Alabama Study Commission for Gynecologic Cancers

March 5, 2019

Alabama Act 2018-86: Establishing the Alabama Study Commission for Gynecologic Cancer

WHEREAS, the Legislature recognizes the prevalence of gynecologic cancers in Alabama, the efficacy of existing efforts for early diagnosis and treatment, and the need for the identification of unmet needs for patients and families;

WHEREAS, identification and presentation of the issues and solutions relative to gynecologic cancers in Alabama should be considered and addressed by a team of experts and representatives including: patients, survivors, caregivers, medical specialists, research specialists, and advocates for gynecologic cancer awareness and support; now therefore, BE IT RESOLVED BY THE LEGISLATURE OF ALABAMA, BOTH HOUSES THEREOF CONCURRING, that there is created the Alabama Study Commission for Gynecologic Cancers.

(a) The Commission shall study and report on the following:

(1) Establishing a mechanism to ascertain the prevalence of gynecologic cancers in the state, and to the extent possible, collecting statistics relative to the timing of diagnosis and risk factors associated with gynecologic cancer.

(2) Determining how to best effectuate early diagnosis and treatment for gynecologic cancer patients.

(3) Determining any unmet needs of persons with gynecologic cancers and those of their families.

(4) Providing recommendations for additional legislation, support programs, and resources to meet the unmet needs of persons with gynecologic cancers and their families.

(b) Membership of the Alabama Study Commission for Gynecologic Cancers shall be comprised of the following: (1) A representative of the Alabama Comprehensive Cancer Control Coalition. (2) The Commissioner of the Alabama Department of Insurance, or his or her designee. (3) Three members appointed by the President Pro Tempore of the Senate, as follows: a. One of whom shall be a survivor of ovarian cancer. b. One of whom shall be a survivor of cervical, vaginal, vulvar, or uterine cancer. c. One of whom shall be a medical specialist in gynecologic cancers. (4) Three members appointed by the Speaker of the House of Representatives, as follows: a. One of whom shall be a survivor of ovarian cancer. b. One of whom shall be a survivor of cervical, vaginal, vulvar, or uterine cancer. c. One of whom shall be a medical specialist in gynecologic cancers. (5) Seven members appointed by the Governor as follows: a. One of whom shall be a caregiver of a woman diagnosed with gynecologic cancer. b. One of whom shall be a medical specialist in gynecologic cancers. c. Two of whom shall be individuals representing gynecologic cancer awareness and support groups in the state. d. One of whom shall be a researcher specializing in gynecologic cancers. e. Two of whom shall be members of the public with demonstrated expertise in issues relating to the work of the commission. (6) A representative of the Alabama Comprehensive Cancer Control Coalition. (7) A representative of the Alabama Statewide Cancer Registry who is an epidemiologist.

(c) The appointing authorities shall coordinate their appointments to assure membership of the Alabama Study Commission for Gynecologic Cancers is inclusive and reflects the racial, gender, geographic, urban, rural, and economic diversity of the state.

(d) (1) Appointments to the commission shall be made within 30 days after the effective date of this act. (2) The commission shall hold its first meeting no later than July 1, 2018, with the date, time, and location of the meeting designated by the President Pro Tempore of the Senate. (3) At the first meeting, the commission shall elect a chair, vice chair, and other officers as determined by the commission, and shall set dates, times, and locations of subsequent meetings.

(e) The House of Representatives and the Senate shall provide the necessary staff and support to the commission to perform its duties.

(f) Members of the commission shall serve without compensation or reimbursement from the commission, but may be reimbursed for necessary expenses to attend meetings of the commission according to the policies and procedures of the respective appointing authority.

(g) The commission shall submit its findings and recommendations in writing to the President Pro Tempore of the Senate, the Speaker of the House of Representatives, the Governor, the Senate Chair of the Health and Human Services Committee, and the House Chair of the Health Committee no later than March 5, 2019, at which time the commission shall be dissolved.

BE IT FURTHER RESOLVED, That all state agencies are urged to cooperate fully with the commission in accomplishing the objectives of the commission, and that a copy of this resolution be presented to the appointing authorities set out above so that our sincere and continuing interest in this matter is known.

Members of the Alabama Study Commission for Gynecologic Cancers

Governor-Appointed Members		
Michael Birrer, MD, PhD	Director	O'Neal Comprehensive Cancer Center at UAB
Sara Cooper, PhD	Faculty Investigator	HudsonAlpha Institute for Biotechnology
Jim Crandall		Family member/caregiver
Warner Huh, MD	Director	UAB Division of Gynecologic Oncology
Mary Anne King	Executive Director	Laura Crandall Brown Foundation
Tyler Kirby, MD		Tennessee Valley Gynecologic Oncology
Susan Leighton		Ovarian cancer survivor/Lilies of the Valley

Senate-Appointed Members		
Regina Parker		Ovarian cancer survivor/Lilies of the Valley
Sonya Patterson-Shelton		Cervical cancer survivor
Jennifer Young-Pierce, MD, MPH	Professor of Interdisciplinary Clinical Oncology	Mitchell Cancer Institute

House-Appointed Members		
Beth Butz		Endometrial and ovarian cancer survivor
Kelly Rice		Ovarian cancer survivor
J. Michael Straughn, MD	Fellowship Director	UAB Division of Gynecologic Oncology

Alabama State Agency Representatives		
Justin George, MPH	Director of Cancer Epidemiology	Alabama Department of Public Health
Gavin Graf	Director, Cancer Prevention Program	Alabama Department of Public Health
Marie McKitt	Insurance Consumer Specialist	Alabama Department of Insurance

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EXECUTIVE SUMMARY

The five types of gynecologic cancers are ovarian, cervical, uterine/endometrial, vulvar and vaginal cancer. These cancers represent a significant financial and emotional burden for the women affected and their families.

Of all of the gynecologic malignancies, **ovarian cancer** is associated with the worst prognosis. The incidence rate of ovarian cancer in Alabama is slightly lower than the national average, but the mortality rate is significantly higher ranking as the third highest among the states. Almost two-thirds of ovarian cancer cases are diagnosed at an advanced stage after the cancer has spread and when survival rates are significantly lower. There are no screening tests, signs or symptoms specific to ovarian cancer that may lead to earlier detection. Among the most important factors that contribute to poor outcomes experienced by ovarian cancer patients is access to treatment by a specialist in gynecologic cancers. The main risk factors of ovarian cancer include having a breast cancer gene mutation (BRCA) or other high-risk genetic mutation, having endometriosis, a family history of ovarian, breast, colon or endometrial cancers, personal history of breast, colon or endometrial cancers, and increasing age. There is a critical knowledge gap among the general public and primary care physicians concerning ovarian cancer symptoms, risk factors, and the use of the US Preventive Services Task Force (USPSTF) guidelines and screening tools to determine genetic risk.

Cervical cancer is almost entirely preventable and yet in 2015, Alabama ranked 1st for cervical cancer mortality in the entire country and 3rd for incidence. The disease is even more deadly for African American women who experience a mortality rate twice that of white women in Alabama. Cervical cancer can be primarily prevented with the human papilloma virus (HPV) vaccination of adolescents per Center for Disease Control (CDC) recommendations. Secondary prevention is achieved with appropriate screening services of women aged 21-64 with necessary follow-up and treatment of precancerous lesions. Alabama is ranked 45th in HPV vaccination rates. Contributing to these alarming rates are limited access to gynecologic services in rural areas and vaccination rates far below the national average. More than 50% of new cases are diagnosed in late stages and the majority of these women report not having undergone recommended screening in the previous five years. Barriers to HPV vaccination reported by parents include lack of knowledge and that the vaccine was not recommended by their pediatrician. Pediatricians report that parents are often reluctant to vaccinate against a sexually transmitted disease and some parents express safety concerns.

Uterine cancer is the most common gynecologic malignancy in the United States and is the 4th most common cancer in women. The incidence and mortality rates in Alabama are significantly lower than the national average. The majority of patients are diagnosed with disease confined to the uterus and have a 90% 5-year survival rate. Risk factors associated with uterine cancer are Lynch syndrome and obesity. Women with endometrial cancer should be screened for genetic mutations associated with Lynch syndrome. Obesity is associated with increased risk of endometrial cancer particularly among women at a young age and weight loss is an important aspect of follow-up and survivorship for women with endometrial cancer.

The incidence and mortality rates of vaginal and vulvar cancers in Alabama are not significantly different than the national average. Vaginal cancer is exceedingly rare in our state and requires specialized surgical and/or radiation procedures in conjunction with a gynecologic oncologist at a high volume center. HPV vaccination prevents up to 90% of vaginal cancer. Vulvar cancer risk factors include increasing age and smoking in addition to HPV and**,** as with cervical and vaginal cancers, it is preventable with the HPV vaccine. Vulvar cancer is completely curable if caught in the earliest stages. Women who present with late stage disease often experience such as poverty, rurality, and lack of insurance.

The diagnosis of a gynecologic cancer can produce shock, disbelief and emotional turmoil for the patient and her family. Over 53% of patients surveyed indicate that the disease has had a severe or very severe impact on their lives. There is a critical gap between the information physicians thought they were communicating and the information the patients felt they were receiving. Identifying patients experiencing these needs and who want support helps direct resources appropriately. Many studies demonstrate that structured group interventions improve psychological well-being, reduce anxiety and depression, and improve quality of life. Geographic distance presents a barrier to access to such interventions.

Gynecologic cancer patients and their families face many unmet needs including the paucity of patient navigation services, lack of survivorship plans, barriers to healthcare access secondary to cost, lack of insurance coverage, lack of transportation, geographic disparities, and lack of hospice and palliative care services. Many of these factors contribute to financial distress for the patient. Financial distress associated with the cost of cancer care has been identified as "financial toxicity," and research has shown it has the potential to lower quality of life and increase mortality for both insured and uninsured patients.

The Commission makes the following recommendations aligned with the four charges outlined in Alabama Act 2018-86

Charge 1: Establishing a mechanism to ascertain the prevalence of gynecologic cancers in the state, and to the extent possible, collecting statistics relative to the timing of diagnosis and risk factors associated with gynecologic cancer.

1. Establish a hospital discharge database.
2. Develop a method for collecting data concerning genetic counseling and testing.

Charge 2: Determining how to best effectuate early diagnosis and treatment for gynecologic cancer patients.

1. Provider Education: Educate primary care providers, gynecologists, medical oncologists and other medical specialists as appropriate to increase their awareness and knowledge of gynecologic cancers and to effect clinical changes for reducing delays in diagnosis and implementing standard of care. Key messages should include:
    a. Ovarian cancer
        i. All women with ovarian cancer, including women with clinically suspicious pelvic masses, should be referred to a gynecologic oncologist for evaluation and management.
        ii. All women diagnosed with ovarian cancer should be offered genetic counseling and testing to include appropriate family member referral.

iii. All women with a known family history of ovarian, breast, colon and/or endometrial cancer or a personal history of breast, colon and/or endometrial cancer should be referred for genetic counseling.

b. Cervical cancer
   i. Cervical cancer patients should be referred to a high volume center as this is associated with highest survival.

c. Uterine cancer
   i. All patients with persistent abnormal uterine bleeding or postmenopausal bleeding should undergo appropriate workup including endometrial pathologic sampling prior to proceeding with definitive treatment such as hysterectomy.
   ii. All patients with complex atypical hyperplasia or suspected endometrial cancer should be referred to a gynecologic oncologist for evaluation and management.
   iii. Consider minimally invasive surgery (MIS) and evaluation of the lymph nodes for all patients with endometrial cancer or suspected endometrial cancer.
   iv. Patients with recurrent endometrial cancer who have failed two lines of therapy, should be referred for a clinical trial
   v. Universal testing of microsatellite instability (MSI) should be performed on all hysterectomy specimens in patient with endometrial cancer.
   vi. All women with uterine cancer and evidence of high MSI on testing should be referred for genetic counseling and testing.

d. Vaginal and vulvar cancers
   i. Recommendations as outlined under cervical cancer.

