



MA & ME Cancer Advocacy Call June 24, 2020

Attendees: Hilary Schneider (ME Staff), **Melissa Stacy (MA Staff)**, Patti Morris (MA SLA), Mikala Bosquet (ME SLA), Deb Cornwall (MA CD9 Lead), Bethany Zell (ME CD 2 Co-Lead), Diane Aston (ME CD 1 Lead), Dana Bernson (MA CD 4 Lead), Carol Pesti (ME CD 2 Co-Lead), Dan Treacy (MA CD 5 Lead), Emily Poulin (MA CD 8 Lead), Kate Weissman (MA CD 7 Lead), Jeff Bennett (ME NAT Member), Abby L. (MA/ME Intern), Lauren C. (MA/ME Intern), Brock Cordiero (MA CD 9), Matthew Carvalho (MA CD 9), Terry Baker (ME CD 1), Elizabeth Zell (ME CD 3), Jenny Brown (MA CD 8), Alice Pomponio (MA CD 4), Tom Keating (ME CD 1), Carol Coles (ME CD 2), Dan Bahr (ME CD 2), Peter Bridgeman (ME CD 1), Rebecca Hoffman (MA CD 7)

AGENDA

- Welcome and Introductions
- Updates and Action Items
- Lights of Hope 2020
- Global Cervical Cancer Initiative
- Wrapping Up



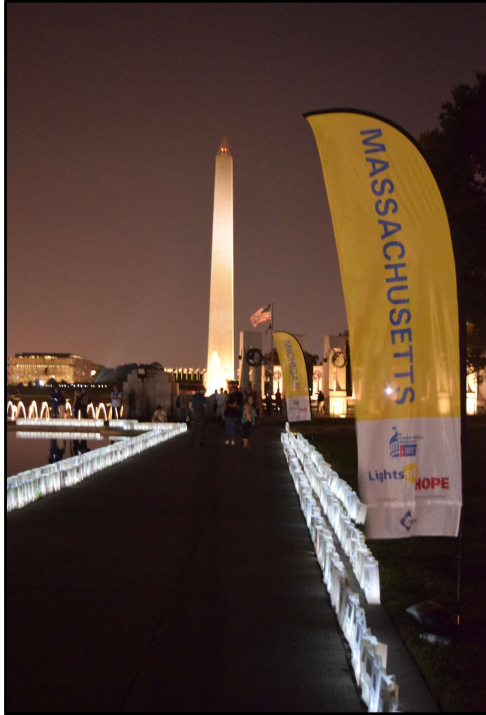
PATTI:

Reviewed agenda and led off intros, kick to Mikala and welcome her and the Maine volunteers to the call, then other attendees

- Name
- State
- Years as a volunteer
- Rocky beach or sandy beach or swimming pool

Important to note that we will not be doing intros on every call. This was a one time occurrence as this is our first meeting as Maine and Mass. 😊

****Note:** This was Dan Treacy's first meeting as the new lead in CD5!



Updates & Action

- Diversity and Inclusion
- Ambassador Action Center
- July Meeting
- State Updates
- Story Collection



PATTI:

Diversity & Inclusion:

- As you all know, we are working hard to ensure that our ACT! Teams reflect the demographics of the districts we live and volunteer. Based on the changes to our structure, and with Melissa becoming Maine's as well as Massachusetts Grassroots Managers, we are going to revisit our Diversity and Inclusion plans to ensure that we have the capacity to complete the entire plan. If you are interested in helping us revisit these plans, please let me, Mikala, or Melissa know. The more of you that are involved the more we can accomplish!

Ambassador Action Center:

- Shout out to Dan and Dana here in Massachusetts for logging actions in the Ambassador Action Center since our May call. And a shout out to Mikala in Maine for logging actions via fundraising.
- Reminder that fundraising dollars from CAN Raiser (including Lights of Hope) automatically transfer each month. However, for every ACS CAN membership you get as part of Lights of Hope you do need to go in and record the membership under activities. It will get you extra points!

- Don't have access to the Ambassador Action Center? Email Melissa (melissa.stacy@cancer.org) and she'll hook you up!
- *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! 😊 If you're looking for questions to ask, let Melissa know.

