



MA Cancer Advocacy Call

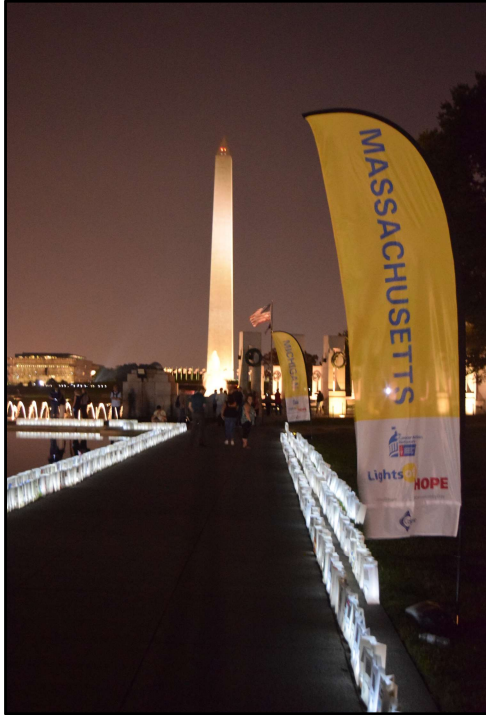
April 22, 2020

Attendees: Alice, Brock, Dana, Ally, Dan, Carol C., Kate, Patti, Melissa, Marc, Rebecca, Steve, Tim, Marisa, Deb, Jenny, Nancy, Carole S., and Annette.

Today's Agenda

- ❑ **Welcome and Roll Call**
- ❑ **Updates and Action Items**
- ❑ **The Henrietta Lacks Enhancing Cancer Research Act**
- ❑ **Book Club Discussion**
- ❑ **Wrapping Up**





Updates & Action

- Diversity and Inclusion
- Lights of Hope
- Ambassador Action Center
- Letter to the Editor Opportunities
- May Meeting

www.fightcancer.org/MALightsOfHope



Diversity & Inclusion:

- 2020 Boston Pride has been canceled. We are looking for other ways to engage the LGBTQ Community in Massachusetts. If you have ideas, please let Melissa know by emailing her at melissa.stacy@cancer.org.
- As a cancer advocacy organization, our power comes from our volunteers. We know that in order to truly represent the districts we work in, our volunteer teams need to reflect the congressional district and overall state demographics. With this in mind, we are trying to get a base line of our current Massachusetts team. We have developed a survey that would help us collect this information. The information you share with us on this survey will only be seen by Melissa and our leadership volunteers to help us identify areas and groups that we need to reach out to and engage in our work. This survey is completely volunteer and you only need answer the questions that you are comfortable with. A link to the survey can be found in the slide above, as well as on our Legislative Ambassador home page and should only take about 3 minutes to complete. If you have any questions or concerns, please don't hesitate to reach out to Melissa at 508-834-4017 or via email at melissa.stacy@cancer.org.

Lights of Hope:

- This is the 10th year for Lights of Hope! We encourage everyone to set up their page today by visiting www.fightcancer.org/lights. ACS CAN MA has set up their page (see the

slide above) and will be using it to promote the event on social media starting next week. As you set up your page, please let Melissa know and she'll link your fundraising page to our state page, helping amplify your reach! And stay tuned! ACS CAN will be holding a nationwide Lights of Hope Challenge the first week of June. We'll talk more about it on our May call.

- Lastly, if you plan to send anything to the ACS office, especially donations, please let Melissa know first. In these unique times, we have a new system for mail processing, and we are asking everyone to include specific information when they mail in donations. Please reach out to Melissa at melissa.stacy@cancer.org or via cell at 508-834-4017.

Ambassador Action Center:

- Shout out to Dan and to Dana for logging actions in the Ambassador Action Center. Don't forget that everything you do, from social media posts to sending emails via our easy action system count. I know that many of you responded to the email alert about the COVID19 packages, as well as a few other asks that national has sent out. Don't forget to log them!
- **Suggestion by Dan:** A lot of lawmakers are doing virtual Town Halls, either via Facebook Live or other ways. Joining one of them is a great way to hear what our lawmakers are focusing on! And yes, you can log your participation in them! 😊

Letter to the Editor Opportunities: We have template letters to the editor available both for Lights of Hope and about cancer patients accessing treatment during the current public health crisis. If you're interested in submitting a letter to the editor, please let Melissa know. Thanks to Deb and Tim who have already reached out!