2. General public education: Alabama Department of Public Health (ADPH) in coordination with gynecologic advocacy groups and healthcare providers should expand public awareness through campaigns focused on:
   a. Need for annual well-woman examinations.
   b. Symptoms and risk factors of all gynecologic cancers.
   c. Alabama Breast and Cervical Cancer Early Detection Program (ABCCEDP)
   d. HPV vaccinations
   e. Genetic counseling and testing programs available in the state.

Charge 3: Determining any unmet needs of persons with gynecologic cancers and those of their families.

1. Psychological/Emotional
   a. Administer a National Comprehensive Cancer Network (NCCN) Distress Thermometer and Problem List (DT/PL) periodically throughout the course of treatment and after completion of treatment referring patients with a positive distress screen to the appropriate resource.
   b. Advocacy groups should develop a Directory of Resources for gynecologic cancer patients.
   c. Cancer treatment centers should post support group information provided and kept current by advocacy groups.
   d. Local advocacy groups should assess the need for family member support group services and explore feasibility of establishing a group.

2. Patient Navigation

    a. Encourage employment of certified oncology navigators with specialized training in gynecologic cancer in treatment centers and develop or expand the use of general patient navigators and/or lay navigators in the absence of certified gynecologic cancer navigators.
3. Survivorship Plans
    a. Increase implementation of survivorship plans for gynecologic cancer patients.
    b. Provide all patients diagnosed and treated for a gynecologic cancer a copy of Guide for Gynecologic Cancer Survivors" published by The Foundation for Women's Cancer (FWC).
4. Financial
    a. Providers should encourage patients to be proactive about learning about their out-of pocket financial obligations.
    b. All patients should have access to financial counseling services.
5. Transportation and Geographic Disparities
    a. Expand access to non-emergency medical transportation services for Alabamians living in rural areas and encourage improved coordination among existing providers.
    b. Decrease geographic distance as a barrier to patients' access to gynecologic oncologists, including consideration of innovative and technology driven strategies such as telemedicine and outreach clinics.
6. Hospice/Palliative Care
    a. Direct regional palliative care programs to develop improved resources such as hospice houses and outpatient palliative care programs.

Charge 4: Providing recommendations for additional legislation, support programs, and resources to meet the unmet needs of persons with gynecologic cancers and their families.

1. Continue to work with parents, providers, and payor organizations to promote policies that increase HPV vaccination across the state.
2. Continue and consider increasing funding of the ABCCEDP.
3. Abnormal cervical screening tests need immediate and appropriate follow up including available resources of health departments, free clinics, and available colposcopy clinics.
4. Grade 1 endometrial adenocarcinoma related to concurrent obesity should be considered a medical condition secondary to obesity and an indication for medical and surgical weight management.
5. Legislators in coordination with the Alabama Department of Insurance (ADOI)and the National Society of Genetic Counselors (NSGC) should consider recognition of certified counselors as healthcare providers.
6. Genetic counseling and testing programs should be available throughout the State with consideration given to technology-driven strategies such as telemedicine and outreach clinics.
7. Support efforts to increase research funding through federal and private funding sources.
8. Legislators in coordination with the ADOI should consider implementing oral chemotherapy parity in the administration of group and individual health plans**.**
9. Work with Alabama Medicaid, BC/BS and other payors to address appropriate funding of palliative care services.

I. AIM OF REPORT

The aim of this report is to provide recommendations for reducing the burden of gynecologic cancers in the State of Alabama. Based on the State's Alabama Study Commission for Gynecologic Cancers (ASCGC) statutory language, the recommendations made in this report focus on the following charges: (1) Establishing a mechanism to ascertain the prevalence of gynecologic cancers in the state, and to the extent possible, collecting statistics relative to the timing of diagnosis and risk factors associated with gynecologic cancer; (2) Determining how to best effectuate early diagnosis and treatment for gynecologic cancer patients; (3) Determining any unmet needs of persons with gynecologic cancers and those of their families; (4) Providing recommendations for additional legislation, support programs, and resources to meet the unmet needs of persons with gynecologic cancers and their families.

II. METHODS

The Alabama Study Commission for Gynecologic Cancers convened for the first time on June 20, 2018, and four additional times on August 22, 2018, September 26, 2018, November 14, 2018, and January 11, 2019. The Director of Cancer Epidemiology of the ADPH supported the work of the Commission with pre-meeting materials and statistics necessary to complete the work of the Commission. Members of the Commission conducted an extensive literature review. Members shared their expertise in diagnosing, treating and providing support to gynecologic cancer patients throughout the State; personal experiences as gynecologic cancer patients/survivors or caregivers; and understanding of health insurance coverage of these cancers. Patient advocacy groups developed and conducted a survey of gynecologic cancer patients to assess needs of the community.

Of note, there were several questions Commission members wanted to address surrounding patient care and status of people living with cancer. Such information is not available through the State Cancer Registry. Implementation of a State hospital discharge database would allow more thorough evaluation and could enhance outcomes even further.

III. LANDSCAPE AND TREATMENT OF GYNECOLOGIC CANCERS IN ALABAMA

The five types of gynecologic cancers covered in this report are ovarian, cervical, uterine/endometrial, vulvar and vaginal cancer. These cancers are the uncontrolled growth and spread of abnormal cells originating in the female reproductive organs. The American Cancer Society (ACS) estimated that there would be approximately 110,070 new cases diagnosed and

32,120 deaths from gynecologic cancers in the United States during 2018. These cancers represent a significant financial and emotional burden for the women affected by these cancers and their families. A 2017 study of the "Cost of Care for the Initial Management of Ovarian Cancer," revealed the average cost of care for women with ovarian cancer in the first year after surgery was approximately $100,000 of which patients bear approximately 3% in the form of out-pocket expenses.[1] The cost of management of cervical or uterine cancer can range from $2,000 for early stage to $100,000 for late stage. These costs can include surgery, chemotherapy and radiation therapy.[2]

While the financial impact is significant for these women as well as the State, there are numerous other factors that impact the overall outcome from these cancers. Unfortunately, outcomes in Alabama lag behind other states with Alabama ranking 1st in the nation for mortality from cervical cancer, a preventable cancer. As a state, we seek to provide better care for the women of Alabama to prevent and treat these potentially deadly cancers. Foremost among these issues is access to preventive/risk reduction and screening programs, awareness of the cancers and their risk factors and symptoms, diagnosis at earlier more treatable stages, healthcare access to include appropriate access to gynecologic cancer specialists, and access to multiple patient supports known to improve outcomes including patient navigation, psychosocial support, genetics counseling, palliative care, and family support.

A. OVARIAN CANCER

Table 1 Alabama and United States Ovarian Cancer Incidence and Mortality Rate Comparisons[3,4,5]

Incidence Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**12.1**	**11.9**	**21st**
White	**12.7**	**12.6**	**12th**
African-American	**9.6**	**9.9**	**6th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.

Mortality Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**7.6**	**8.4**	**3rd**
White	**7.9**	**8.6**	**3rd**
African-American	**6.5**	**7.9**	**5th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.
The mortality rate for Alabama is significantly higher than the mortality rate for the United States across all groups.($p<0.05$)

Of all of the gynecologic malignancies, ovarian cancer is associated with the worst prognosis. The vast majority of new ovarian cancer cases continue to be diagnosed at an advanced stage, and despite significant improvements associated with radical surgery, chemotherapy and targeted therapy, survival continues to be alarmingly low. Women diagnosed at an early stage,

before the cancer has spread, have a much higher survival rate than those diagnosed at a later stage. Approximately 15% of ovarian cancers are found before the cancer has spread beyond the ovary at stages IA and IB, in which the 5-year relative survival rate is 92%. Almost two-thirds of ovarian cases are diagnosed at stage III in which there is a 39% survival rate or stage IV in which there is a 17% survival rate.[6,7]

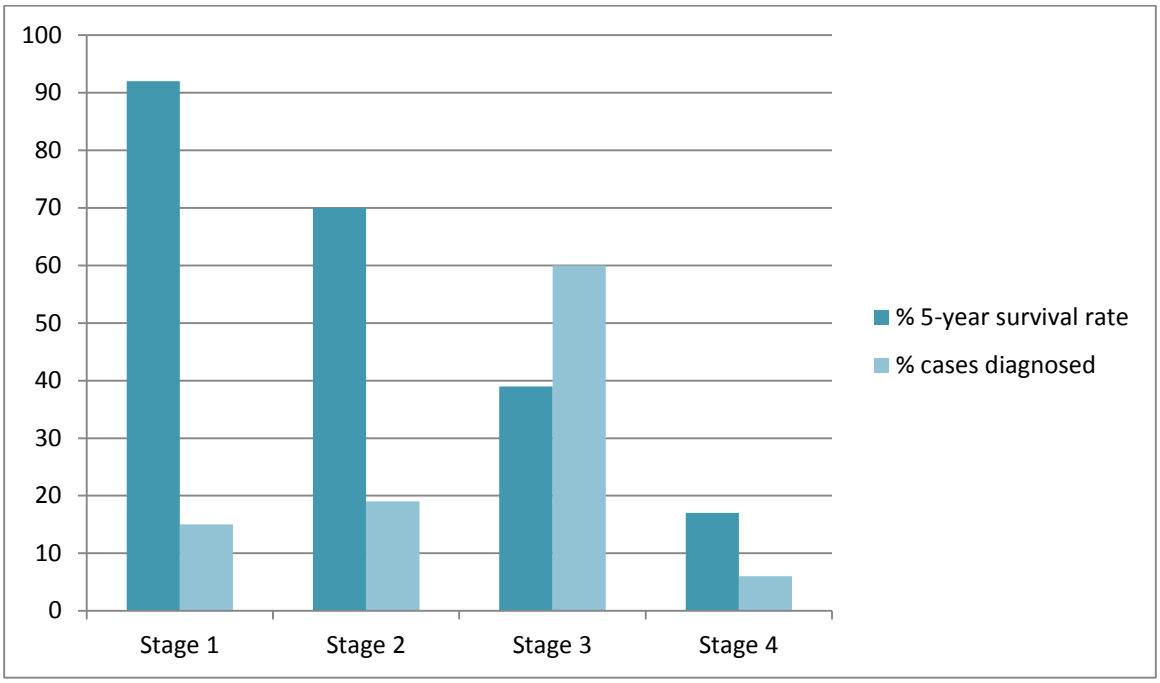

Figure 1 – Survival rate versus rate of diagnosis by stage[6,7]

Unlike cervical cancer, there are no recommended screening tests. Studies on screening for ovarian cancer have not shown significant impact in survival. Further, there are no signs or symptoms specific to ovarian cancer that may lead to earlier detection. The symptoms can be indolent and nonspecific, ultimately delaying diagnosis.