July Meeting Date and Topic: Our next volunteer meeting will be July 22 at 7pm. An updated invite will be sent out to all Maine and Massachusetts volunteers later in July with a new call in number and link. We'll come together as a full group for the ½ of the meetings and then breakoff into state groups for state specific updates and actions.

ACTION: Please let Melissa, Patti, and/or Mikala know if there is a policy issue topic you'd like us to deep dive into.

State Updates:

- For this week, state updates will be including in the meeting notes that will come from your District Leads so stay tuned!

Story Collection: - MELISSA

- We are very blessed to have two high school interns helping out for a total of 60 hours this summer. Lauren and Abby, who you met earlier, are helping establish our ACS CAN Story Bank for BOTH Massachusetts and Maine. Starting tomorrow, if you've shared your story with ACS CAN online, Abby and Lauren will be reaching out with follow up questions, drafting a final story, or two, sharing that with you for any edits, and gathering your permission for ACS CAN to use the story. So, when you get a call from 508.834.3317 don't run and hide. 😊
- If you haven't submitted your story yet, but would like to, there's not time like today. 😊 visit www.fightcancer.org/share-your-story or email ACSCANStories@gmail.com.



Lights of Hope

ACROSS AMERICA
BRINGING HOPE HOME



fightcancer.org

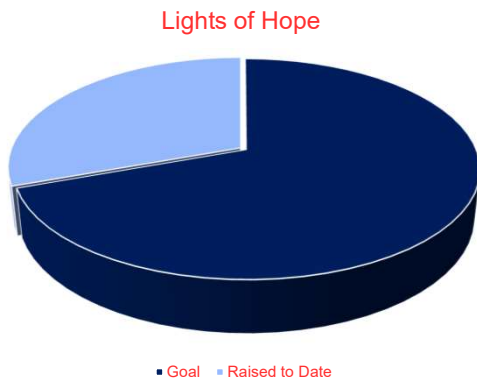
www.fightcancer.org/MALightsOfHope

Patti:

Lights of Hope:

- As we talked about last month, this is the 10th year for Lights of Hope! We encourage everyone in both Maine and Massachusetts to set up their page today by visiting www.fightcancer.org/hope
- Don't forget, the next ACS CAN nationwide Lights of Hope Challenge is July 16 at noon to July 20th at 3:59pm. It's the \$100 in 100 hours challenge! Raise \$100 online in that time frame and receive special recognition! (See attachment in email that these notes came in.)
- Have cash or check donations? Reach out to Melissa and she'll send you the information you need to include on your donations to ensure that your state gets credit for the money you're raising to support the mission of ACS CAN.

2020 Massachusetts Lights of Hope



- **Goal: \$15,000**
- **Raised to date: \$6,585**



PATTI:

- As promised, we'll update you each month on our progress to goal
- Our Massachusetts 2020 REVISED Lights of Hope Goal is \$15,000. We currently have raised \$6,585 to date. You all are rocking it!
- Shout out to Alice for raising \$2,695 to date, and being the top fundraiser in MA...for now. 😊 Dana is only \$60 behind her, so look out!
 - Point of order: As of the meeting last night, Dana had surpassed Alice (sorry Alice!) and is the lead fundraiser in the country! Congratulations Dana!



Bring Hope Home

- Massachusetts Challenge
- Who can participate
- Instructions
- Info sheet



PATTI:

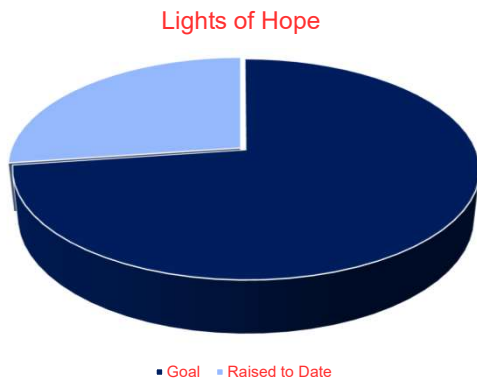
Bring Hope Home is an opportunity to for ALL Legislative Ambassadors to participate in Lights of Hope.