May Meeting Date and Topic: Our next volunteer meeting will be May 27 at 7pm. We'll focus on the Global Cervical Cancer work as well as have at least 30 minutes allocated for a book discussion on *The Immortal Life of Henrietta Lacks*!

Boston Research Breakfast:

- *Update by Alice:* The Boston Research Breakfast has been moved from June 15th to September 24th. If you're interested in helping out with sponsorship ideas, spreading the word, or day of, Melissa will include information in the email along with the meeting minutes.

Hot Topic:

**Henrietta Lacks
Enhancing
Cancer
Research Act**



Why is this a CAN priority?

Clinical Trials - key step in advancing potential new cancer treatments from the research setting to the cancer care clinic.



As many as one out of five cancer clinical trials **fails** because of lack of participation.

Why is this an ACS CAN Priority? We need cancer research to generate new knowledge that can be used to improve survival and quality of life for patients living with cancer. Clinical trials are a key step in advancing treatments to cancer clinicals, therefore patient participation is essential to success. When asked, patients express a willingness to participate, yet only a small number of patients enroll in clinical trials because of the barriers that they say make it difficult and sometimes impossible for them to participate.

This is important to ACS CAN because low cancer clinical trial participation rates have long been identified as a challenge that faces the cancer research community. These low rates result in 1 out of 5 clinical trials failing due to lack of participation.

ACS CAN wants to increase both the overall participation in clinical trials as well as increase the diversity of cancer clinical trials to ensure every group is being represented.



www.fightcancer.org/policy-resources/clinical-trial-barriers#figures

How Did We Get Here?

In 2018 ACS CAN and our partners released a report on the patient barriers to clinical trials. I've shared the link in the past, and will include in the minutes sent out tomorrow. The report examined common barriers to cancer clinical trial participation. From that report we made 23 recommendations on ways to overcome those barriers, including recommendations for removing disparities in enrollment in cancer clinical trials.

One recommendation being that clinical trial sites selected for multi site trials have diverse patient participation that reflect the broader population with cancer. That recommendation aligns with ACS CAN's commitment to health equity and decreasing disparities in cancer care to make sure everyone has a fair and just opportunity to prevent, find, treat, and survive cancer. We want everyone to have the opportunity to be as healthy as possible.

What are the Patient Barriers?



Costs



Childcare



Transportation



Lack of diversity in healthcare workforce



Geographic location



Time off from work

80% of the public if asked are willing to participate in a cancer clinical trial, especially when a trial is recommended by a healthcare provider that they know and trust.

So what barriers prevent them from actually participating?

Cost: Additional costs paying to park, childcare, and transportation have been identified as barriers.

Logistical challenges: Many trials require additional travel time because of where they are located. Many studies showing us that often times patients have to travel 30 or more miles to get to a trial site, which strongly decreases their desire or ability to participate in a cancer clinical trial. In addition to the distance, the location creates the added barrier of extended time off for those that don't have paid time off from work. Patients may also not be able to drive or have personal transportation that can take them to the trial.

Another barrier for underrepresented groups participating in clinical trial is a lack of diversity in the healthcare workforce. We know that patients are more likely to enroll in a clinical trial if they have a healthcare provider that looks like them who recommends they participate in the trial. And they have that confidence in their patient/provider relationship that this trial is the best option for them. So we have to focus on developing a healthcare

workforce that is representative of our nations population and these under represented groups.

This bill is ACS CAN's first legislative step into clinical trials work. And it's built on our barriers report in addition to our health equity work to help us determine how to increase access and the availability of cancer clinical trials for all.

Request the Government Accountability Office (GAO) to:

1. Review federal agencies conducting cancer clinical trials
2. Identify barriers to participation by underrepresented groups and actions to address these barriers
3. Report findings and recommendations to Congress

S.946 & HR. 1966

**Henrietta Lacks
Enhancing
Cancer
Research Act**

Bill introduced in March of 2019

The Government Accountability Office, or GAO, would be responsible for reviewing all the federal agencies that conduct federally funded cancer clinical trials and assess the barriers preventing underrepresented groups from participating in these trials.

