

Alabama Comprehensive Cancer Control Coalition (ACCCC)

Meeting Minutes

Date: Friday, January 18, 2019

Location: Tuskegee Municipal Complex

Address: 101 Fonville St. Tuskegee, AL 36083

Order of Agenda

10:25 a.m. – Carol Garrett invited attendees to introduce themselves to the group.

10:32 a.m. – Casey Daniel, Coalition Chair, welcomed attendees.

10:34 a.m. – Mary Boyd, CDC Program Consultant – Ms. Boyd provided an update on the CDC Comprehensive Cancer Control Program. Priorities are centered around six areas and four domains: primary prevention, health equity, survivorship, and evaluation. Ms. Boyd complimented the Alabama team on its exemplary communication and collaboration. CDC is in the process of providing additional funding for years 3-5 through an additional grant opportunity focused on survivorship. Ms. Boyd encouraged Alabama to apply.

10:40 a.m. – Panel Discussion - A Cancer Diagnosis: The Burden and its Impact on the Family

- Moderator - Rhonda Benton, Advocate/Activist for Social Justice Issues in Healthcare, Education and Agriculture
- Panelists: Margaret Jernigan, Community Health Advocate; Doretha Heard, Co-founder & President Macon MEANS; Darlene Adams, cervical cancer survivor; Ronald Smith, parathyroid cancer survivor
- Question for the panelists: What advice do you have for patients and families facing the same issues that you and/or your spouse did?
 - Ron Smith – Listen to your caregivers. Include your family and let them support you.
 - Darlene Adams – Cancer is not death.
 - Audience perspectives – If you have any questions or anything abnormal bothering you, make sure you see your physician. When in doubt, check it out.
- Question: What are some of the frustrations you faced with the healthcare system?
 - Margaret Jernigan - Not receiving complete information. Communication between healthcare provider and patient is inadequate. Take family members with you and write things down. Don't be afraid to ask questions and/or get another opinion.
 - Doretha Heard – There's a gap between information that is needed and provided. Having someone you can go to that's been through it before helps with feeling supported.
- Question: What are some of the important elements of support?
 - Audience perspectives – Important to act as a guide and advocate when needed. In beginning stages, it is important to do research and be there when asked. Everything you read on the internet is not accurate. Make sure you get the sources you're getting information from to ensure they are reputable. Caregivers and other family members need support too.

- Darlene Adams – Caregivers also need support.
- Ronald Smith – Humor can help. Be open with your family and other members of your support system. Encourage yourself and your family, and listen to your physician.
- Doretha Heard – Sometimes patients don't know what they need. Just reaching out and letting them know you're there can help. Navigators are crucial to helping patients.
- Question: How has cancer changed your feelings/thoughts about food and/or exercise?
 - Ronald Smith – All of us need to be cognizant of our eating and exercise habits and focusing on healthy living/habits.
 - Darlene Adams – Trying to eat right is a struggle, try to keep healthy foods around. It's expensive to eat healthy, which can be a barrier for some people, and comorbid conditions (like diabetes), as well as multiple interacting medicines can make it even more difficult.
 - Margaret Jernigan – Access the registered dietitian at your treatment facility. Be honest about your diet and what you like so you can get customized advice.
 - Audience Perspective – Make sure you tell your doctor everything you're taking (supplements, herbs, etc.). They can interact with your medication/treatment regimen.
- Question: What important discovery would you like us to talk about next time?
 - Doretha Heard – Medicinal plants and how they're used.

11:30 a.m. – Presentation – Community Patient Navigators: Bridging the Gap in Cancer Treatment and Health Care in Rural Alabama Black Belt Counties

- Presenter – Ada Britt and Patient Navigator Team, Morehouse School of Medicine/Tuskegee University/University of Alabama at Birmingham Comprehensive Cancer Control (MSM/TU/UAB CCC Partnership)
- Overall goal of partnership is to implement and evaluate an enhanced care coordination model, including effects of lay navigators.
- Focused on Bullock and Macon Counties; patients were recruited from UAB and Montgomery cancer centers.
- Handouts for the program were made available to attendees.

11:43 a.m. – Presentation – Promoting Collaboration within our Coalition to Reduce the Cancer Burden on Alabama Residents

- Presenter – Mary Brooks, Med, Community Health Educator Outreach Core, MSM/TU/UAB CCC Partnership
- Target Areas – Macon and Bullock Counties
- Main role is outreach activities, education, disseminating information about related resources
- Trying to learn more about the impact of evidence-based strategies of health education
- Partner or perish. You can't work effectively in a silo.
- Each community is different and has its own barriers, leaders, etc.

- Coalition can help encourage collaboration and keep the cancer community abreast of what various organizations are doing.

11:54 a.m. – Update from Claudia Hardy, UAB O’Neal Comprehensive Cancer Center

- UAB tries to provide education and outreach, and focuses on evidence-based strategies.
- We are the state’s coalition; we should try to be more integrated and collaborate more. If we’re not coordinating, we’re not working effectively.

12:15 p.m. – Networking Lunch

- Attendees signed up for various workgroup committees and networked among the membership.

12:55 p.m. – Presentation – Raising Awareness of Colorectal Cancer

- Presenter – Jacky Turner, Development Assistant, Rumpshaker, Inc.
- Rumpshaker works to educate people on the importance of screening and early detection and provides emotional support and financial assistance to patients with needs.
- Colorectal car tag was approved and will be available for purchase in Spring 2019.
- Attendees received a handout with more information on Rumpshaker and colorectal cancer.

1:13 p.m. – Jasmine Abner – Update on Collected Works Catalog

- Members can add information on any project/initiative that affects or is relevant to the coalition’s work.
- The catalog’s purpose is to help encourage collaboration and ensure we are informed of what’s happening throughout the state.
- The eventual goal is to populate a database that will be functional and searchable.

1:20 p.m. – Mayor Tony Haygood of Tuskegee welcomed the coalition.

1:30 p.m. – ACCCC Executive Committee Panel – Coalition Goals and Future Expectations

- Executive Committee Members: Casey Daniel, Chair; Ginny Campbell, Vice Chair; Mary Anne King, Secretary
- Casey Daniel said the Executive Committee is working on revising the bylaws and would have revisions proposed and ready for a vote at the next meeting. During her term, she wants to focus on creating functional committees that each take something from the state cancer plan, create a goal and a work plan to achieve it.
- Ginny Campbell stressed the importance of advocacy and offered to provide resources and training to the membership on advocacy.
- Mary Anne King said her goals are to encourage collaboration and foster communication. She would like to develop a quarterly newsletter and spotlight a different coalition member each month.

2:00 p.m. – The meeting adjourned.