It's simple:

- Create and customize your fundraising page at fightcancer.org/hope.
- Ask friends and family to donate a bag (they start at \$10) and include an annual ACS CAN membership
- Ask Melissa to send you bags
- Display your bags for the month on July 12th and August 12th
- Take photos of them and post to social media tagging ACS CAN Massachusetts
- Submit a letter to the editor letting your town know what you're doing and ask them join you.
- On September 12th display all your bags as part of Hope Across America and attend the live streaming ceremony
- While this started as a Massachusetts Challenge, we are welcoming our ACS CAN Maine family members to join us if you would like! Melissa will include directions in the meeting minutes for those of you that would like to join us! (See

attachment in email that this came in for more instructions if you would like to participate!)

2020 Maine Lights of Hope



- **Goal: \$3,500**
- **Raised to date: \$1,308**



MIKALA:

- We'll update you each month on our progress to goal
- Our Maine 2020 Lights of Hope Goal is \$3,500. We currently have raised \$1,308, putting us off to a great start!
 - Mikala shared that she has money to log and send in as well so Maine is closer to \$1,500!
- Shout out to Diane for raising \$585 to date, and being the top fundraiser in ME.



Lights of Hope Corporate Sponsorship

- Maine Started in 2019
- Who can participate
- Instructions
- Info sheet



DIANE:

Last year, Maine began the Lights of Hope Corporate Sponsorship program, and did an incredible job of engaging the business community in Maine in Lights of Hope. So well in fact that ACS CAN national picked up their program and made it a nationwide initiative.

It's simple:

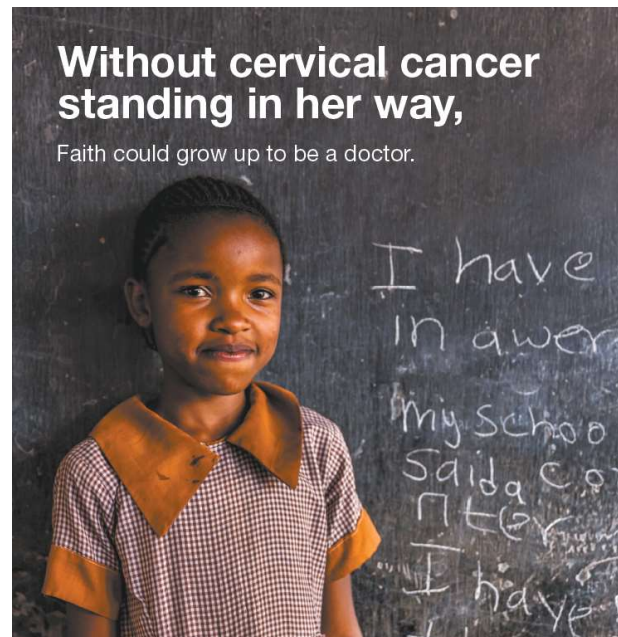
- Create and customize your fundraising page at fightcancer.org/hope.
- Ask a business or two you frequent to become a sponsor.
- Sponsorship levels are \$200, \$350, and \$500.
 - The sponsor receives bags and recognition for their sponsorship. They can decorate bags and put them out on September 12th as part of Lights Across America if they want to participate. If not, you can put them out as part of your bags. Work with the sponsor to ensure they are decorated in the way they would like.
- Ask Melissa for bags
- If the sponsor is displaying them, ask them to take photos and post to social media tagging the ACS CAN state page.

- We have an easy letter with the steps that you can edit and submit to a sponsor. And are challenging Massachusetts volunteers to join us this year! (See attachment for updated letter that anyone can use!)

The Advocacy Component:

Ending Death from Cervical Cancer Worldwide

[www.fightcancer.org/
GlobalCervical](http://www.fightcancer.org/GlobalCervical)



MELISSA:

ACS and ACS CAN are actively engaged in reducing cervical cancer rates in the U.S.

ACS CAN is working hard to prevent cervical cancer by advancing federal and state funding for critical cancer screenings and supporting evidence-based efforts to increase uptake of the HPV vaccine.

