

ACCCC Meeting – 10/18/19

Meeting Minutes

Montgomery, AL

Welcome – Casey Daniel, ACCCC Chairperson

Presentation – ACCCC Current Progress – Renee Desmond

- Provided overview of progress of ACCCC
- Coalition can implement policy change, system change
- Explained purpose of Collected Works Catalog
- Gave examples of appropriate projects
- Need to track this for the CDC grant
- Also important for collaboration and for work groups
- Projects at your paid job count, and collaborations with partners within ACCCC especially

Survivors Panel – Moderated by Angela Davis

- Lucinda and Karen, Endometrial and breast cancer survivors
- Shared personal stories and experiences on diagnosis, treatment, survivorship, etc.
 - Themes:
 - Be your own health advocate; persist and take control when you know something is abnormal with your body
 - Support systems are really important. If you don't have existing support systems, be sure to ask about external systems, as they are out there with programs and services to help.
 - Exercise and diet are very important to focus on during treatment and throughout survivorship.
 - Tell your story and reach out to others to let people know that there is support out there.
 - FOR MAK – Offering a digital library of GYN cancer resources/podcasts that patients can access during/before/after treatment?
 - Include Harvest for Health in newsletter – 60+ cancer survivors done with treatment – North & Central AL – visit web site
- An overview was given of the Harvest for Health program

Announcements from the Chair

- Submit projects for collaboration corner, members for member spotlight, etc. for newsletter
- Definitely need meeting topic and speaker suggestions
- Send social media updates to Jasmine so she can share through ACCCC FB account
 - If you take pictures of an event, make sure you have a media release unless it is a wide distance group shot.
- If you have interest in HPV-related cancers, sign up to attend the AAVTF in-person meeting in Birmingham on Tuesday, October 22nd.

Work Group Open Forums

- Access to Care – Mary Brooks
 - Advocacy Training
 - Next Up: Rural Transportation
 - Two New Members
- Prevention – Chelsea Green
 - Focusing on targeted HPV vaccine education
- Survivorship – Veronica Wehby-Upchurch
 - New co-chairs – Jennifer Hicks and Veronica Wehby-Upchurch
 - Want new members and to determine regular call times
- Early Detection – Dina Avery
 - Completed 60 kits for Susan G. Komen that were distributed to faith-based organizations. Kits included info on breast density and resources.
 - Alabama Hope Project – Cancer survivor + lay educator – visit churches to educate on the importance of breast and cervical cancer screening

Work Group Meetings

- Access to Care
 - Focusing on Rural Transportation for cancer patients
 - Cross-promoting ACS Road to Recovery, Uber Health & Moovmo to increase access in rural areas
 - Jeannie and MAK will create draft collateral
 - Each committee member will submit two prospects to target (ex: churches, civic organizations, etc.) at the next committee call.
- Early Detection
 - All members will send church contacts to Janelle.
 - Create resource card providing tips and resources on vaping.
 - A conference call will be scheduled before the end of the year.
- Prevention
 - HPV education for pharmacists
 - College-age educational messaging
 - Coordinate with AAVTF
- Survivorship
 - Set their calls for 1st Wednesday of the month at 2 p.m.
 - Evaluating gaps and what they might want to address.

Advocacy Training

- Mary Brooks of Access to Care Committee welcomed attendees.
- How to Advocate Panel

Panelists:

Anna Pritchett, AARP

Crystal James, Chair of Graduate Public Health in Veterinary Medicine at Tuskegee University

Sarah Domm, Grassroots Manager, ACS Cancer Action Network

Advocacy vs. Lobbying

Anna: 501c3—NPO so not allowed to work directly with partisan issues
Allowed to educate, raise issues and awareness and raise people's voices
Not allowed to lobby

Sarah: ACS CAN is separate from ACS so they are allowed to lobby (ex. Ginny Campbell can lobby)
Donations to ACS CAN are not tax deductible

Crystal: Very thin line between lobbying and advocating
If you can get tax-exemption then you cannot lobby because you have agreed not to advocate for only one side, issue, etc. *But*, you can still educate and raise awareness

When you contact lawmaker, how does it amplify your voice?

Anna: Really puts a face on the issue, represents human beings and makes lawmakers see their constituents

Legislators are regular people and cannot be experts on every single issue and rely on people to raise their voices, educate them, and tell their stories

Legislators don't hear from constituents very often and if you take the time and effort to reach out then it shows the legislator how important that issue is to you and your dedication to it

What are preparation steps to reach out to representatives—how to get started?

Crystal: Be as prepared as possible—elected officials don't have a lot of time

Have a fact sheet

Know how they have voted in the past—can say, "I know you voted for this in the past, etc."

Here are the demographics of your district and here is why it's important that you get this *right*

Leave them with something (short)—3-5 points, less than a page (even something from another state)

For people who want to advocate, advice on how to tell your story?

Sarah: Who, What, and Why

Who you are, if you have a connection to them

What you are there to talk about—very short and clear

Why this is important to you, the community, and the personal touch

Working with the staff—you can't always meet with legislator but staff can have a lot of influence so be respectful, make sure to follow-up—create and maintain relationships to show that you are dedicated to efforts in long-term

Additional Information:

Crystal: When you're working on an issue, you are an expert, but can't assume a legislator knows the information that you take for granted

Have as much data as possible at your fingertips in case they ask a question about it

Bring short info for them

Anna: Look for ways to see and be seen by lawmakers—be upfront and smile at them when they speak, etc.

Building those relationships is key

Understand their motivations so you can play on that and they're more likely to hear you

Use social media—legislators are active and so are their staffs—very effective in retweeting and thanking

Make the ask—and *get an answer* (a real answer)

Crystal: Make sure your social media image is clean if you are advocating—they want to make sure your reputation is clean and respected, professional, *non-partisan* so they'll take advice from you as a source

Sarah: Don't be too intimidated or scared to meet with elected officials
They know it's part of their job and they want to hear from their constituents
They don't necessarily expect you to be a professional lobbyist

Sarah: How to Tell Your Story

- Advocacy is so often just telling your story, can have such a huge impact
- Need to put a face on these issues
- Legislators depend on constituents to inform them
- Putting a face on things makes it less abstract so it's not just numbers or statistics—makes it so much more *real*
- Stories can invoke a far more impactful response
- A lot of times these legislators have been affected by cancer, themselves
 - Can touch them and remind them of their own experiences
 - Reminds them that a decision about a cancer issue affects real people
- How you tell your lived experience is important
 - Be cautious, especially if tying it into a policy ask
 - Keep it brief
 - Focus on specific parts that will move the legislator and are memorable
 - Stick to the highlights
 - Stick to 1-2 minutes
 - Don't overwhelm them by you crying or getting them crying—need to stay focused on message and purpose, not just drawing out emotion
 - Frame story in positive way—emphasize hope and recovery and draw realistic picture of what could be done
 - Leave them with the *action goal* and *motivation* in mind
 - Make sure you make an ask—something you want them to do.
 - Legislators expect this
 - Make sure you get a real response from them
 - Hold them accountable if they say yes
 - If they say no then figure out how you can work together to change that no
- Let them know why you are there pretty up front
 - Lean more on your story than facts
 - End with final ask and pause—waiting for response
- Small Group Activity – Mary Anne King, Sarah Domm, Virgie Townsend
 - Attendees wrote down their own stories utilizing a worksheet template.
- Role Play – Heather Adams & Jeannie Smith (ACS)

Meeting Adjourned – 2 p.m.