state that if a health plan covers these treatments, the patients' out-of-pocket costs must be fair, regardless of how the therapy is administered.

WHO BENEFITS FROM THESE LAWS?

In the 40 states and D.C. with these laws in place, patients in state-regulated health plans have access to these protections.

State laws can only impact certain health plans. These laws do not impact Medicare and Medicaid. Health plans covered under the federal ERISA law (usually large, multi-state health plans) are also exempt.

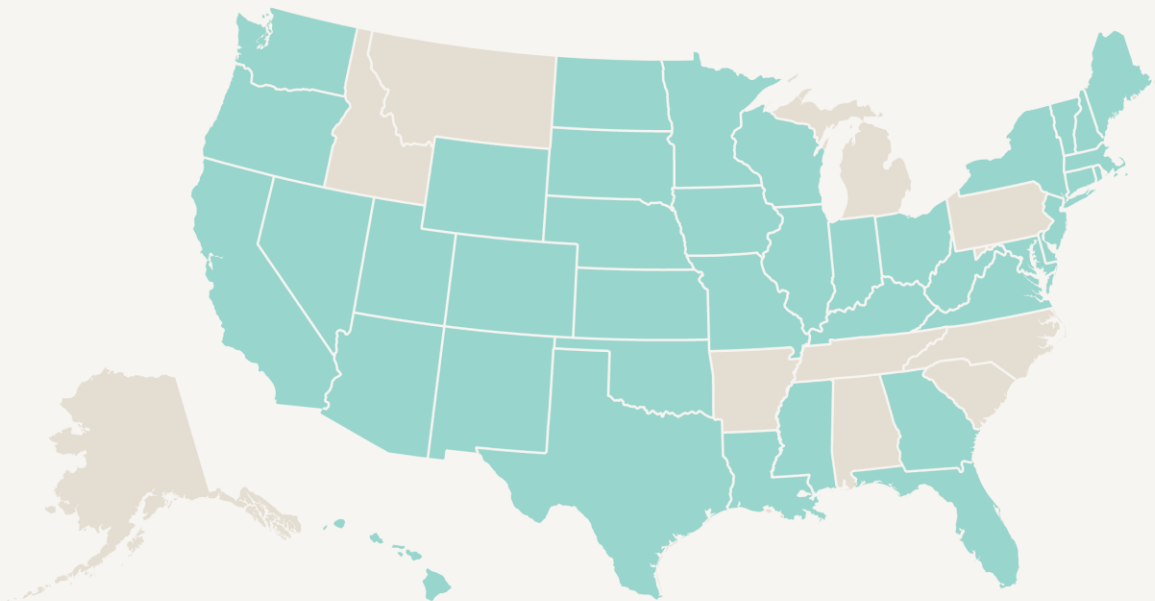


Cancer treatment fairness laws allow many patients and physicians to choose the right therapy that offers the most hope — without worrying about an outdated health plan benefit design that charges patients more simply because the drug they need is only available in pill form.



Oral anti-cancer medications are the wave of the future.

It is estimated that 25-35% of the drugs in the oncology pipeline will only be available in pill form. These laws ensure that patients fighting cancer today—and those who will be diagnosed in the future—have access to the innovative therapies offering them the best chance at survival.



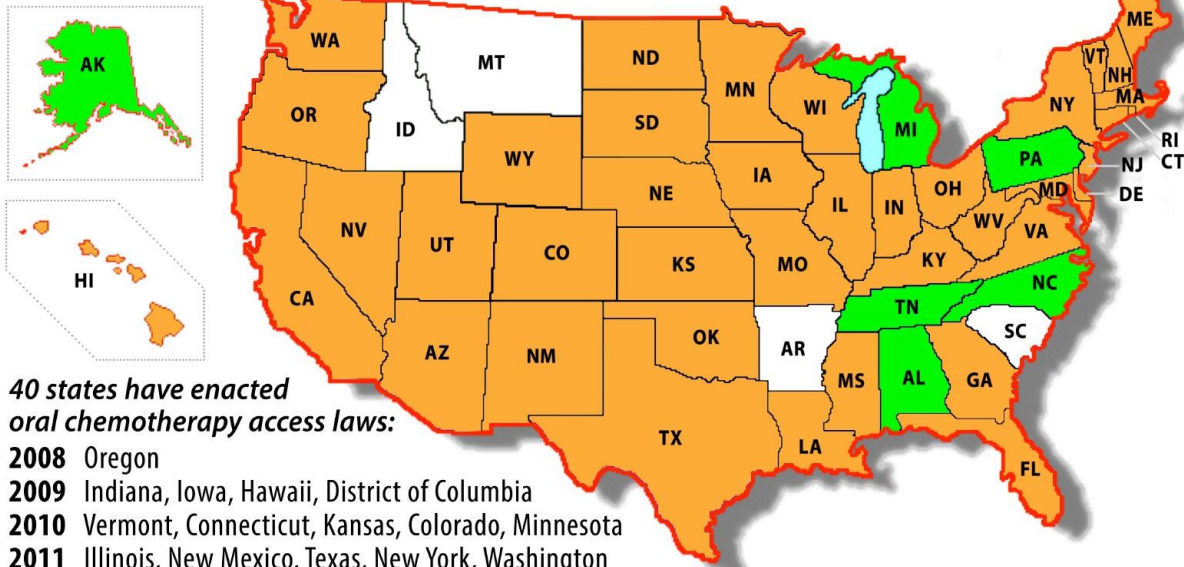
Where can I go for more information or to learn about the law in my state?

