

## **May ACS CAN MA Volunteer Call Agenda**

**Attendees:** Melissa, Julia, Casey, Dana, Emily, Dan, Brock, Marisa, Ally and Michelle

### **House Keeping:**

- New Call Format – Informative and Action Focused
  - We want to be respectful of your time
  - We know you all are here because you want to stay informed, but also do something about this disease. And we want to empower you take action whenever possible.
- Calendar invitation – Melissa will send out for the rest of the year
- Weekly Emails – We commit to sending this out to you weekly

### **Federal Updates**

#### **Appropriations Update:**

- The House is expected to vote on their budget the week of June 1<sup>st</sup>
- In the House budget is a \$2 Billion increase for medical research funding to the National Institutes of Health, including a \$300 million increase to the National Cancer Institutes, a \$40 million increase to the Center for Disease Control cancer prevention programs, and a \$40 million increase for the Office of Smoking and Health.
- The House did not address the spending caps
- We expect the Senate to mark up their budget in mid-June.

#### **One Voice Against Cancer:**

- As part of our advocacy work for increased funding to the NIH and NCI, we work with our partners through the One Voice Against Cancer (OVAC) coalition to send volunteers from targeted districts to DC to meet with their Representatives. Here in Massachusetts, Julia Small – an NIH funded researcher and Legislative Ambassador went to DC to represent ACS CAN earlier this month. Julia shared an update about her experience.

**6 Protected Classes:** A quick update on the 6 Protected Classes of Medicare Part D that we talked about last month. Two weeks ago, an ACS CAN media team flew in and filmed ACS and ACS CAN volunteer Jenn Wall's story, which we highlighted last month, for TV and Internet ads to target the administration and HHS. We expected this campaign to last at least through the summer. In a surprising twist the Department of Health and Human Services (HHS) issued its final rule one week ago today for Medicare Part D which does not include the full range of proposed changes to drugs in the 'six protected classes' of cancer, epilepsy, HIV/AIDS, mental illness and organ transplants. HHS had proposed allowing plans to use additional utilization management, like prior authorization and step therapy, for all drugs in these classes, however the final rule would not interfere with already established medication regimens for cancer patients. In addition, the proposal that would have allowed insurers to exclude new therapies that exceeded a specific price was also omitted. If you'd like to see the ads, you can watch all 3 of them on the [ACS CAN website by clicking here](#).

### **State Updates:**

#### **FY2020 Senate Budget:**

- Massachusetts Tobacco Cessation and Prevention Program (Amendment #682 sponsored by Senator Jo Comerford). Senator Comerford's amendment would have increased funding for the program by \$4

million by allocating a percentage of the expected revenue from the proposed new e-cigarette tax, bringing the total program funding to \$8 million. This amendment was rejected.

- Prohibiting the sale of flavored tobacco products (Amendment #561 sponsored by Senator John Keenan). Senator Keenan's amendment would prohibit the sale of all flavored tobacco products in Massachusetts, including menthol, building off the work the legislature started last year through the passage of Tobacco 21. This amendment was withdrawn after Senator Keenan made a 20 minute speech on the Senate Floor, encouraging his colleagues to make this legislation a priority. In his speech he thanked ACS CAN and our partners for all their work on this issue.
- Funding for research, education and awareness on prostate cancer (Amendment #517 sponsored by Senator Mike Rush). Senator Rush's amendment would match language included in the House version of the budget to ensure that funding appropriated by the House and Senate is released annually for prostate cancer research, awareness and education program (line item 4590-0925). By providing awareness and education programs more men will have the opportunity to make an informed decision with their healthcare provider about prostate cancer screening. This amendment was rejected.
- Funding for the Healthy Incentives Program (HIP) (Amendment #544 sponsored by Senator Anne Gobi). We are greatly appreciative of the increased funding for the Healthy Incentives Program (HIP) (line item 4400-1004) proposed in the FY '20 Senate Ways and Means budget. Senator Gobi's amendment to fund the program at \$8.5 million would ensure that low-income residents of the Commonwealth have access to fresh fruits and vegetables for the entire year. This amendment was withdrawn.