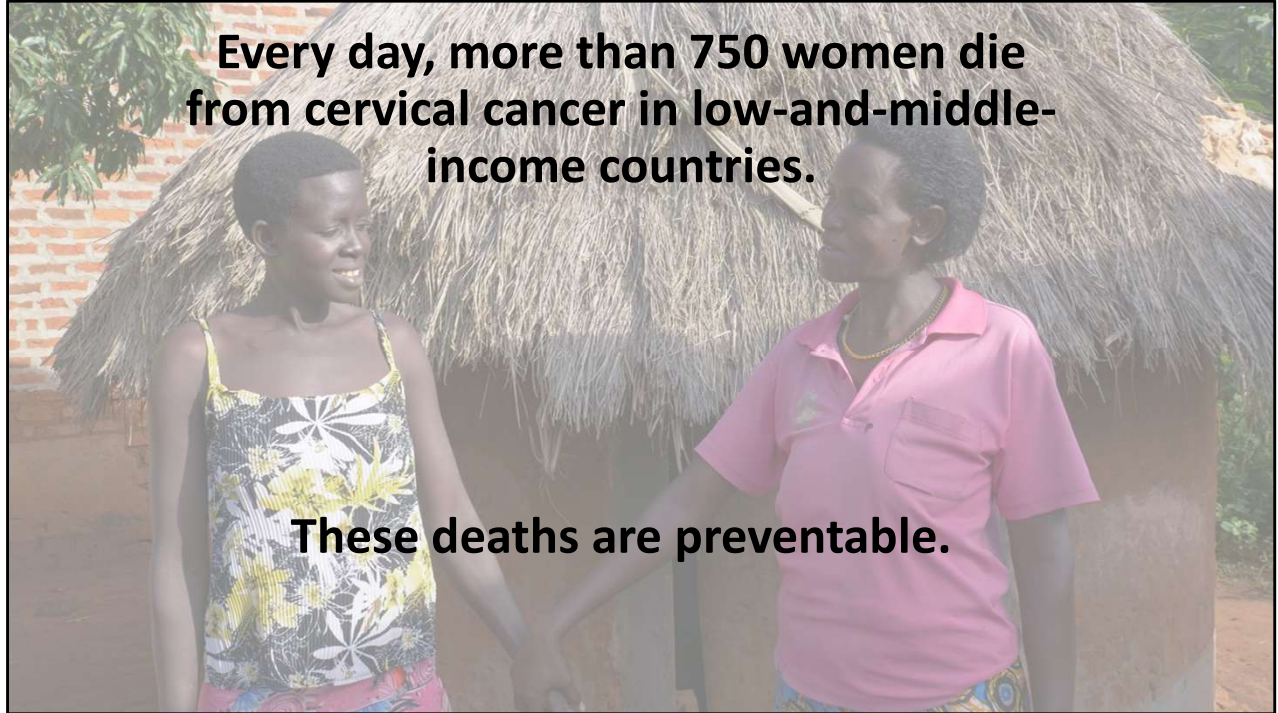
To increase the rates of HPV vaccination and to fight HPV associated cancer, ACS is working to educate individuals on the safety and effectiveness of the HPV vaccine; expand provider education and training; improve health disparities; reduce barriers to access; and identify evidence-based opportunities for effective policy change.

ACS Health Systems staff have engaged key stakeholders as conveners, connectors and change-makers to prioritize HPV vaccination. Over 90 percent of ACS Health Systems staff are engaged in HPV vaccination efforts across the U.S.

ACS's partnerships with state health departments and other state-based entities facilitate system changes that increase the availability and utilization of the HPV vaccine.

ACS and ACS CAN have made an enterprise-wide commitment to increase HPV vaccination rates among preteens and reduce gender and geographic vaccination

disparities.



Every day, more than 750 women die from cervical cancer in low-and-middle-income countries.

These deaths are preventable.

We have the opportunity to end deaths from cervical cancer worldwide.

In low -and middle-income countries (LMICs), cervical cancer remains the primary cause of cancer-related deaths among women.

Today, 90 percent of all cervical cancer deaths globally occur in LMICs.

In 2018, 85 percent of the estimated 569,000 new cervical cancer cases occurred in LMICs.

Death from cervical cancer is preventable with vaccination, screening and treatment. No woman has to die from this disease.

Currently not a priority

US provides funding for HIV/AIDS, malaria, etc, just to let people die of this disease – has been focused on communicable diseases only.

Cervical cancer in the U.S.



Cervical cancer in low and middle income countries



We have the tools we need to get the job done.

Cervical cancer was once one of the most common causes of cancer death for American women. But over the past 30 years, the cervical cancer death rate in the U.S. has dropped 50 percent.

This drop is thanks to screening and early detection efforts.

While we will continue to work to prevent the more than 4,000 deaths each year from cervical cancer in the U.S. we must, at the same time, use what we've learned here to help save more lives around the world.