Visit the State Patients Equal Access Coalition (SPEAC) website at **www.speac.myeloma.org** for more information on the important role Cancer Treatment Fairness laws play and to download state-specific fact sheets on all the existing state laws.



Oral Chemotherapy Access Legislative Landscape – October 2015

● Active Campaign ● Signed into law



**40 states have enacted
oral chemotherapy access laws:**

- 2008** Oregon
- 2009** Indiana, Iowa, Hawaii, District of Columbia
- 2010** Vermont, Connecticut, Kansas, Colorado, Minnesota
- 2011** Illinois, New Mexico, Texas, New York, Washington
- 2012** New Jersey, Virginia, Maryland, Nebraska, Delaware, Louisiana
- 2013** Massachusetts, Oklahoma, Utah, Nevada, Florida, Rhode Island, California
- 2014** Maine, Missouri, Wisconsin, Kentucky, Georgia, Arizona, Ohio
- 2015** Wyoming, South Dakota, West Virginia, Mississippi, North Dakota, New Hampshire

The Michigan Cancer Treatment Fairness Coalition

The following patient advocacy organizations are part of the coalition:

AIM at Melanoma Foundation

American Cancer Society-Cancer Action Network

American Lung Association

American Society of Clinical Oncology

American Society of Hematology

Arab Community Center for Economic and Social Services

Cancer Support Community Ann Arbor

Colon Cancer Alliance

Community Oncology Alliance

Gilda's Club Detroit in Royal Oaks

Greater Lansing Area Oncology Nursing Society

International Myeloma Foundation

Karmanos Cancer Institute

The Leukemia & Lymphoma Society

Michigan Breast Cancer Coalition

Michigan Ovarian Cancer Alliance

Michigan Society of Hematology and Oncology

National Patient Advocate Foundation

Oncology Nursing Society Metro Detroit Chapter

Sisters Network Greater Metropolitan Detroit

Sisters Network Greater Metropolitan Detroit

Susan G. Komen Michigan

Susan G. Komen Race for the Cure Detroit



Metro Detroit Chapter
Oncology Nursing Society

What is the status of the bill?

Sponsor: Senator Goeff Hansen (R- Muskegon)

Senate Bill 625

- **Passed the Senate Insurance Committee with a vote of 7 (yes) to 0 (no).**
- **Passed the Senate Chamber with a vote of 36 (yes) to 1 (no).**
- **Referred to the House Insurance Committee**

The Meeting

How to Lead a Successful In-district meeting

Prepare for the meeting

- Do research on your legislator beforehand. You can search for their bio and other information by going to the following site: <http://www.house.mi.gov/mhrpublic/>

Know the issue

- Although you do not need to be an expert on every aspect of a bill, you need to know basic information about the issue that is being addressed.

Be organized

- Have brief (one or two-page) written material available. It should state the issue, your position and requested action.

Introduce yourself

- Be sure to include your city so the representative knows you are in their district.

Share the materials

- Share the illustrated one-page paper, the national map, and the press release (all attached in the e-mail)

Explain your position

- Inform your congressman or senator, but do not attack.

Be concise

- Stick to basics, and stay focused. You may only be given 10-20 minutes total to speak with him/her.

Tell your story

- This is the most important part of the meeting. Share why SB 625 is important to you and include any personal stories and/or experiences.

Most legislators do not have a health care background

- Make no assumptions about their level of knowledge of health care systems, financing, or delivery.

Maintain a professional appearance and attitude

- Dress in business attire. Always maintain a courteous attitude. Although it is appropriate to disagree with the positions held by a legislator, it is not appropriate to let that disagreement be evidenced by anger, rudeness, or disrespect.

When you leave the meeting, be sure the legislator knows your position and the expectations you have of him or her ("Please help SB 625 get a hearing in the House Insurance Committee this fall.") Also, be sure to thank them for their time.

Follow Up After the Meeting

Over the course of the meeting, the legislator may have specific questions about the bill. If you don't know the answer or are unsure, don't be afraid to tell them, "I don't know the answer to that, but I would be glad to find out and follow up with you."

If possible, obtain their business card before leaving the meeting.