The incidence of ovarian cancer in the United States is 1 in 79 women. The disease affects all ages with a median age of diagnosis of 63 years. The overall incidence in Alabama is similar to the national average with over 300 women per year diagnosed with ovarian cancer. The mortality of ovarian cancer in Alabama is significantly worse that the national average (7.6 nationally versus 8.4 deaths per 100,000 in Alabama). In fact, Alabama women experience the third worst rate of mortality among the states in the United States.[3,4,5] Caucasians have the highest incidence in our state.

A variety of factors contribute to the poor outcomes experienced by ovarian cancer patients. Among the most important factors is access to care. It has been reported throughout the medical literature that treatment by a gynecological oncologist, or other specialist in gynecological cancer, significantly improves patient outcomes and reduces mortality. High volume providers are five times more likely to completely remove an ovarian tumor; patients who see a gynecologic oncologist increase their chances of five-year survival by 10%; and patients who have surgery by a gynecologic oncologist are more likely to receive the recommended standard

of care which reduces surgical complications and increases survival by a median of 14 months.[8] With this in mind, we assessed access to these specialists in our state and determined that, in Alabama, only about 57% of women with ovarian cancer are seen by a gynecologic oncologist at any point in their treatment. The benefits of management by a gynecologic oncology specialist include evidence-based surgical intervention, genetic counseling and testing (which includes testing of relevant family members), tumor-specific testing, evaluation and consideration of oral targeted therapy, integration of palliative and supportive care services, and access to clinical trials.[8,9,10] All women in the State of Alabama, with suspected, proven or recurrent ovarian cancer should have access to a gynecologic oncology specialist.

Over the past twenty years, our understanding and management of ovarian cancer has grown considerably. Advances in genetic testing (e.g., BRCA mutation), risk reducing surgery, focus on symptom control, and more strategic implementation of debulking surgery has led to a considerable improvement in the quality of life of women with ovarian cancer.[10] Improved care for all women in Alabama ensures access to these advances.

KEY POINTS:

- **The overall incidence of ovarian cancer in Alabama is similar to the national incidence rate.**
- **The mortality for women diagnosed in Alabama is significantly worse than the national average. Despite having the 21st highest incidence rate of ovarian cancer in the nation, Alabama has the third highest mortality rate.**
- **Important factors contributing to poor outcomes include access to care, particularly treatment by a gynecologic oncologist. In Alabama, 57% of women with ovarian cancer are seen by a gynecologic oncologist.**
- **There are no screening tests, signs or symptoms specific to ovarian cancer that may lead to early detection.**
- **Women with suspected, proven or recurrent ovarian cancer benefit from a formal evaluation and treatment plan by a gynecologic oncologist at initial diagnosis as well as at any interval change in treatment or recurrence.**

RECOMMENDATION:

- **All women with ovarian cancer, including women with clinically suspicious pelvic masses, should be referred to a gynecologic oncology specialist for evaluation and management**

B. CERVICAL CANCER

Table 2 Alabama and United States Cervical Cancer Incidence and Mortality Rate Comparisons[3,4,5]

Incidence Rate Comparisons 2006-2015 by Race			
Race Group	**United States**	**Alabama**	**State Rank**
All Races	**7.7**	**8.8**	**10th**
White	**7.7**	**8.6**	**7th**
African-American	**9.0**	**9.9**	**15th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.
The incidence rate for Alabama is significantly than the incidence rate for the United States across all groups. ($p<0.05$)

Mortality Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**2.3**	**3.2**	**3rd**
White	**2.2**	**2.8**	**4th**
African-American	**3.9**	**5.0**	**3rd**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.
The mortality rate for Alabama is significantly higher than the mortality rate for the United States across all groups ($p<0.05$)

Cervical cancer is almost entirely preventable and yet in Alabama there are areas where women are dying at a rate similar to that of developing nations. The most current data available for Alabama from 2011 to 2015 shows a continued increase in cervical cancer incidence and mortality while rates are falling or stable in every other state. Alabama is now ranked first for cervical cancer mortality in the entire country and third in incidence.[11]

Cervical cancer can be primarily prevented with vaccination of adolescents per CDC recommendations. Secondary prevention is achieved with appropriate screening services of women aged 21-64 with necessary follow-up and treatment of precancerous conditions. In Alabama access to gynecologic services is very limited in rural areas with only 35 of 67 counties having an obstetrician/gynecologist.

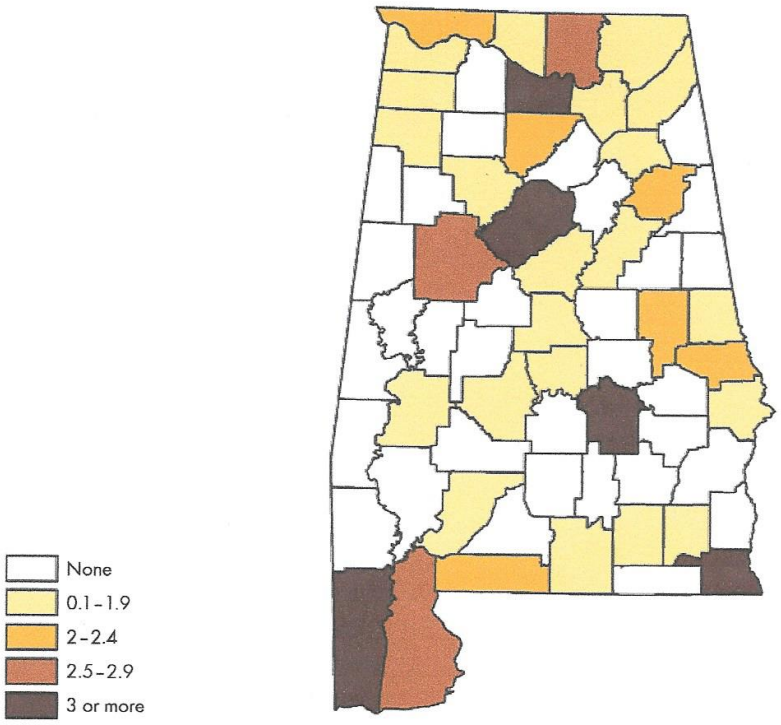

Figure 2 - Obstetricians-gynecologists per 10,000 women in Alabama.[12,13,14]

Alabama ranks 45th for HPV vaccination rates in the country. Racial disparities make this disease even more deadly for African American women with a mortality rate twice that of white women in Alabama. These factors contribute to the ongoing human rights crisis recently reported on by Human Rights Watch in their report "It should not happen: Alabama's failure to prevent Cervical Cancer in the Black Belt."[15]

Cervical cancer affects on average over 230 women in Alabama every year. This equates to 9/100,000 putting Alabama in the top third nationally for cervical cancer rates. Alabama currently ranks first for cervical cancer mortality in the country (3.5/100,000).[16] On average, one third of women with cervical cancer in Alabama will die of their disease.

Several factors contribute to this mortality rate including that only 54% of cervical cancer patients ever see a gynecologic oncologist, a specialist who treats cervical cancer. Gynecologic oncologists are located in Birmingham, Huntsville, and Mobile so women often travel over a hundred miles for these appointments making them logistically and financially prohibitive. That being said, Jefferson County has one of the highest mortality rates from cervical cancer in the state so efforts also need to be focused on prevention, screening and treatment of early stage disease to prevent deaths.

Women diagnosed with cervical cancer are more likely to be uninsured and underinsured. This lack of insurance prevents women from seeking prevention and screening services on a regular basis while the precancer or cancer is asymptomatic. Once the cancer is symptomatic it is at

least locally advanced and has a much lower rate of cure. More than 50% of cases are diagnosed in late stage and most patients report not having recommended screenings in the last 5 years.

Alabama is ranked 45th in the country in HPV vaccination rates with 58% of Alabama teens age 13-17 having received at least one HPV vaccine and 40% having completed the series.[17] Rates by county range from 11% to 56% for series completion. County by county HPV vaccination rates are most closely associated with HPV cancer rates with higher HPV vaccination rates in counties where cancer rates are high.

Cervical cancer after diagnosis of invasion often requires specialty services for appropriate treatment, even in the earliest stages. It is recommended that patients with early stage cervical cancer undergo counseling regarding fertility preservation followed by sentinel or full lymphadenectomy, and radical hysterectomy procedures that should only be provided by a gynecologic oncologist. Further, more than half of all cervical cancer is diagnosed as at least locally advanced when surgery is no longer recommended. A team approach is recommended combining women's cancer specialists and radiation oncology for best outcomes. Brachytherapy is a key component of clinical cure for locally advanced cervical cancer and all providers who treat cervical cancer should stress this component of the curative intent treatment. Treatment at a high volume center (>2.4 patients per year) is independently associated with improved survival and increased likelihood of receiving treatment in keeping with national guidelines.[18]

There are new options and clinical trials available for treatment of women with recurrent or metastatic cervical cancer for both palliation and life prolongation. With FDA approved medications and new medications including targeted and immunotherapy agents, survival of recurrent and metastatic cervical cancer is on the rise and referral to a high volume center for consideration of palliative options is strongly recommended.

KEY POINTS:

- **Alabama ranks number one in the country in cervical cancer mortality and ongoing disparities exist by race, poverty and insurance status.**
- **Most cervical cancer is diagnosed in an advanced stage.**
- **Recommendations for radical cancer procedures and /or specialized cancer therapies including brachytherapy, immunotherapy, and others are improving survival and should be discussed with all cervical cancer patients.**

RECOMMENDATIONS:

- **Cervical cancer patients should be referred for treatment at a high volume center as this is associated with highest survival.**

C. UTERINE CANCER

Table 3 Alabama and United States Uterine Cancer Incidence and Mortality Rate Comparisons[3,4,5]

Incidence Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**24.0**	**18.0**	**50th**
White	**24.9**	**18.0**	**50th**
African-American	**22.1**	**19.4**	**28th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.
Rates are for malignant tumors only and exclude sarcomas.
The incidence rate for Alabama is lower than the incidence rate for the United States for all groups ($p<0.05$)

Mortality Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**4.5**	**3.4**	**49th**
White	**4.1**	**2.5**	**51th**
African-American	**7.9**	**6.8**	**34th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard. #
The mortality rate for Alabama is s lower than the mortality rate for the United States for all groups. ($p<0.05$)

Uterine cancer is the most common gynecologic malignancy in the United States and is the fourth most common cancer in women.[19] The incidence and the number of deaths from uterine cancer are rising, despite the fact that most are diagnosed at an early stage. Adenocarcinoma of the endometrium (lining of the uterus) is the most common type of uterine cancer. Other types of uterine cancer include sarcoma, papillary serous, and clear cell. Abnormal uterine bleeding is the cardinal symptom of endometrial cancer. Between 75% and 90% of women with endometrial cancer present with abnormal uterine bleeding.[20] The majority of patients are diagnosed with disease confined to the uterus and have a 90% 5-year survival rate. Suspicion for endometrial cancer depends upon symptoms, age, and the presence of risk factors. The amount of bleeding does not correlate with the risk of cancer. Any vaginal bleeding, including spotting should be evaluated in postmenopausal women. Up to 20% of women with postmenopausal bleeding are found to have endometrial cancer, and another 10% have endometrial hyperplasia.[21] Prior to menopause, if abnormal uterine bleeding is persistent or occurs in the setting of a history of unopposed estrogen exposure (obesity, chronic anovulation), an evaluation should be performed. There should be increased concern regarding endometrial cancer after age 45. The risk of endometrial hyperplasia and carcinoma is fairly low prior to age 45 and increases with advancing age.[22]

KEY POINTS:

- **The majority of women with endometrial cancer will have abnormal uterine bleeding.**

- **Appropriate work-up of these women will allow early diagnosis of endometrial cancer**

RECOMMENDATION:

- **All patients with persistent abnormal uterine bleeding or postmenopausal bleeding should undergo appropriate workup including endometrial pathologic sampling prior to proceeding with definitive treatment such as hysterectomy.**

Prior to treatment, the patient should have a complete evaluation, including history, physical examination, and endometrial sampling, to establish the diagnosis of cancer. Treatment planning is guided by the patient's ability to tolerate surgery and by the cancer histology. Additional testing may include imaging or tumor marker studies to assess for metastatic disease if suspected. A medical and surgical history is taken to evaluate for comorbidities that may impact surgery or adjuvant therapy. A complete family cancer history should be taken as a means to screen for hereditary susceptibility to cancers.[23] Preoperative diagnosis of endometrial cancer allows potential use of morbidity-sparing sentinel lymph node evaluation techniques. If diagnosis is made after hysterectomy has already been performed patients are limited to either more morbid and costly complete lymph node resection or radiation.