Virtually all cervical cancers are caused by the human papillomavirus (HPV). There is an effective and safe vaccine that prevents most HPV-related cancers.

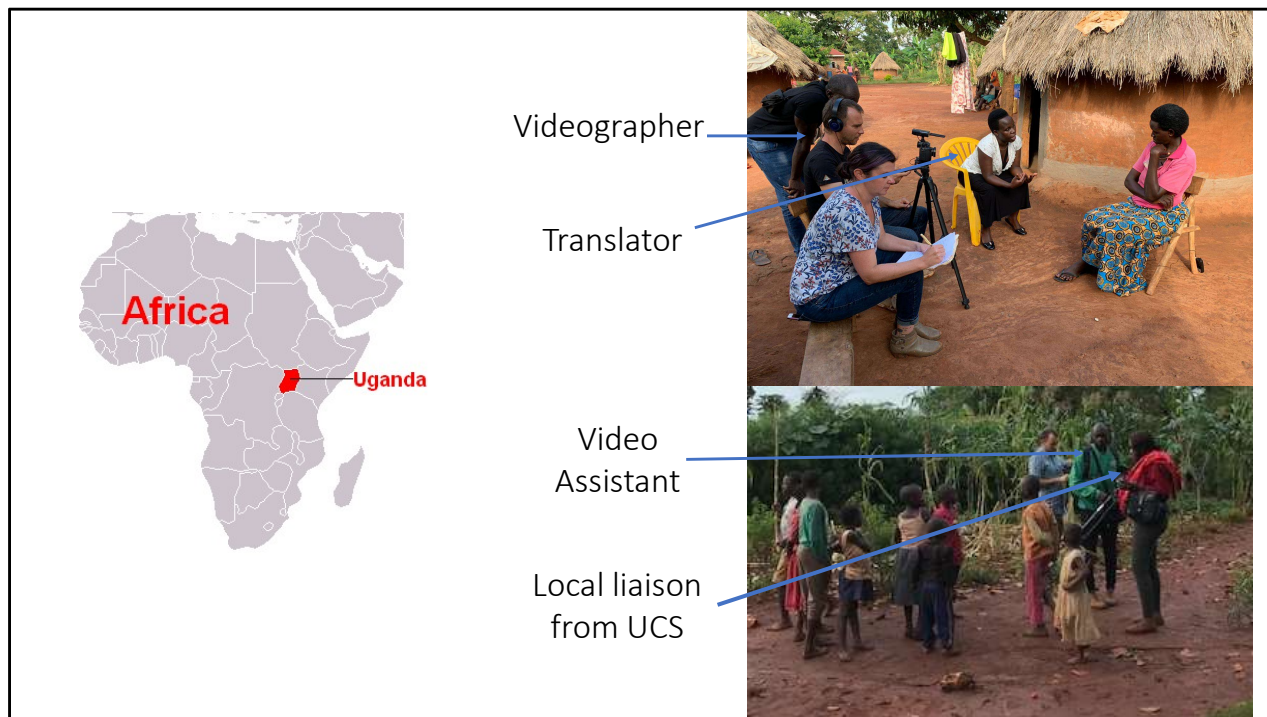
In LMICs, this vaccine cost just \$4.50 per dose, making it one of the most cost-effective cancer prevention methods available.

It's also critical that women have access to simple screening and treatment methods that can be easily implemented in these countries. During these screenings, precancerous lesions can be found and removed, saving women's lives.

- One of the keys to all of our campaigns is stories, making it clear the impact that Congress can make
- We know what cancer looks like in the US, and we can bring those stories to

Congress

- But it's harder when we're talking about LMICs
- We can hear about the situation and try to understand what it's like, but seeing their faces, and hearing their personal stories from women who are going through this is a whole different thing.
- So two of our national staff went to Uganda last fall to get those stories, so we could bring them to Congress, and to our volunteers and the media



- ACS CAN put together a team, as you can see here, with the help of the Ugandan Cancer Society, and traveled around the country.
- We met with and interviewed cervical cancer patients, some who were currently in treatment and some who weren't, their families, and service providers.
- We started in Kampala, the capital city, which is where everyone has to go to get treatment
- And we went out to some rural areas