The GAO is an independent non-partisan agency respectfully known as the congressional “watchdog”. They help congress meet its congressional duties and improve the performance of congress and ensure accountability of all federal government on behalf of the American people. They look at how tax dollars are being spent, and provide congress and other fed agencies with objective and reliable information to help the fed gov save money and work more efficiently.

GAO report is a compilation of info. They receive a request from congress – either via a bill, or a letter from a committee chairman. They assemble a team of experts that works with the requestor to determine the scope of work, and what the finished product will look like.

For the Lacks bill we already have our questions laid out in the legislation. We want them to look at all federal cancer clinical trials agencies, what the barriers to participation – go through participation enrollment, look at whose participation and why or why not. Based

on that data, they will come up with recommendations on what the fed agencies can do. They will meet with fed agencies to gather support for the findings of their work.

The findings and report can take 3 to 12 months to outline objectives and recommendations to present to congress.

Congress then takes the recommendations and creates policies and legislation based on those recommendations. The GAO recommendations will give us a roadmap for the best legislative solutions to help implement policies and regulations to remove barriers to all groups participating in cancer clinical trials. These recommendations will also help private companies and organizations doing cancer clinical trials to increase representation as well.

GAO would have 2 years to compile a report of their findings and make a list of actions that each site could implement to address patient barriers to participation in clinical trials. This report would be submitted to Congress for review.

What Groups Are Underrepresented?

- Ethnic Groups
- Older Americans
- Poorer Americans
- Rural Americans

What are the Federal Agencies?

- National Institutes of Health
- Department of Veterans Affairs
- Department of Defense
- Food and Drug Administration
- Health Resources and Services Administration

What groups are underrepresented?

African American, Latinx, and Native American populations are underrepresented right now in cancer clinical trials. Legislation will help identify the barriers that prevent these groups from participating. Identifying these barriers and taking legislative action to remove them is vital to these groups being able to participate in trials. Research needs to be reflective of racial and ethnic groups that make up our country so that everyone has access to the newest treatments and therapies available, helping improve outcomes for all who are facing a cancer diagnosis, regardless of race or ethnicity.

Only 25 to 30% of participants are 65 or older. This is concerning given that 2 out of 3 cancer patients are 65 or older. While older patients are more likely consent to trials, fewer trials are available for them to participate in due to comorbidities common in the age group. Additionally, they are not really asked to participate in cancer clinical trials...an easy barrier to overcome.

The economical status can affect patients ability to participate in cancer clinical trials. Access to resources has a huge influence on whether or not someone participates. Patients that earn less than \$50,000 a year are less likely to participate. These patients have fewer resources. Co-pays, co-insurance, time off, and travel can present a significant barrier that they can not over come in order to participate.

Lack of availability of clinical trials in rural areas sets up a geographic barrier. We need to think about distance they have to travel. Advocate for localized trials that are in a person geographic region, that makes reasonable sense for them to be able to travel to. Needs to be addressed by moving trials into community.

What federal agencies will be looked at?

GAO will work with these agencies when compiling the report. All do some type of cancer clinical trials. Please note that this is not an exhaustive list.

National Cancer Institute (NCI), Center for Disease Control (CDC) and the Cancer Registries fall under the National Institutes of Health

- **Question by Alice:** It's my understanding the CDC falls under Health and Human Services (HHS). **Answer:** Alice is correct. Both the CDC and NIH fall under the umbrella of HHS. The NIH conducts and funds basic and applied biomedical and behavioral research. The CDC engages in health promotion, prevention of disease, injury and disability, and preparedness for new health threats, and FDA ensures the safety of drugs, medical devices, and many other products that stem from biomedical research.

Focus is to sit with agencies and talk with them about barriers they are facing in regards to when it comes to patients participating. Talking with the leaders of these orgs will help us understand patient populations they are relying on clinical trials, This gives us an eye into what federal agencies are doing. identify barriers that prevent patients from participating, thus forming their recommendations.

Why is the bill named Henrietta Lacks?

Henrietta's Grandchildren:
Jeri Lacks Whye and David Lacks



Why is the bill named Henrietta Lacks Enhancing Cancer Research Act.

Born in 1920 in VA, she was a tobacco farmer who settled in Baltimore with her husband in her early 20's.

Diagnosed in 1950 with Cervical cancer shortly after giving birth to her last child. She was treated at John Hopkins in Baltimore MD, which at the time, was the only hospital that would treat black patients.