KEY POINTS:

- **After the diagnosis of endometrial cancer, referral to a gynecologic cancer specialist will allow appropriate treatment planning.**

RECOMMENDATION:

- **All patients with complex atypical hyperplasia or suspected endometrial cancer should be referred to a gynecologic oncologist for evaluation and management.**

Endometrial cancer is surgically staged and includes total hysterectomy, bilateral salpingo-oophorectomy, and lymphadenectomy. The approach to surgery has evolved significantly over time. Traditionally, patients underwent exploratory laparotomy through a midline incision. Today, the majority of women with early-stage disease undergo minimally invasive surgery (MIS). Additionally, changes in the approach to lymph node assessment have varied across time and institutions.

MIS (laparoscopy or robotic surgery) is recommended for women who are surgical candidates with disease confined to the uterus (based on physical examination or pelvic imaging). This is based on consistent data from randomized trials that MIS compared with open hysterectomy results in lower morbidity and comparable oncologic outcomes. The likelihood of a successful minimally invasive procedure is based on several factors, including the patient's surgical history

and the size of the uterus. The goal of surgery is to remove the tumor and to identify prognostic factors to determine whether adjuvant therapy is required. This is done in most cases with MIS (laparoscopy or robotic surgery). For patients whom MIS is not feasible (e.g., due to excessive uterine size, medical comorbidities, or known adhesive disease), laparotomy through a midline incision is the appropriate surgical approach.

The approach to lymph node evaluation is a subject of debate and several options exist. Options for evaluation of lymph nodes (in the absence of grossly metastatic disease) include no lymph node dissection (LND), systematic LND only if the risk of lymph node metastasis exceeds a certain threshold, routine sentinel LND following lymphatic mapping, or systematic LND in all patients. Patients should be counseled about the options and engage in shared decision-making regarding the approach to lymphadenectomy. Since the decision to recommend adjuvant therapy after surgery is strongly influenced by surgical stage and status of the lymph nodes, referral to a gynecologic oncologist is paramount. Patients who do not have a lymph node assessment are more likely to require adjuvant radiation which increases cost and long-term morbidity.

KEY POINTS:

- **The majority of patients with endometrial cancer will benefit from MIS and lymph node assessment.**

RECOMMENDATION:

- **Consider MIS and evaluation of the lymph nodes for all patients with endometrial cancer or suspected endometrial cancer.**

For women who develop metastatic endometrial cancer, a platinum-based combination regimen should be offered provided patients are candidates for a combination regimen and understand the risks associated with treatment. The most common regimen to treat metastatic endometrial cancer is carboplatin and paclitaxel. Second-line therapy may include endocrine therapy or immunotherapy. However, women who relapse following first- and/or second-line chemotherapy have a poor prognosis. The median overall survival in clinical trials after first- or second-line agents is generally 12 months or less. For women who desire further treatment and maintain a good performance status, we encourage the participation in clinical trials.

KEY POINTS:

- **The prognosis of women with recurrent endometrial cancer is poor if they fail first-line chemotherapy.**

RECOMMENDATION:

- **Patients with recurrent endometrial cancer who have failed two lines of therapy, should be referred for a clinical trial.**

D. VAGINAL AND VULVAR CANCER

Table 4 Alabama and United States Vaginal Cancer Incidence and Mortality Rate Comparisons[3,4,5]

Incidence Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**0.7**	**0.8**	**6th**
White	**0.7**	**0.8**	**4th**
African-American	**1.0**	**0.9**	**13th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.

Mortality Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**0.2**	**0.3**	**4th**
White	**0.2**	**0.3**	**3rd**
African-American	**0.3**	**0.3**	**8th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.

The incidence and mortality rate for these two cancers are not significantly different than the national average. Risk factors are similar to those for cervical cancer.

Vaginal cancer: Approach to patients with vaginal cancer is similar to cervical cancer with an increased need for prevention and screening behaviors as well as early referral to high volume centers. Vaginal cancer is exceedingly rare in our state and requires specialized surgical and/or radiation procedures in conjunction with a gynecologic oncologist at a high volume center. HPV vaccination would prevent up to 90% of vaginal cancer and efforts need to also focus on increasing HPV vaccination.

Alabama and United States Vulvar Cancer Incidence and Mortality Rate Comparisons[3,4,5]

Incidence Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**2.4**	**2.6**	**32nd**
White	**2.7**	**2.9**	**26th**
African-American	**1.8**	**1.7**	**25th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.

Mortality Rate Comparisons 2006-2015 by Race			
	United States	**Alabama**	**State Rank**
All Races	**0.5**	**0.4**	**36th**
White	**0.5**	**0.5**	**33rd**
African-American	**0.3**	**0.3**	**10th**

Rates are per 100,000 and age-adjusted to the 2000 US (19 age groups) standard.

Vulvar cancer: Vulvar cancer is rare in the United States but unfortunately all too common in Alabama. Vulvar cancer risk factors include increasing age and smoking in addition to HPV. The HPV vaccine would prevent up to 90% of vulvar cancers. There is no routine screening test

recommended for vulvar cancer other than routine pelvic examination for visualization of the vulvar skin as per women's care guidelines. Vulvar cancer is completely curable if caught in the earliest stages. However, women often present late due to disparities with poverty, rurality, and lack of insurance. Advanced disease requires radical surgery, radiation, and chemotherapy and should be treated at high volume centers with a multi-disciplinary team often including a gynecologic oncologist, radiation oncologist, and even plastic surgery for reconstruction.

E. GYNECOLOGIC CANCER CARE IN ALABAMA

Gynecologic cancer care in Alabama is available in three metropolitan areas: Birmingham, Mobile, and Huntsville. Cancer centers in these areas offer services of gynecologic oncologists, medical oncologists, and radiation oncologists as well as access to specialized services (genetic counseling and testing, tumor specific testing, evaluation and consideration of oral targeted therapy, integration of palliative and supportive care services, and access to clinical trials). Referral to a gynecologic oncologist serves as a patient's entry to this team approach to specialized care.

A gynecologic oncologist is a physician who specializes in diagnosing and treating cancers that develop on a woman's reproductive organs. Gynecologic oncologists have completed an obstetrics and gynecology residency and then pursued subspecialty training through a gynecologic oncology fellowship. A fellowship involves three to four additional years of intensive training including surgical, chemotherapeutic, radiation, and research techniques that are important to providing the best care for gynecologic cancers.

Statistics from ADPH document that approximately 57% of women with ovarian cancer and 40-60% of women with cervical cancer in Alabama are not evaluated by a gynecologic oncologist either at diagnosis or during their treatment course. The mortality rate for women diagnosed with these cancers in Alabama is significantly higher than the national rate. Alabama ranks third in mortality in the United States for both ovarian cancer and cervical cancer.

Women diagnosed with ovarian or cervical cancer are more likely to visit a gynecologic oncologist if they reside in an urban area versus a rural area and if they have medical insurance compared to no insurance. Patients with ovarian cancer are more likely to be seen by a gynecologic oncologist if they are younger than 70 years of age and for cervical cancer are younger than age 65. Women diagnosed with ovarian cancer are more likely to visit a gynecologic oncologist if they have been staged with local/regional compared to distant cancer staging; staging of cervical cancer has no bearing on the likelihood of being seen by a gynecologic oncologist. Race also has no bearing on the likelihood of being seen by a gynecologic oncologist across all gynecologic cancer types.[24]

Nationally there are approximately .62 gynecologic oncologists per 100,000 women. There are 16 gynecologic oncologists practicing in Alabama or .63 per 100,000.[25] While the number of gynecologic oncologists does not differ significantly from the national average and is adequate for the population, the poor rate of referral is secondary to other barriers including geographic

distance, lack of insurance, financial concerns, and lack of awareness by physicians of the need for referral. All gynecologic oncologists in the state are committed to decreasing referral issues related to access with increasing numbers of outreach clinics, regular contact with locoregional referring physicians, and financial support services to meet the needs of the uninsured/underinsured. Further statewide education on the importance of referral would improve outcomes in Alabama. Investment in telemedicine opportunities could help expand gynecologic oncology services in hard to reach service areas.

KEY POINTS:

- **Treatment by a gynecologic oncologist or other specialist in gynecologic cancer significantly improves patient outcomes and reduces mortality.**
- **Information surrounding patient care and status of people living with gynecologic cancers is needed to better evaluate outcomes and such information would be available through a State hospital discharge database.**

RECOMMENDATIONS:

- **Educate health care providers of the need to offer referral to a gynecologic oncologist to patients who meet criteria for specific gynecologic cancer type as defined in this report.**
- **A State hospital discharge database should be established**

IV. PREVENTION AND RISK REDUCTION

An annual well-woman examination is recommended for women by the American College of Obstetricians and Gynecologists (ACOG). It is recommended that the first gynecologic examination be done between the ages of 13 and 15 years. Recommendations for these exams are based on age and risk factors and may include general health screening, cancer screening, contraception, vaccinations, sexually transmitted infections screening, weight control and other issues as appropriate.[26]

There are no screening tests or vaccinations against either ovarian cancer or uterine cancer. Identifying women with an increased risk of developing a gynecologic cancer can lead to interventions which may decrease risk. Additionally, educating women about risk factors and possible risk-reducing behaviors could potentially lead to decreased risk.

