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March 2019

To the Honorable JB Pritzker, Governor
And Members of the General Assembly:

Enclosed please find the report to the General Assembly related to “breast reconstruction and prostheses options and education” for fiscal years 2014 through 2017, pursuant to Section 2310/670 of the Civil Administrative Code of Illinois, Department of Public Health Powers and Duties Law (Law) (20 ILCS 2310/2310).

This report details the breast cancer activities and education carried out during this period pertaining to the aforementioned mandates. This report is also an evaluation of the extent to which the activities have been effective in improving the health of racial and ethnic minority groups, and future plans for the next reporting period.

I hope you find this report informative as we work together to educate patients in the State of Illinois about breast cancer and work to improve the health of Illinois residents.

Sincerely,

A handwritten signature in black ink, appearing to read "Ngozi O. Ezike", is written over a light blue circular stamp.

Ngozi O. Ezike, MD
Director
Illinois Department of Public Health

Background

In 2014, the Illinois General Assembly found that: “(1) Annually, about 207,090 new cases of breast cancer are diagnosed, according to the American Cancer Society; (2) Breast cancer has a disproportionate and detrimental impact on African-American women and is the most common cancer among Hispanic and Latina women; (3) African-American women under the age of 40 have a greater incidence of breast cancer than Caucasian women of the same age; (4) Individuals undergoing surgery for breast cancer should give due consideration to the option of breast reconstructive surgery, either at the same time as the breast cancer surgery or at a later date; (5) According to the American Cancer Society, immediate breast reconstruction offers the advantage of combining the breast cancer surgery with the reconstructive surgery and is cost effective; (6) According to the American Cancer society, delayed breast reconstruction may be advantageous in women who require post-surgical radiation or other treatments; (7) A woman suffering from the loss of her breast may not be a candidate for surgical breast reconstruction or may choose not to undergo additional surgery and instead choose breast prostheses; (8) The federal women’s Health and Cancer rights Act of 1998 requires health plans that offer breast cancer coverage to also provide for breast reconstruction; (9) Required coverage for breast reconstruction includes all the necessary stages of reconstruction. Surgery of the opposite breast for symmetry may be required. Breast prostheses may be necessary. Other sequelae of breast cancer treatment, such as lymphedema, must be covered; and (10) Several states have enacted laws to require that women receive information on their breast cancer treatment and reconstruction options.”¹

The Director of the Illinois Department of Public Health (Department) is required to “provide for the planning and implementation of an education campaign to inform breast cancer patients, especially those in racial and ethnic minority groups, anticipating surgery regarding the availability and coverage of breast reconstruction, prostheses, and other options.” 20 ILCS 2310/2310-670. The campaign must, at a minimum, include dissemination of the following information on the Department’s website and other relevant State health websites: (1) Breast reconstruction is possible at the time of breast cancer surgery or in a delayed fashion; (2) Prostheses or breast forms may be available; (3) Federal law mandates both public and private health plans to include coverage of breast reconstruction and prostheses; (4) The patient has a right to choose the provider of reconstructive care, including the potential transfer of care to a surgeon that provides breast reconstructive care; and (5) The patient may opt to undergo breast reconstruction in a delayed fashion for personal reasons or after completion of all other breast cancer treatments.²

In developing the information to be disseminated pursuant to Section 670 of the Law, the Department was required to “consult with appropriate medical societies and patient advocates related to breast cancer, patient advocates representing racial and ethnic minority groups, with

¹ 20 ILCS 2310/2310-670

² 20 ILCS 2310/2310-670

a special emphasis on African-American and Hispanic populations' breast reconstructive surgery, and breast prostheses and breast forms.”³

Breast Cancer Educational Materials

In 2008, the Department, through its Office of Women’s Health and Family Services (Office) consulted with Southern Illinois University’s (SIU) School of Medicine to create the *Your Right to Know (YRTK)* booklet, which is available online in both [English](#) and [Spanish](#). The booklet included information on reconstructive breast surgery and breast prosthetic options. The Department is currently working with SIU to update the booklet to ensure that the information provided represents the most current developments and research in breast cancer screening, detection, diagnosis, and treatment options. Once updated, using information included in the booklet, the Department and SIU will collaborate to create topic-specific one-page educational handouts. Additionally, educational information on [breast cancer](#), the [Illinois Breast and Cervical Cancer Program](#) (IBCCP), and the [Illinois WISEWOMAN Program](#) (WISEWOMAN) can be found on the Department’s website.

Summary of Educational Activities Carried Out Pursuant to Section 670⁴

Activities Carried Out During Fiscal Years 2014 and 2015

IBCCP offers free mammograms, breast exams, pelvic exams, and Pap tests to eligible women,⁵ and has been providing breast and cervical cancer screenings to the women of Illinois since 1995. During fiscal years (FY) 2014 and 2015, IBCCP collaborated with the American College of Radiology to provide breast education materials. The materials were distributed statewide and were also available on the Department’s website.