- Listening to Brittany talk, it's so inspiring! Similar to the video you all watched as "homework". 😊
- First of all, the HPV vaccine is not AT ALL widely available in Uganda. In fact, very few people have even ever heard of the vaccine, or knew that there was something that could be done to help prevent cervical cancer in the first place.
- Second, we found that women were not getting diagnosed until they were in very late stages of the disease, if at all. These aren't communities where it's normal to go in for a regular gynecological exam, and most women in countries like Uganda will never be screened for cervical cancer even a single time in their lives.
- So they usually don't even know they have cancer until they are in late stages, and there aren't many opportunities for them to get treatment.
- Those who are fortunate enough to get treatment, they have to travel to the capital city of Kampala to do that, leaving their families behind.
- One woman we spoke to, Grace, would need to take a 10-hour bus ride from her home to the capital city in order to get treatment. Not something she could afford to do regularly to get her treatment.
- Grace is only 35, and she's a mother.
- Luckily, she was connected with an aid organization there that works with ACS's global department, and they've given her a place to stay in Kampala so she can be

close to where she's getting treatment.

- She's one of the lucky ones, but even so, she's been away from her children for over a year. In order to get the treatment that could save her life, Grace's children had to stop going to school, and her oldest daughter, who is 15, had to find a job to be able to feed her younger siblings anything at all, since their mother isn't there to take care of them.
- These are the kinds of choices that women with cervical cancer are making every day in low and middle-income countries.
- Another woman we spoke to, Edith, is in very late stages of her cervical cancer. She lives in a very rural, remote village with her 10 children and her grandchildren.
- When she found out she had cervical cancer, she couldn't afford to get treatment, so she didn't. She's in a lot of pain, and didn't have much time left when we met with her.
- She was really excited to talk to us about her experience when we explained to her why we were there. She wants to do everything she can to make sure that other women in her village don't have to go through what she's gone through.
- And frankly, it can't come soon enough.
- The stories these women shared with us were absolutely devastating, but I want to remind you all that there's hope.

The Ask for 2020

- ACS CAN calls on Congress to dedicate a portion of U.S. global health funding to help accelerate the elimination of death from cervical cancer.
- **We're calling on members of Congress to submit language to the Appropriations Committee that requires USAID to prioritize programs in LMICs.**
- With U.S. investment, we can accelerate the elimination of cervical cancer death globally, saving hundreds of thousands of lives. It's time to take action.

JEFF BENNETT– National Advocacy Team Member

There is something we can do about it. We've launched a campaign to end death globally from cervical cancer.

- The USAID is part of the appropriations process, which is the same process as our ask for Research Funding.
 - USAID is in the ground in lower to middle income countries
 - Focuses on communicable diseases only, which means the HPV vaccine is a great fit for the program
 - Currently, there is not a curriculum in the program about HPV prevention or cervical cancer screening or treatment.
 - No additional funds would be needed to make this a part of the work USAID does. It's simply a matter of integrating education around the vaccine, screening, and treatment into the program.
 - The head of USAID is supportive and wants to do this work, we just need congress to give him permission as part of the appropriations ask.
- So we're asking Congress to act and to do something about this
 - We're asking them to add the language to include cervical cancer screening and treatment, as well as the HPV vaccine into USAID's program of work.

We want it to be part of this year's budget.

- Trying to get it in this year's budget

Where are we now?



JEFF BENNETT– National Advocacy Team Member

- We had a mini lobby day on Feb. 11th, talked to targeted lawmakers
- Been getting very good response from them. The House is supposedly following their normal approps process this year
 - Weeks of July 6th & July 13th will be markups in committees
 - Weeks of July 20 & July 27th will be the votes on all 12 approps bills.
- Then we'll turn our full attention to the Senate, the timeline there is super unclear but most likely won't see anything other than a continuing resolution in September, followed by budget work in the lame duck session between the November elections and the end of the year.
- In the meantime, we're doing our work to grow our team of volunteers who care about this issue especially in targeted states, but all over the country. Right now the only target we have in our two states is Senator Collins in Maine.
- The lead sponsor of the appropriations ask would like her to be the lead republican sponsor, and Jeff is working on that. 😊
- If you want to be included in updates and ways to take action as the campaign moves forward, text COLLEGE to 40649 to sign the petition and stay up to date on ways you can work on this campaign.

- And we need to keep up the drumbeat and make sure that even in these strange times, lawmakers don't forget about this

Q&A