A. OVARIAN CANCER

Ovarian cancer is associated with several risk factors. Risk factors include having a BRCA or other high-risk genetic mutation, having endometriosis, a family history of ovarian, breast, colon or endometrial cancers, personal history of breast, colon or endometrial cancers, and increasing age. Factors correlated to a decreased risk of ovarian cancer include oral contraceptive use, parity (the condition of having given birth), tubal ligation (surgical interruption of the fallopian tubes) or salpingectomy (surgical removal of the fallopian tubes).[27,10]

The Society of Gynecologic Oncology (SGO) Position Statement: Genetic Testing for Gynecologic Cancer issued in October of 2014, recommends, "Women diagnosed with epithelial ovarian, fallopian tube, and peritoneal cancers should receive genetic testing. Women who do not have gynecologic cancer but have a close family member (such as a mother, sister or daughter) diagnosed with ovarian, fallopian tube, or primary peritoneal cancer or who have a family history of ovarian and breast cancer in several relatives should also receive genetic counseling."[28]

Opportunities are being missed to identify women at risk of developing ovarian cancer because of their family history. The "Every Woman Study" revealed that of those women with two or more relatives with ovarian cancer in their family, 80% had not been tested prior to their own diagnosis. In the absence of screening, knowing genetic susceptibility is a potentially vital source of primary prevention. While genetic testing of the general population is not recommended as a primary prevention, educating women with a family history or personal history of certain cancers about the availability of counseling and testing could result in identification of more women at increased risk of developing ovarian cancer.[29]

KEY POINTS:

- **There is no screening test for or vaccination against ovarian cancer.**
- **Risk factors associated with an increased risk of ovarian cancer include a BRCA or other high-risk genetic mutation, a family history of ovarian, breast, colon or endometrial cancer, and/or a personal history of breast, colon or endometrial cancer as well as increasing age.**
- **Oral contraceptive use, parity, tubal ligation or salpingectomy may be associated with decreased risk of ovarian cancer.**

RECOMMENDATIONS:

- **All women with diagnosed ovarian cancer should be offered genetic counseling and testing to include appropriate family member referral.**
- **All women with a known family history of ovarian, breast, colon or endometrial cancer or a personal history of breast, colon or endometrial cancer should be offered genetic counseling.**

B. CERVICAL CANCER

Cervical, vaginal, and vulvar cancers as well as all other HPV-related cancers (anal and head and neck cancer in men and women as well as penile cancer in men) can be prevented 90% of the time by the HPV vaccine. Over 99% of cervical cancer is caused by the HPV. The nonavalent HPV vaccine (Gardasil TM, Merck & Co) is currently the only available vaccine on the US market. The vaccine protects against 9 different HPV types including seven cancer-causing HPV types and two HPV types that cause genital warts. Vaccination is recommended as part of routine adolescent vaccinations for girls and boys at ages 11, 12 but can be given as early as age 9 and up to age 27 as part of catch-up vaccination. The FDA recently approved the HPV vaccine for men and women up to age 45. The CDC will meet in 2019 to determine if the HPV vaccination should be added to the adult immunization schedule above the age of 27.

Barriers to HPV vaccination reported by parents include lack of knowledge and that the vaccine was not recommended by their pediatrician. Pediatricians report that parents are often reluctant to vaccinate against a sexually transmitted disease and some parents express safety concerns. Overall, a strong recommendation by a trusted health care provider followed by reassurance that the vaccine is completely safe often results in high vaccination rates. The vaccine is covered by all private insurance carriers in the state as well as the Federal Vaccines for Children program for all children with Medicaid, uninsured and underinsured for vaccinations.

The ADPH has formed the Alabama Adolescent Immunization Task Force (AAITF) to bring together stakeholders across the state toward the common goal of increasing vaccination rates in the state. Current efforts include participation in national, regional, and statewide meetings to coordinate efforts, statewide awareness campaigns including social media, traditional media, billboards, and letters to school nurses. This group will also undertake reeducation of state health providers including dentists to get the word out about this life saving vaccine.

KEY POINTS:

- **Annual well-woman examinations are recommended for all females beginning between age 13 and 15.**
- **The HPV vaccine if given as recommended can prevent up to 90% of HPV related cancers including cervical cancer.**
- **Alabama HPV vaccination rates fall below recommended Healthy People 2020 goals and Alabama ranks 45th nationally for HPV vaccination.**

RECOMMENDATIONS:

- **ADPH, Cancer Prevention and Control, in coordination with gynecologic cancer advocacy groups and heath care providers will expand public awareness campaigns focused on need for annual well-woman examinations.**

- **ADPH should continue to work with parent, provider, payor organizations, and advocacy organizations to promote policies that increase HPV vaccination and HPV vaccine access across the state.**

Papanicolaou (Pap) tests are recommended to diagnose cervical cell abnormalities before they become cancer. Pap tests should be initiated at age 21, recur every 3 years and at age 30 with an HPV test added. HPV co-testing increases the sensitivity of the Pap tests and diagnoses lesions earlier than Pap test only or Pap test with reflex HPV testing, particularly adenocarcinomas which can be difficult to detect on routine Pap.[30]

Currently the USPSTF recommends Pap test and HPV test every 5 years for women aged 30-64 (preferred) or Pap test alone every 3 years. HPV testing as primary screening may be used and has been FDA approved but only for a limited number of products and is not widely available at this time. Women in Alabama get their Pap tests at rates similar to women across the United States with 78.3% of Alabama women compared to 75.2 % of U.S. women. In addition, African American women in Alabama have higher rates of Pap screening at 85% compared to 78.9% in U.S. These statistics fail to explain the racial disparities that seen in the state. Most women diagnosed with cervical cancer describe that they are not up to date on a Pap or knew that they needed follow-up for an abnormal test but did not have the time, money, or resources to attend necessary follow-up diagnostic testing.

Alabama uninsured and underinsured women have access to Breast and Cervical Cancer Early Detection Program through the ADPH. This program provides free Pap testing as well as diagnostic and treatment services for any woman found to have an abnormal Pap test. Women who have a Pap test outside the program, can be enrolled in emergency Medicaid if they have a qualifying diagnosis. Unfortunately, too often this program is underfunded and unable to cover all the women in the state who need these services. Awareness of the existence of the program is limited.

KEY POINTS:

- **Cervical cancer can be prevented by getting recommended screening tests on time and appropriate follow-up of abnormal tests**
- **HPV testing either as co-testing over the age of 30 or as primary screening has the advantage of increased sensitivity over a Pap test and may diagnose lesions earlier in their course.**
- **Alabama has Medicaid coverage for screening, diagnostic and treatment services for uninsured and underinsured women through the Breast and Cervical Early Detection Program but the program is underfunded and cannot reach all women in need of its services.**

RECOMMENDATIONS:

- **Continue and consider increasing funding of the ABCCEDP.**
- **Abnormal screening tests need immediate and appropriate follow-up including available resources of health departments, free clinics, and available colposcopy clinics.**

C. UTERINE CANCER

Uterine cancer is associated with Lynch syndrome. Lynch syndrome is the most common cause of inherited colorectal cancer (CRC). It is characterized by a significantly increased risk for CRC and endometrial cancer as well as a risk of several other malignancies. Women with endometrial cancer should be screened for Lynch syndrome.[23] Genetic evaluation for Lynch syndrome can be performed by testing the tumor for MSI via immunohistochemistry (IHC) testing. The absence of MSI and intact expression of all four mismatch repair (MMR) proteins on IHC rules out most cases of Lynch syndrome. In individuals with evidence of high MSI (MSI-H) or loss of expression of a MMR protein, further evaluation is needed. Germline testing for a deleterious mutation in the MMR (*MLH1, MSH2, MSH6*, and *PMS2*) is required to establish the diagnosis of Lynch syndrome.

KEY POINTS:

- **There is no screening test for or vaccination against uterine cancer.**
- **Women with endometrial cancer are at risk of Lynch Syndrome.**
- **Testing of the hysterectomy specimen can identify patients who need germ-line testing.**

RECOMMENDATIONS:

- **Universal testing of MSI should be performed on all hysterectomy specimens in patients with endometrial cancer.**
- **All women with uterine cancer and evidence of high MSI on testing should be referred for genetic counseling and testing.**

Obese women are more likely to develop endometrial carcinoma.[31] Higher body mass index (BMI) is also associated with the development of endometrial carcinoma at a young age. Obesity appears to play a similar role as a risk factor for endometrial carcinoma in black, Hispanic, and white women.[32] In the United States, obesity rates are higher in blacks and Hispanics than in whites; however, rates of endometrial carcinoma are higher in whites than in blacks or Hispanics. One explanation for the role of obesity in endometrial carcinoma is that obese women have high levels of endogenous estrogen.

Obese women may also have other endocrine abnormalities which may contribute to the increased risk of endometrial cancer in these women. Premenopausal obese women, especially those with polycystic ovary syndrome, are often anovulatory as well. Among women with endometrial cancer, severe obesity is also associated with an increased risk of death.[33] The pathophysiology of this is uncertain, but may be due to continued stimulation of metastatic cells by endogenous estrogen or may result from obesity-associated conditions, such as diabetes or cardiovascular disease.

KEY POINTS

- **The majority of women diagnosed with endometrial cancer are obese.**
- **Weight loss is an important aspect of follow-up and survivorship for women with endometrial cancer.**

RECOMMENDATION:

- **Grade 1 adenocarcinoma related to concurrent obesity should be considered a medical condition secondary to obesity and an indication for medical and surgical weight management.**

D. GENETIC COUNSELING AND TESTING SERVICES

As noted in the previous section, genetic testing is standard of care for women with ovarian and/or uterine cancers. Such testing can help direct treatment and also alert relatives of their risk should there be a positive test result. Many women are not offered genetic testing and/or fail to undergo the testing. Unfortunately, current data collection does not tally whether women receive this test or whether they receive a positive result. Improved records would allow a better understanding of where we are succeeding and where we might improve when it comes to genetic testing. For women who receive a positive result, they can share that result with family members and potentially prevent ovarian cancer in their relatives.

Opt-in genetic screening initiatives have gained popularity in Alabama during the last few years. The Alabama Genomic Health Initiative (AGHI) offers free genetic testing to residents of Alabama and to date has screened almost 5000 individuals. Other commercial entities offer testing on a direct-to-consumer basis. Both of these have the potential to improve early diagnosis and prevent disease, with optional surgical intervention, but to ensure women receive the information they need with their test result and that the information is part of their medical record so that they can work with their physicians to receive the recommended screening, the goal is to conduct the recommended genetic testing and counseling under the supervision of a physician.

Implications of genetic testing and its possible impact on treatment and risk assessment are complex. It is essential that those referred for testing meet with a certified genetic counselor to discuss personal health and family history and the testing itself. One barrier to genetic testing

and counseling in Alabama is access to the services of certified genetic counselors. These counselors are professionals who have specialized education in genetics and counseling to provide personalized help patients may need as they make decisions about their genetic health. Genetic counselors are not currently considered providers by the Board of Medicine and therefore unable to bill for professional services that further limits access. The Access to Genetic Counselor Services Act of 2018 to allow the Center for Medicare and Medicaid Services (CMS) to recognize certified genetic counselors as healthcare providers facilitating payment for services is pending re-introduction in the US House of Representatives.[34]

KEY POINTS:

- **Patients and family members referred for genetic testing should be seen by a genetic counselor before testing and upon receipt of results under the supervision of a physician.**
- **Reimbursement for services of genetic counselors would improve access.**
- **There is no statewide data collection concerning referral for and completion of testing nor of results.**

RECOMMENDATIONS:

- **Legislators in coordination with the ADOI and the NSGC should consider recognition of certified genetic counselors as healthcare providers.**
- **ADPH, advocacy groups and healthcare providers should coordinate to disseminate information about factors which may reduce a woman's risk of developing ovarian cancer as well as availability of genetic counseling and testing programs throughout the state.**
- **Access to genetic counseling and testing programs should be expanded throughout the state with consideration given to innovative and technology-driven strategies such as telemedicine and outreach clinics.**
- **ADPH epidemiologists should develop a method for collecting and reporting data concerning genetic counseling and testing.**

E. STATE OF GYNECOLOGIC CANCER RESEARCH IN ALABAMA

Alabama is a leader in gynecologic oncology research at a national level with two major academic medical centers and two of the largest academic gynecologic oncology divisions in the Southeast. Faculty from these institutions are members or leaders of national committees for clinical trials in cervical, uterine, and ovarian cancer, as well as immunotherapy and cancer control and prevention committees. Many of Alabama's gynecologic cancer specialists are leaders in their areas of expertise at a national or international level. They are at the forefront of the effort to develop novel therapies and cancer prevention tools. Both academic cancer center directors, Drs. Birrer and Rocconi, treat gynecologic cancers as their area of clinical expertise.