The House and Senate will now elect members to a conference committee beginning in early June to work out the differences in their budgets before sending a final version onto the Governor. We will keep you updated on opportunities to take action.

#### **Pancreatic Cancer Study Commission: - Brock**

Last year, you may remember that we advocated for the inclusion of language to direct the Executive Office of Health and Human Services to provide staff to support the Pancreatic Cancer Study Commission. The writer of the original legislation to establish the Pancreatic Cancer Study is ACS CAN Legislative Ambassador and the House Minority Leader appointee to the Commission – Brock Cordeiro. Brock has agreed to join us and share a little bit about the Commission and what they are currently working on. If you'd like more information, please visit the [Commission website by clicking here](#).

#### **ACS Corner**

- As many of you know, our non-profit partner, the American Cancer Society, funds millions of dollars in cancer research a year. In fact, there are currently 94 active ACS funded research grants in Massachusetts, totaling just over \$44 million dollars. One grantee based at Dana-Farber Cancer Institute made headlines earlier this week with his research into a rare and deadly kidney cancer called renal medullary carcinoma (RMC). Dr. Andrew Hong was inspired by a teenage patient to ask the question "are there vulnerabilities – the molecular equivalent of Achilles' heels – that could be exploited to engineer more effective treatments for this devastating cancer?" He and his colleagues have found that a drug, already FDA-approved for the treatment of other adult forms of cancer, can thwart RMC tumors growth in lab models. While more studies need to be done in the lab as well as clinical trials before this discovery can be applied to childhood cancer patients, this finding is an important first step. We'll include a link to the full article with more details in our meeting minutes for you to read. <https://tinyurl.com/y3qrjhf>

#### **Fundraising Corner**

- Monday night, a High School Senior at Tabor Academy completed his Senior Project. He interviewed cancer survivors and caregivers, turned their stories into music and dance, and brought his vision to the stage. In the words of one viewer "some how he conveyed the emotion of the survivors into the

dancers.” Matthew Carvalho packed the house for two showings, and in the process raised \$1,800 for ACS CAN. He video taped the performance and we’ll share it with you in the near future.

- Lastly, mark your calendars for July 12 from 6 to 9pm! I’ll be holding a fundraiser at the Hammer and Stain in Easton. Join us for a fun night out creating your own sign/design. Tickets start at \$45 and at least \$15 per person will be donated to ACS CAN. [You can register for this fun event by clicking here.](#)

### **Other Action Items:**

Other upcoming ways you can take action:

- June 8<sup>th</sup> Day of Hope Table in Worcester – On Saturday, June 8<sup>th</sup>, ACS CAN will be having a table at the Worcester Day of Hope from 10am to 2pm. We are looking for volunteers to help share info about ACS and ACS CAN event either from 9am to 11am, 11am to 1pm or 1pm to 3:30pm. Please email Melissa if you are interested in helping out.
- June 12 at 6:30pm: Tobacco Hot Topic info call – [to register for the call, please click here.](#)
- June 14<sup>th</sup>: Help prepping for the breakfast 12pm to 4pm on Friday in Framingham
  - Stuffing name tags
  - Stuffing programs with petition
  - Counting out pens by 10
- June 20<sup>th</sup> at 6:30pm: Critical Condition: Stories of Health Documentary Screening and Discussion. You can view a [two-minute trailer for the film here](#). To register for the June 20<sup>th</sup> call, please click here. For more information on Medicaid Covers Us, please visit [www.medicaidcoversus.com](http://www.medicaidcoversus.com).

### **Next call:**

Our next call will be June 27<sup>th</sup> at 6:30pm. The call-in number is [+1 \(917\) 727-7985](tel:+19177277985) and the passcode is 1916494#. As a reminder, you’ll see an invitation from Melissa early next week.