In May 2015, The Illinois Department of Insurance released a [fact sheet](#) to consumers titled *Coverage for the Diagnosis and Treatment of Breast Conditions*. The fact sheet informed insurance groups, HMOs, and the public that all policies are required to cover reconstructive surgery related to mastectomy, and to cover prosthetic devices such as breast prostheses and bras. The fact sheet also stated that all group and individual health insurance and HMO policies are required to cover inpatient care following a mastectomy, as well as all pain medication and pain therapy related to treatment of breast cancer. During FY 2015, the *YRTK* booklet and *Dense Breasts* fact sheet remained accessible on IDPH website for public viewing and downloading.

Activities Carried Out During Fiscal Years 2016 and 2017

During FY 2016 and 2017, IBCCP collaborated with the Illinois Medicaid Program (Medicaid), housed in the Illinois Department of Healthcare and Family Services (HFS). Collaboratively, IBCCP and HFS worked on the new State of Illinois mandates related to breast cancer and

³ 20 ILCS 2310/2310-670

⁴ 20 ILCS 2310/2310-670

⁵ Eligible women are women who live in Illinois, do not have insurance, and are between the ages of 35 and 64, although younger women may be eligible in some cases.

provided education opportunities through Northwestern University and the Illinois Critical Access Health Network (ICAHN) on breast health, including mastectomy options. Breast health education was made available through the Department’s website, conferences, and webinars.

During FY 2017, IBCCP co-sponsored the 18th Annual Lynn Sage Breast Cancer Symposium. Attendees included IBCCP lead agency staff, as well as the IBCCP Quality Assurance Nurses. The Lynn Sage Breast Cancer Symposium is widely considered by practicing medical clinicians to be the most valuable breast cancer conference worldwide. The symposium’s primary focus was on the treatment of breast cancer and included topics on mastectomy and breast-conserving surgery. IBCCP also co-sponsored a webinar through ICAHN: *Using Evidence-Based Resources to Improve Cancer Care*. The webinar covered guidelines related to lumpectomy and total mastectomy, which extended into discussions about breast prostheses options. The webinar was available for viewing online for approximately 90 days before being removed. During FY 2017, the YRTK booklet remained accessible on the Department’s website for public viewing and downloading.

Website Access

The YRTK booklet provides educational information about breast cancer diagnoses and available treatment and test options. The publication includes a written summary of methods used in early detection, diagnosis, and treatment of breast cancer. The different stages of breast cancer are explained, and information pertaining to treatment and emotional healing is provided. The publication also contains information on breast reconstructive surgery, including the use of breast implants and their potential side effects.

Table 1 shows Department data for the number of events or “views” to the IBCCP webpage as well as the individual educational publications indicated below. These data show a steady interest in the educational materials found on the Department’s website. Through additional marketing and an update of materials, we anticipate an increase in the number of visitors viewing and downloading the materials during the upcoming fiscal year. This information will be made available in the FY 2018/2019 biennial report.

Table 1: Number of Events (Views) for the Department’s IBCCP Webpage and Breast Cancer Educational Materials, 2016 and 2017

Source Material	2016		2017	
	Total Events	Unique Events	Total Events	Unique Events
IBCCP Webpage	4,385	3,471	4,336	3,415
Your Right to Know (English)	24	21	46	46
Your Right to Know (Spanish)	50	47	26	23

Source: Illinois Department of Public Health

Next Steps

The Office has begun to reach out to breast cancer advocacy organizations to seek collaboration on developing educational materials on breast reconstruction and prostheses. However, the Office has not been successful thus far in identifying partners. The Office will continue to seek collaborations with organizations, per the mandate, to develop educational materials which provide information on breast reconstruction and prostheses, and which are targeted to ethnic minorities after breast cancer treatment. The messaging will be culturally appropriate and provide guidance on accessing these medical services as part of the continuum of care.

The Office will also work on the following for FY 2018 and FY 2019: (1) finalize revisions to the *YRTK* booklet; (2) encourage IBCCP lead agencies to disseminate the revised booklet to all breast cancer clients; (3) collaborate with University of Illinois School of Public Health to create topic-specific one-page educational handouts on [breast care](#) to post on the IBCCP and WISEWOMAN webpages of the Department's website; (4) partner with two to three IBCCP lead agencies located in hospital settings that provide treatment to conduct a small educational campaign on reconstructive surgery options; (5) collaborate with HFS on the Refer to Treatment Act program to obtain data on the number of breast prostheses provided at the time of surgery, in a delayed fashion, or not provided at all to IBCCP breast cancer clients both before and after the *YRTK* booklet is revised and disseminated; (6) work with ICAHN to conduct a training for statewide medical providers on breast reconstruction; and (7) monitor the number of visits to the Department's website to view and download the pre- and post-revision *YRTK* booklet to determine effective ways of reaching and educating women.

Conclusion

We will continue to focus our attention on education and awareness efforts related to the availability and coverage of breast reconstruction, prostheses, and other options for breast cancer patients anticipating surgery, especially those in racial and ethnic minority groups. The next biennial report will include data for FY 2018 and FY 2019.