The University of Alabama at Birmingham (UAB) is nationally recognized as having one of the top gynecologic oncology programs in the country with seven full-time gynecologic oncologists and a gynecologic oncology fellowship program. The UAB Gynecologic Oncology Division has an extensive portfolio of basic and translational research in gynecologic cancer and was a founding member of the NCI funded Gynecologic Oncology Group (GOG). The UAB gynecologic oncology research program currently holds, in collaboration with Johns Hopkins, the only NCI funded Cervical Cancer SPORE. UAB receives over $5.3 million direct cost and $7.0 million total in research funding to support gynecologic cancer research as well as an additional $750,000 in research training awards and cancer related research (prevention). In the last 3 years, the division participated in 26 trials enrolling 172 patients. Faculty and trainees at UAB regularly present research at all major national cancer conferences and publish extensively. This research supports or partially supports 40 faculty and staff.

The University of South Alabama (USA) in Mobile is the largest Gynecologic Oncology Division on the Gulf Coast between Houston and Tampa. There are 5 full time gynecologic oncologists serving patients in this region and participating in cancer research. USA Gynecologic oncology division has received over $ 3.6 million in government funding as well as another $ 2 million in development funds towards gynecologic oncology and cancer prevention research. This includes 12 clinical trials in the last 3 years enrolling a total of 89 patients. This research supports or partially supports 14 faculty and staff.

HudsonAlpha Institute for Biotechnology faculty and staff are involved in several research projects focused on gynecological cancers. The majority of these projects involve collaboration with UAB or USA. In recent years, over $350,000 has been spent on research focused on gynecological cancers at HudsonAlpha. An additional $600,000 goes toward general cancer research which impacts and includes gynecologic malignancies. The funds the institution receives have partially supported the salaries of 9 employees, including two trainees.

KEY POINTS:

- **Alabama is a leader in gynecologic oncology research nationally.**
- **This research generates revenue and creates and supports jobs in the State.**

RECOMMENDATION:

- **Support efforts to increase research funding through federal and private funding sources.**

V. PATIENT NEEDS AND SUPPORT

A. PSYCHOLOGICAL AND EMOTIONAL SUPPORT

The diagnosis of a gynecologic cancer can produce shock, disbelief and emotional turmoil for the patient and her family members. Emotions most often experienced include depression, anxiety, and anger following initial diagnosis with 23% of gynecologic cancer patients meeting the criteria for major depressive disorder as compared to 5-6% meeting those criteria in the general population. Emotional stressors may continue during and following treatment. In a survey conducted by TESARO Pharmaceuticals with input from the Ovarian Cancer Research Alliance (OCRA) and the National Ovarian Cancer Coalition (NOCC), many patients with ovarian cancer and other gynecologic cancers were found to be uncertain of what to expect after diagnosis and that this uncertainty can be challenging. More than half of the patients surveyed (53%) indicated that the disease has had a severe or very severe impact on their lives. Additionally, there was a gap between the information physicians thought they were communicating ant the information patients felt they were receiving. The authors concluded that health professions could better support survivors by better understanding their needs and perspectives.[35] Identifying women experiencing these needs and those who want support for those needs helps direct resources appropriately.[36] The NCCN Guidelines for Distress Management define distress as "a multifactorial, unpleasant experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment." The NCCN developed the DT/PL as a tool for distress screening.[37]

Over the last two decades psychological group interventions have been developed to help cancer patients cope better with the psychosocial effects of a cancer diagnosis and treatment. Beyond the use of individual therapy which may be cost prohibitive, support groups can address cancer-related issues to enable patients to gain emotional support from other patients with similar experiences. Many studies have provided evidence-based knowledge that structured group interventions for cancer patients improve psychological well-being, reduce anxiety and depression, and improve quality of life, coping and mental adjustment. Such groups are helpful not only for patients but also for their spouses and other family members in relieving cancer-related distress. The most concerning emotional side effect validated was the fear of recurrence (26%) and patients reported with a median score of 9 out of 10 that the support group helped relieve their fear of recurrence. Patients reported higher quality of life score and perceived a positive impact on cancer therapy.[38]

In July 2018 the Alabama Study Commission for Gynecologic Cancers (ASCGC) conducted a survey of 67 women diagnosed with gynecologic cancers and treated in Huntsville, Birmingham

or Mobile. Approximately 70% of the respondents reported attending a support group for gynecologic cancer survivors.[39]

There are three gynecologic cancer specific support groups and one peer-to-peer support program in Alabama. These support groups are open to any woman in Alabama. Members of the Lilies of the Valley in Huntsville reside in the counties of Lauderdale, Limestone, Madison, Jackson, Colbert, Morgan, Marshall, Franklin, Etowah, Dekalb, Cullman, Blount and Lawrence. Members of The Teal Magnolias in Opelika, reside in Lee, Russell, Macon, Tallapoosa, Chambers, and Montgomery counties. Members of CanSurvive, a program of the Laura Crandall Brown Foundation, in Birmingham reside in Blount, Calhoun, Cullman, Jefferson, Shelby, St. Clair, Talladega, Tuscaloosa, and Walker counties. Laura Crandall Brown Foundation, in partnership with OCRA, now offers the Woman to Woman program, a peer-to-peer support program that pairs gynecologic cancer patients with trained survivor volunteers who provide emotional support and mentoring. Currently this program has women enrolled in Jefferson, Shelby, Cullman, Lee, Tuscaloosa, and Marion counties. Geographic distance is a barrier for many women particularly those in the southernmost and southwestern portions of the State. There is no gynecologic cancer-specific support group for spouses and other family members.

There are web-based support groups offered by various national organizations that provide an alternative to women who cannot physically attend a support group.

KEY POINTS:

- **Gynecologic cancer may produce significant emotional and psychological distress.**
- **Identifying women experiencing these needs who want support helps direct resources.**
- **Patients attending support groups validate positive impact on reduction of fears and anxiety as well as improved quality of life.**
- **There are three gynecologic cancer-specific support groups in Alabama**
- **Geographic distance limits access to support groups in the southernmost and southwestern portions of the state.**
- **Web-based support groups offer an alternative to attending physical support groups.**
- **There are no support groups for spouses and other family members.**

RECOMMENDATIONS:

- **A NCCN DT/PL should be administered to patients by a member of the medical treatment team periodically throughout the course of treatment and after completion of treatment, referring patients with a positive distress screen to the appropriate resource.**

- **Advocacy groups in coordination with healthcare providers and ADPH should develop and distribute a Directory of Resources for gynecologic cancer patients.**
- **Cancer treatment centers should post support group information provided and kept current by advocacy groups in treatment areas**
- **Local advocacy groups should assess the need for family member support group services and explore feasibility of expanding such services if the need exists.**

B. PATIENT NAVIGATION

Cancer patients face many challenges when trying to understand and navigate the health care system. As more cancer patients live with chronic illness, the length of time a patient is engaged with the health care system is increasing. Patient navigation is seen as one possible solution to these issues.

In 2012, American College of Surgeons Commission on Cancer (ACSCC) released a new standard that required all cancer programs seeking accreditation to have a patient navigation program. It enhances interaction among physicians, increases patient self-management, improves patient/family education and satisfaction, and allows oncologists to focus on treatment management. It also increases referrals for nutrition, physiological care, and physical/service needs. Other benefits include increased collaboration among the patient and the health care team and increased multi-disciplinary care.[40]

University of Alabama at Birmingham researchers looked at their program, which assigned 42 lay navigators to help 6,743 cancer patients. They found the number of hospitalizations, emergency room visits and admissions to intensive care declined more sharply among people assisted by navigators, as did costs.[41]

In a July 2018 survey conducted by the ASCGC, 59% of Alabama gynecologic cancer patients reported that they did not receive available support resources information and only 30% reported that they were connected to a patient navigator.[39]

The Alabama Comprehensive Cancer Control Coalition (ACCCC) set forth in the Alabama Cancer Control Plan 2016-2021 that patient navigation is a particularly important tool in decreasing health disparities in groups that have difficulty accessing healthcare services or limited knowledge of the healthcare system. The ACCCC supports increased awareness and utilization of patient navigation to help achieve the goals and objectives outlined in the Plan.[42]

KEY POINTS:

- **The ACSCC Standards require all cancer programs seeking accreditation to have a patient navigation program.**

- **Benefits of patient navigation include improved patient/family education and satisfaction, increased collaboration and communication among the patient and health care team, and increased multi-disciplinary care.**

- **UAB reported that the number of hospitalizations, emergency room visits and admissions to intensive care declined more sharply among people assisted by navigators, as did costs.**

RECOMMENDATIONS:

- **Encourage employment of certified oncology navigators with specialized training in gynecologic cancer in treatment centers and develop or expand the use of general patient navigators or lay navigators in the absence of certified gynecologic cancer navigators.**

C. SURVIVORSHIP PLANS

There are over one million gynecologic cancer survivors currently living in the United States and this population is expected to increase by 33% over the next decade.[43] In a July 2018 survey conducted by the, 70% of Alabama women with a gynecologic cancer diagnosis reported that no survivorship plan was implemented for them. Additionally, only 43% were provided with information on symptoms to monitor for recurrence, 42% were provided with information regarding long-term side effects, and 41% were provided with support services information.[29]

In 2006 the Institute of Medicine (IOM) reported that the U.S. healthcare system is failing these survivors because there is no organized and comprehensive system of care for those who have completed active treatment. In response, the IOM recommends that every cancer patient receive an individualized survivorship care plan that includes guidelines for monitoring and maintaining their health.[44]

Cancer care after treatment includes management of chronic conditions, emotional issues, physical limitations and cognitive changes. Preventive and on-going treatment requires close monitoring and coordination.[45] The survivorship period incorporates prevention of new cancer diagnoses, surveillance for recurrence, assessment and management of side effects, and coordination of care between patients and healthcare providers. Focusing on these components may improve quality of life as it allows for a seamless transition for cancer survivors and their caregivers.[46]

Survivorship care plans should include a summary of their treatment, surveillance recommendations, and their follow-up plan. Opportunities to improve lifestyle behaviors and continue general health maintenance should also be maximized. Providing patients with a written, comprehensive plan may decrease stress and improve coordination of care between providers.[47]

KEY POINTS:

- **The IOM recommends every cancer patient receive a survivorship care plan.**
- **70% of the Alabama gynecologic cancer patients surveyed did not receive a survivorship plan.**
- **Providing patients with a written, comprehensive plan may decrease stress and improve coordination of care.**

RECOMMENDATIONS:

- **Increase implementation of survivorship plans for gynecologic cancer patients following guidelines set by the Society of Gynecologic Oncology.**
- **Provide all patients diagnosed and treated for a gynecologic cancer a copy of "Guide for Gynecologic Cancer Survivors" published by FWC.**

D. FINANCIAL

There are financial burdens associated with cancer treatment that can act as barriers to care for patients. Some of these include out-of-pocket healthcare costs, an inability to work and a resulting decrease in income, and transportation.