Whether there was a specific follow up item or not, always e-mail the legislator to thank them for their time again and re-state what you are asking of them.

Also, please e-mail me (brian.sladek@lls.org) with any details from the meeting that may be helpful for the coalition to know. For example: *"The legislator will support this legislation and ask the Committee Chair that the bill receive a hearing as soon as possible"* OR *"the legislator could not commit to support the bill at this time."* Also, let me know if there were any questions you could not answer or if the legislator asked for specific information.

II c. Does My Story Make a Difference?

In 2015, the Congressional Management Foundation, a 501c(3) non-partisan non-profit organization which focuses on improving congressional operations and enhancing citizen engagement, conducted a survey of Congressional staff regarding the effectiveness of advocate involvement.

Here, we are sharing responses to two questions in that survey. In summary, **YOUR VOICE** makes a difference. It is an opportunity to begin to build a relationship with the Member and their staff and speak on behalf of thousands of Michigan cancer patients.

Survey Question 1:

How **helpful** is it for messages from constituents to include the following?

AND

How **frequently** do messages from constituents include the following?

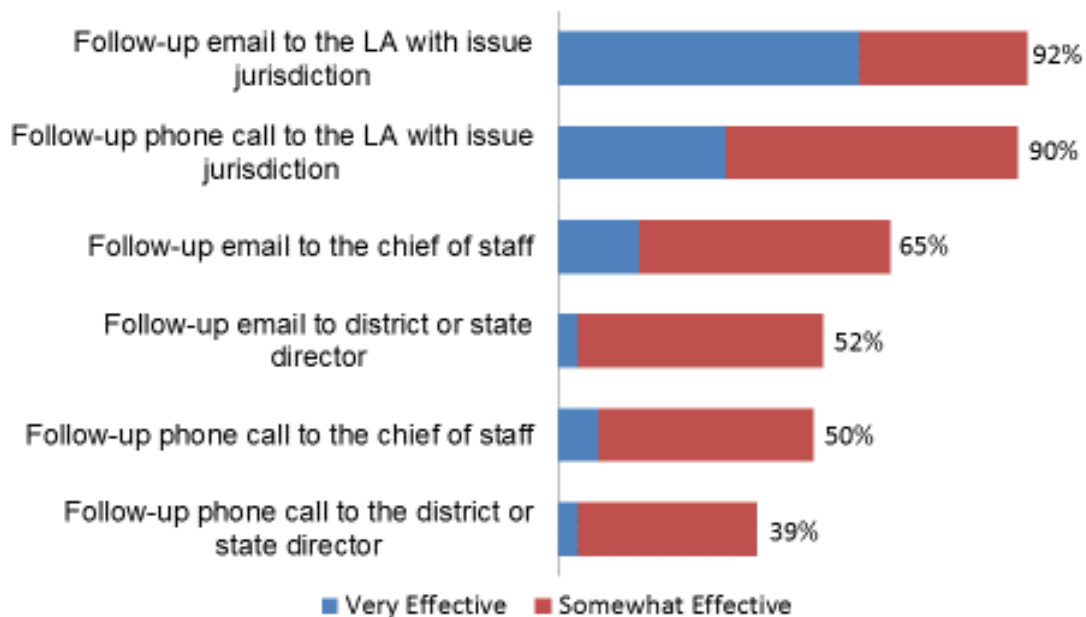
How Helpful vs. How Frequently?

Messages from constituents to include the following	Helpful/Very Helpful	Frequently/Very Frequently
Constituent's reasons for supporting/opposing the bill or issue	90%	50%
Name of the organization generating a campaign	78%	16%
Reference to specific legislation (as opposed to a general issue)	90%	59%
Information about the impact the bill would have on the district or state	91%	9%
Bill number and title	93%	42%
Personal story related to the bill or issue	79%	18%
Specific request or "ask"	88%	59%

Survey Question 2:

If, when meeting with a group of constituents as part of an organized fly-inn or lobby day, the Member or staff are not able to provide a firm decision on the issue(s) or request(s), please indicate **HOW EFFECTIVE** these follow up activities are, if conducted by constituents.

Constituent Follow-up



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Continuing Advocacy Efforts in Your District

After your meeting, there are other ways you can continue to raise your voice in support of SB 625.

Support the legislation on Facebook and/or Twitter.

There are opportunities to put together an op-ed in your local newspaper. We can also put together a patient profile piece that will function as a leave-behind item for future meetings.

Also, if you know of any ways to engage your local media, please let us know. We would be glad to find ways to get your story in the spotlight.

Please contact me (brian.sladek@lls.org) to begin the process on any of the items listed above.

Helpful Links

Below, you will find some helpful links if you wish to do additional research on the subject. This is not “required” reading to have a successful meeting. Remember, you do not need to be an expert!

[Searching for your state representative](#)

[More information on SB 625](#)

[Detroit Free Press article on SB 625](#)