Without her knowledge or consent, Mrs. Lack's cervical cells, both regular and cancer cells, were taken at the request of a cancer research doctor without her knowledge. While her regular cells died, her cancer cells were the first cells in medical history to live, divide, and multiple in 24 hours.

Her cells, called HeLa cells, have been used in research labs across the globe, helping find scientific breakthroughs in chemotherapy, polio, hemophilia, Parkinson's disease, HIV/AIDs, etc. All without her families knowledge. Nearly 70 year's later, her cells are still surviving and being used in research.

ACS CAN worked with Chairman Elijah Cummings, the former Representative from

Maryland, to honor Mrs. Lack's memory and the contribution she has made to the medical community by naming our bill after her. Mrs. Lacks lived in Representative Cummings' district, and he had a relationship with her family. The naming of this legislation is one small way we can honor her legacy.

Rep. Cummings worked with the MD delegation to introduce the bill on the House side. Then he reached to the Senate to intro companion bill there. This gives us more opportunity to get legislation passed.

Current focus is on getting a Republican lead co-sponsor for both House and Senate. We are regrouping and working with our co-sponsors now that Chairman Cummings has passed. Only 24 sponsors on the House bill and 1 sponsor on the Senate bill. We have not done a co-sponsor push yet, and will as things start to return to "normal".

“You do not engage the attention of the reader unless your story has basic human interest elements.”

Roland Berg

~The Immortal Life of Henrietta Lacks by Rebecca Skloot pg 106

www.fightcancer.org/shareyourstory



What Can You Do?

Share your story!

Once Congress returns to some semblance of normal business, we will be making a strong and concerted push on this bill. What we’re going to need, as we always do, are stories. Stories take this out of the hypothetical and show these members that this is a real issue affecting real people. Having a storyteller there in person also makes it harder for the member to tell us no. So right now is a great time to start looking for those.

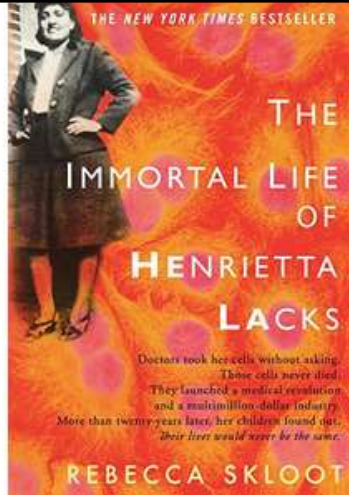
What makes a good story for this campaign? There are a few options, and many people may not realize their story qualifies. When looking at a story, you want to consider ways that we can tie it back to the bill:

The two examples are the obvious ones:

1. Someone who did a trial, but had to leave their home city to do it, or figure out how to manage childcare or take time off from their job while they did their trial. I knew someone who had to leave his family in Missouri to spend weeks in Seattle for his trial; he was lucky to be able to afford to do that, but I don’t think it’s difficult for lawmakers to understand that plenty of people wouldn’t be able to.
2. The second one on here is going to be harder to find, but if we know of a patient who qualified for a trial but wasn’t able to participate because of barriers, that’s a slam dunk.

And this is a good time to emphasize that it doesn't have to be the patient themselves – it can be someone we know who can talk about a loved one's experience.

3. Finally, I think we should all be thinking about ways that our cancer journey, regardless of whether it's linked to cancer clinical trials or not, can be linked to an ACS CAN priority issue. Whether its cancer research related, tobacco related, palliative care related, colorectal cancer screening related, or any other cancer issue, your story can help ACS CAN move our mission forward. And you may have more than one story or your story may fit more than one policy issue. It's ok to share it different ways, or highlight all the areas it touches. It's truly your story that makes a difference. 😊 Our easy Share Your Story link is in the slide above.



Book Discussion



We want to take the opportunity to say THANK YOU to Marisa Lutz, the Congressional District 5 District Lead. Marisa has been the CD5 district lead the past two years, and is stepping back effective May 1. Marisa has done an incredible job growing the district and engaging her team. We're excited that she's committed to staying on as a Legislative Ambassador! Thank you, Marisa, for EVERYTHING you've done and continue to do to move the mission forward.



As this is volunteer appreciation week, we want to take a minute to say thank you to all of you. You are such an inspiration to us. From passing first in the country tobacco flavors legislation to historic increases in federal cancer research funding, you all are moving mountains. Thank you!!