Healthcare Costs:

The cost of cancer drugs has soared in the last decade, as have the out-of-pocket share patients are expected to pay. Insurance plans have become more expensive with higher premiums, higher deductibles, and higher copays, and gynecologic cancer care often entails expensive surgeries, advanced imaging tests, and weeks of chemotherapy infusions and/or radiation. The financial distress associated with the cost of cancer care has been identified as “financial toxicity,” and research has shown it has the potential to lower quality of life and increase mortality for both the insured and uninsured patients.[48, 49, 50, 51]

In an abstract presented at the 2018 Annual Meeting of the Society of Gynecologic Oncology, the authors concluded that "many patients with gynecologic malignancies experience significant financial toxicity likely worsened by treatment costs and decreased earning potential. Patients experiencing financial toxicity are at high risk of medical nonadherence because of financial constraints." Of 60 women enrolled, 36% skipped medical care because of financial concerns, and 28% were unable to cover the cost of care. Forty-four percent of a subset who indicated distress due to financial toxicity reported financially-driven medical nonadherence such as skipping appointments or medications.[52]

In September of 2017 the American Society of Clinical Oncology (ASCO) issued guidelines on patient-clinician communication, which included a strong recommendation that clinicians should "explore whether cost of care is a concern for cancer patients… clarify the specific concerns and either address the concern directly or refer the patient to a financial counselor or social worker."[53] However, findings show that a majority of clinicians do not discuss costs with patients prior to or at the start of treatment.[54]

Many chemotherapeutic agents can now be given in an oral form rather than intravenously. Intravenous anti-cancer medications are typically covered under a health plan's medical benefit that often requires the patient to pay only a small co-pay or no cost at all for the medication. Some oral anti-cancer medications are usually covered under a health plan's benefits often resulting in high out-of-pocket costs. In an effort to ensure equal out-of pocket patient costs for all forms of anti-cancer medications so that patients together with their physicians can choose the right therapy based on the risk and benefit profile instead of the cost to the patient 43 states have enacted oral oncology parity laws. These laws require any health plan that covers chemotherapy treatment to cover oral and IV chemotherapy at the same level with the patients' out-of-pocket costs being the same no matter how the therapy is given. These laws have been enacted in 43 states. There are active campaigns being conducted in an additional 4 states. The 2017 campaign in Alabama failed to result in passage of an oral oncology parity bill, and there is no active campaign at this time. Alabama is one of only 3 states where this type of legislation is not under consideration.[55]

KEY POINTS:

- **Alabama is one of 7 states with no oral oncology parity law to require any health plan that covers chemotherapy treatment to cover oral and IV chemotherapy at the same level with patients' out-of-pocket costs being the same no matter how the therapy is given.**
- **Alabama is one of only 3 states where there is no active campaign to pass such legislation.**

RECOMMENDATION:

- **Legislators, in coordination with the ADOI, should consider implementing oral chemotherapy parity in administration of group and individual health plans.**

Employment and Return to Work

A literature review of ten years of studies on employment in cancer survivors found that 63.5% returned to work after completing treatment, with an average absence from work of 151 days. Cancer survivors were also found to be at a much higher risk for unemployment, and a large percentage experienced a decline in work ability and wages compared to persons without cancer. Some gynecologic cancer survivors could also be considered at a disadvantage for a return to work, as invasive surgery, advanced tumor stage, and chemotherapy are all factors experienced by most ovarian cancer patients, and have all been negatively associated with a return to work.[56]

KEY POINTS:

- **Out-of-pocket healthcare costs, coupled with decline in work ability and wages, creates a financially toxic situation for many gynecologic cancer patients that can lead to debt, depletion of assets, and sometimes bankruptcy.**
- **ASCO and other medical institutions have recognized and indicated the importance of cost considerations being a part of the most important issues addressed through patient-clinician communication.**

RECOMMENDATIONS:

- **Providers should encourage patients to be proactive about learning about their out-of-pocket financial obligations. All patients should have access to financial counseling services and an opportunity to discuss concerns.**

E. TRANSPORTATION AND GEOGRAPHIC DISPARITIES

A comprehensive review of 27 studies involving more than 700,000 cancer patients found that extensive travel burden (defined as 50+ miles one way) was associated with more advanced disease at diagnosis, sub-optimal treatment, and a worse prognosis.[57] In Alabama, the issue of travel burden for gynecologic cancer patients is exacerbated by the fact that access to a gynecologic oncologist is geographically distant for so many. An ASCGC review of the average

statewide distribution of gynecologic cancer patients by county over the last ten years found that 51% of gynecologic cancer patients in the state would have to travel more than 100 miles (round trip) to access the gynecologic oncologist closest to them and 15% of patients would have to travel 200+ miles round trip. Considering patients receiving radiation and/or chemotherapy have treatment schedules that require weekly travel for up to several months, it is reasonable to consider that these distances could be a major barrier for some patients' treatment adherence. (See Figure 3)

For Alabama Medicaid patients, the need for widely available Non-Emergency Medical Transportation (NEMT) is critical in ensuring access to care for gynecologic cancer patients and those suffering from many other chronic health conditions that require multiple visits for care. Currently, Alabama Medicaid patients can have their transportation costs reimbursed for a limited number of appointments on a fee-for-service basis. However, for patients who do not own their own vehicle and lack outside support, there is a basic lack of NEMT service providers across the state and there is no statewide resource to inquire about or coordinate such services, despite the fact that research shows that investments in NEMT can result in overall savings to the health care system.[58] A recent study commissioned by the Medical Transportation Access Coalition (MTAC - a national coalition of NEMT brokers and advocate organizations that support NEMT) confirmed NEMT is a highly cost effective, public-private partnership that assures the health and well-being of millions of Americans and saves Medicaid millions of dollars. In the study, 58% of respondents (all were kidney, diabetic, or substance abuse patients) said they would have been unable to keep their appointments without access to NEMT. Studies have shown that missed or delayed medical appointments can lead to increased hospitalizations and acute care, and poorer health outcomes.[59]

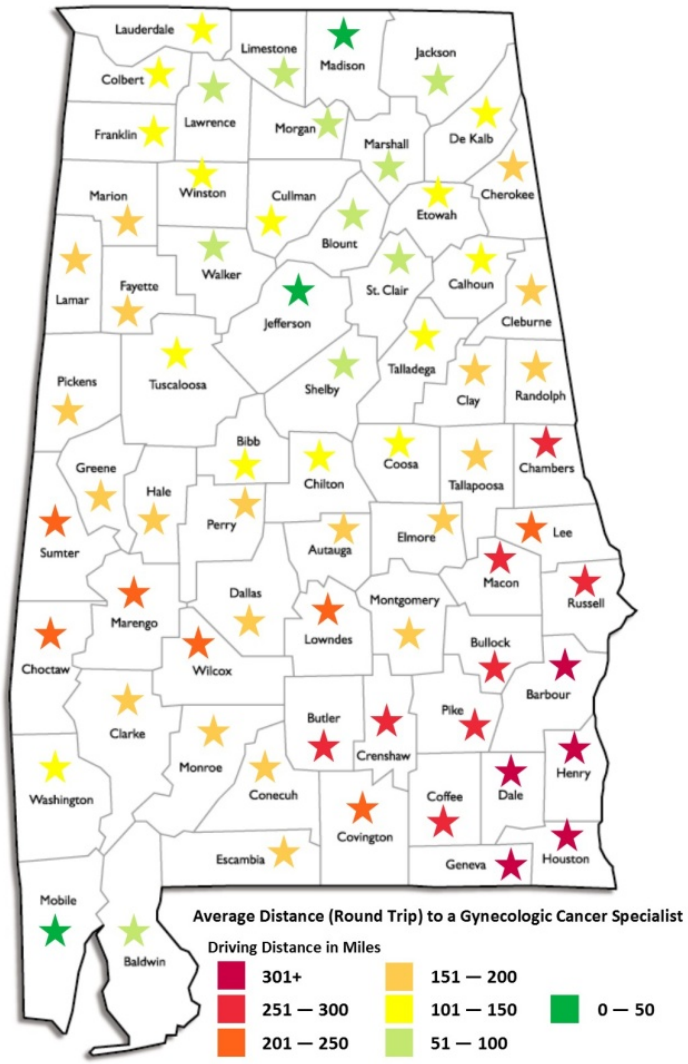

Figure 3 - Average Distance (Round Trip) to a Gynecologic Oncologist

KEY POINTS:

- **Access to a gynecologic oncologist is geographically distant for many Alabama women, which can impact access to care. Over 65% of Alabama patients have to travel an average of 100+ miles to access the closest gynecologic oncologist.**
- **As noted throughout this report, it is important for gynecologic cancer patients to be evaluated by a gynecologic oncologist yet fewer than 60% of these patients in Alabama are seeing a gynecologic oncologist.**
- **Greater access to non-emergency medical transportation is needed, as well as improved coordination among both providers and governmental and human service organizations.**

RECOMMENDATIONS:

- **Expand access to non-emergency medical transportation services for Alabamians living in rural areas and encourage improved coordination among existing providers.**
- **Decrease geographic distance as a barrier to patients' access to gynecologic oncologists, including consideration of innovative and technology-driven strategies such as telemedicine and outreach clinics.**

F. HOSPICE AND PALLIATIVE CARE

Patients with advanced gynecologic cancer face many challenges that significantly impact their ability to receive or continue treatments. These problems are numerous and can include pain, difficulty sleeping, loss of appetite or the inability to eat, all of which can negatively impact both survival and quality of life. Patients frequently experience anxiety and depression. Not only do these challenges impact the patient but family members also experience some of these same emotional challenges leading to distress for the patient. Some patients and their families may face the additional burden of travel for healthcare, insurance issues, financial toxicity, and legal issues. Many patients and their families may face spiritual questions surrounding their belief system and values.

Palliative and hospice care treatments to address these issues include medicine, nutritional guidance, physical therapy, occupational therapy, integrative medicine, and social services. Care is delivered by a team that may include physicians, nurses/nurse practitioners/PA, social workers, psychologists, and chaplains.[60]

Palliative care is designed to treat the associated physical and social situations that arise as a result of the disease. The World Health Organization (WHO) defines palliative care as an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and assessment and treatment. Palliative care is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. Palliative care is not specifically defined and therefore coverage of costs varies by insurance plan.[61]

Studies have demonstrated that palliative care produces significant improvements in clinical outcomes. These include relief from pain and symptoms, less anxiety and depression, and improved quality of life for patients and their families. Patients feel supported by ongoing discussion of their concerns, and are relieved to have help with difficult decision making and with knowing what to expect and how to handle it. Family caregivers feel supported and more satisfied with the care they are able to provide. In small studies among cancer patients on hospice, palliative care has been shown to contribute to significantly better survival rates.

Palliative care outpatient work typically includes a robust interdisciplinary team (including providers such as chaplains and social workers who typically cannot bill insurance for their work) and extensive phone and follow-up support after scheduled clinic visits. As such, palliative care physician and nurse practitioner billing typically is not adequate to support comprehensive outpatient services in a fee-for-service system.

Alabama received a "D" rating by the Center to Advance Palliative Care (CAPC) 2015 State-by-State Report Card. Non-hospice palliative care services are extremely limited in Alabama. Many patients have significant comfort issues as their disease progresses, yet have a hard time deciding not to seek additional treatment.[62] Funding and availability of outpatient palliative care clinics would substantially improve the comfort for these patients and reduce hospital admissions while allowing patients to transition from active treatment to comfort care at their own pace.

Hospice care is the model for quality, compassionate care for people facing a life-limiting illness. At the center of hospice care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so. Hospice care generally requires that a patient is expected to have a life expectancy of fewer than six months and usually prohibits therapies with the goal of curing disease or extending life.[63]

According to ADPH reports there are 133 registered hospices in Alabama. There are six freestanding inpatient hospice facilities that are not within hospital walls. Two of the six are in a wing of a medical facility such as a skilled nursing facility (SNF) and four are freestanding buildings. Most hospices have a contract with their local hospital and SNFs to provide general inpatient care in the hospital since all hospices must provide this level of care if needed. The ability of a hospice program to provide this level of care limits the availability of hospice programs.

Alabama has a shortage of "Hospice Houses." These are non-hospital-based short-term residences for hospice patients. Often these are used for short-term management of uncontrolled pain or discomfort not responding to home intervention, if a home caregiver is unable to provide care, or if the family prefers death occur in a peaceful setting but away from home.

KEY POINTS:

- **Gynecologic Cancer patients face physical, psychological, and social challenges that prevent them from devoting full attention to treatment of their cancer and enjoyment of life**
- **Alabama has inadequate resources, particularly for outpatient palliative care services**
- **While hospice is generally available, "Hospice Houses" that allow for non-hospital higher level care are not.**

RECOMMENDATIONS:

- **Work with Alabama Medicaid, BCBS of Alabama, and other payors to address appropriate funding of palliative care services.**

- **Direct regional palliative care programs to develop improved resources such as Hospice Houses and outpatient palliative care programs**

VI. AWARENESS

Awareness of gynecologic cancer symptoms and risk factors among the general public is poor. With the exception of familiarity with cervical cancer screening, most women have heard of uterine, ovarian and cervical cancers, but are unaware of or cannot recall information regarding risks and symptoms. Many women still believe that the Pap test screens for gynecologic cancers in addition to cervical cancer.[64]

In the absence of effective screening methods for these cancers, educating women and health care providers on gynecologic cancer risks and symptoms is a key strategy for early detection and timely treatment.[65] The Centers for Disease Control and Prevention began distributing gynecologic cancer awareness materials in 2008 through its *Inside Knowledge* campaign after the passage of Johanna's Law.[66] Evaluation of effectiveness of the *Inside Knowledge* materials in 2016 demonstrated that women and providers educated with these materials showed significant increase in knowledge of key messages. The authors concluded that using the *Inside Knowledge* materials to increase knowledge could lead to more empowered patients, better provider-patient communications, and improved care for gynecologic cancers.[67]

More research is needed to ascertain how widespread the use of these materials actually is today. In a 2014 study less than a quarter of providers surveyed (including gynecologists and primary care physicians) reported providing the CDC's gynecologic cancer awareness materials in their offices.[68] A majority of respondents did indicate they provided some form of gynecologic cancer education materials in their office, but a lack of detail calls into question whether these materials actually provided comprehensive information regarding all five gynecologic cancers or were focused on one site, such as the cervix.

A lack of awareness of signs and symptoms is particularly concerning for ovarian cancer since there is no reliable screening method and knowledge of symptoms is vital in earlier diagnosis.[69] Ovarian cancer is usually diagnosed at a late stage (III or IV) that is associated with low survival rates. A consensus statement regarding symptom recognition and prompt medical evaluation, preferably by a gynecologist, to help lead to earlier detection was authored in 2007 by the Society of Gynecologic Oncology, the Gynecologic Cancer Foundation, and the ACS, and endorsed by 38 health professional and gynecologic cancer advocacy organizations.[70] Despite this consensus over ten years ago, the 2018 "Every Woman Study" conducted by the World Ovarian Cancer Coalition revealed over two-thirds of women had not heard of ovarian cancer and did not know any symptoms prior to their own diagnoses.[29] This finding was mirrored in a July 2018 survey of women in Alabama who had been diagnosed with a gynecologic cancer. Of 67 respondents, 57 (85%) had been diagnosed with ovarian cancer equally distributed between stages I/II and stages III/IV. Approximately 51% of these women reported that prior to their

diagnosis they had no knowledge of the risk factors and symptoms of ovarian cancer.[39] Confounding the lack of knowledge of common symptoms and risk factors associated with ovarian cancer is the fact that these symptoms are not specific to ovarian cancer only and are frequently suggestive of other benign medical conditions.

The "Every Woman Study" also revealed this lack of awareness and its potential to impact timely diagnosis and treatment among health care providers. In the United States, the estimated time from experiencing first symptoms to diagnosis was 36.5 weeks (12.9 weeks from appearance of symptoms until consulting a physician and 23.6 weeks from time of first physician visit to diagnosis). Of clinician respondents, almost all felt that the time to diagnosis could be reduced. Guidance for general practitioners, family doctors, gynecologists and emergency doctors on who should have specialist assessment, accredited training programs for general practitioners, and campaigns to alert women of the symptoms of ovarian cancer were considered high or medium priority by 83%.[29]

Other research reinforces a lack of gynecologic cancer awareness, even for those gynecologic cancers with well-established risk factors and symptoms. Despite endometrial/uterine cancer being the most common gynecologic cancer and the fourth most common cause of cancer among women, almost a third of women surveyed in a 2014 study reported not knowing the symptoms, and 67% reported being unaware of risk factors for the disease.

Advocacy groups throughout the State currently organize, develop and carry out awareness efforts that include passing out materials at health fairs, speaking to women's groups and healthcare professional students throughout the year, as well as gynecologic cancer awareness month campaigns. ADPH, county health offices and providers disseminate awareness materials.

Across all gynecologic cancer sites, more work is needed to ensure women have critical knowledge to understand their gynecologic cancer risk and identify symptoms in order to seek care in a timely manner.

KEY POINTS:

- **Awareness of gynecologic cancers among the general public is poor.**
- **Guidance for health care providers on risk factors and symptoms and who should be referred for specialist assessment could reduce the time to diagnosis and potentially lead to diagnosis of the cancer at an earlier more treatable stage.**

RECOMMENDATIONS:

- **ADPH, Cancer Prevention and Control, in coordination with gynecologic cancer advocacy groups and heath care providers will expand public awareness campaign.**
- **Educate health care providers of the need to offer referral to a gynecologic oncologist to patients who have a suspected or confirmed diagnosis of a gynecologic malignancy.**

VII. ENDNOTES

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VIII. APPENDIX

ABBREVIATIONS AND ACRONYMS

AAITF	Alabama Adolescent Immunization Task Force
ABCCEDP	Alabama Breast and Cervical Cancer Early Detection Program
ACCCC	Alabama Comprehensive Cancer Control Coalition
ACOG	American College of Obstetricians and Gynecologists
ACS	American Cancer Society
ACSCC	American College of Surgeons Commission on Cancer
ADOI	Alabama Department of Insurance
ADPH	Alabama Department of Public Health
AGHI	Alabama Genomic Health Initiative
ASCGC	Alabama Study Commission for Gynecologic Cancers
ASCO	American Society of Clinical Oncology
BMI	Body mass index
BRCA	Breast Cancer Gene
CDC	Center for Disease Control
CMS	Center for Medicare and Medicaid Services
CPAC	Center to Advance Palliative Care
CRC	Colorectal cancer
DT/PL	Distress thermometer/problem list
FWC	Foundation for Women's Cancer
HPV	Human papilloma virus
IHC	Immunohistochemistry
IOM	Institute of Medicine
LND	Lymph node dissection
MIS	Minimally invasive surgery
MMR	Mismatch repair proteins
MSI	Microsatellite instability
MTAC	Medical Transportation Access Coalition

NOCC	National Ovarian Cancer Coalition
NSGC	National Society of Genetic Counselors
NCCN	National Comprehensive Cancer Network
NEMT	Non-Emergency Medical Transportation
OCRA	Ovarian Cancer Research Alliance
Pap test	Papanicolaou test
SGO	Society of Gynecologic Oncology
USPSTF	US Preventive Services Task Force
WHO	World Health Organization

DEFINITIONS

Anovulatory: Absence of the development of a mature ovarian follicle or the release of the oocyte (egg) during a menstrual cycle.

Brachytherapy: Internal radiation therapy delivered using a radioactive source placed within the vagina.

BRCA: Either of two tumor suppressor genes (BRCA1 or BRCA2) that are associated with an increased risk of developing hereditary breast and ovarian cancer when inherited in a mutated state.

Colposcopy: A medical procedure to examine an illuminated, magnified view of the cervix and the tissues of the vagina and vulva.

Debulking surgery: The surgical removal of as much of a tumor as possible.

Genetic counseling: The process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease

Genetic mutation: Any persisting change in the genetic material of a cell. [1]

Germline testing: Evaluation of a patient's DNA to detect inherited mutations present at birth which increase the risk of certain cancers.

Human papilloma virus: A group of viruses that cause genital warts and cervical, vaginal, and vulvar cancers.

Hysterectomy: Surgical removal of the uterus and the cervix.

Incidence: The number of newly diagnosed cases of a disease.

Laparoscopy: Minimally invasive surgery in which a laparoscope (video camera and light) is inserted into the body and used to visualize the internal structures.

Laparotomy: Surgical incision into the abdominal wall.

Lymphadenectomy: Surgical removal of lymph nodes.

Lymph node dissection: Surgical removal of lymph nodes.

Metastatic: Spread of a cancer from one area of the body to another.

Minimally invasive surgery: A surgical procedure that limits the size of incisions allowing faster recovery with less pain and infection.

Mortality rate: The number of deaths in a certain period of time divided by the total of a given population.

Ovarian cancer staging:

- Stage 1A - tumor confined to one ovary or fallopian tube.
- Stage 1B - tumor has reached both ovaries or fallopian tubes.
- Stage 1C - tumor in ovaries or fallopian tubes has broken through the surface of the ovary.
- Stage 2 - tumor has spread to nearby organs in the pelvis (colon, bladder, rectum).
- Stage 3 - tumor has spread to the lymph nodes and/or outside of the pelvis into the abdomen.
- Stage 4 - tumor has spread beyond the pelvis and may be found in the liver, lungs, or brain.

Papanicolaou (Pap) test: A method to detect pre-cancerous and cancerous changes in the cervix.

Pre-cancer: Relating to or being a condition that typically precedes or develops into cancer.

Recurrent cancer: A cancer that reappears in a site where it was eradicated.

Robotic surgery: The performance of surgical procedures with the assistance of computer-controlled devices that works in response to controls manipulated by the surgeon.

Salpingectomy: Surgical removal of fallopian tubes.

Salpingo-oophorectomy: Surgical removal of a fallopian tube and an ovary

Sentinel lymph node: The first lymph node or group of nodes draining a cancer.

Tubal ligation: Surgical procedure performed for sterilization in which the fallopian tubes are clamped or blocked preventing eggs from reaching the uterus for implantation.

Tumor suppressor gene: A gene that protects a cell from one step on the pathway to cancer.