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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 2022 through 2023 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 regarding the mandates, an evaluation of the extent to which the activities have been effective in improving the health of racial and ethnic minority groups, and plans for the next reporting period.

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

Sincerely,

Dr. Sameer Vohra, MD, JD, MPH
Director

Background

In 2014, the Illinois General Assembly found that breast cancer has a disproportionate and detrimental impact on African Americans and is the most common cancer among the Latinx population and that African Americans under the age of 40 have a greater incidence of breast cancer than White women of the same age. The General Assembly also found that 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 later. Additionally, 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 and other sequelae of breast cancer treatment, such as lymphedema. Several states have enacted laws to require that patients receive information on their breast cancer treatment and reconstruction options.¹ According to the American Cancer Society, immediate breast reconstruction offers the advantage of combining breast cancer surgery with reconstructive surgery and is cost-effective; however, delayed breast reconstruction may be advantageous in patients who require post-surgical radiation or other treatments. A patient suffering from the loss of their breast may not be a candidate for surgical breast reconstruction or may choose not to undergo additional surgery and instead choose breast prostheses.²

In 2022 and 2023, the American Cancer Society (ACS) estimated that in the United States, 300,590 (297,790 female and 2,800 male) new cases of invasive breast cancer and about 55,720 new cases of ductal carcinoma will be diagnosed; and about 43,700 (43,170 female and 530 male) patients will die from breast cancer.³ Additionally, the ACS states that overall, the breast cancer death rate among females peaked in 1989 and has since declined by 43% as of 2020, mainly because of earlier detection through screening mammography, increased breast cancer awareness and improved treatment. This decrease translates to approximately 460,000 fewer breast cancer deaths during this period than would have been expected in the absence of this progress. However, mortality rates in Black women remain about 40% higher than in White women despite lower incidence.⁴

Based on what the Illinois General Assembly found in 2014, beginning in 2016, two years after the effective date of Public Act 98-479, the director of the Illinois Department of Public Health 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

¹ 20 ILCS 2310/2310-670

² https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/whcra_factsheet

³ www.cancer.org 2023 Cancer Facts and Figures, page 11

⁴ www.cancer.org 2023 Cancer Facts and Figures, page 11

regarding the availability and coverage of breast reconstruction, prostheses, and other options.”⁵ The campaign must, at a minimum, include dissemination of the following information on IDPH’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.⁶

In developing the information to be disseminated pursuant to Section 670 of the Law, IDPH was required to “consult with appropriate medical societies and patient advocates related to breast cancer, patient advocates representing racial and ethnic minority groups, with a special emphasis on African American and Hispanic populations’ breast reconstructive surgery, and breast prostheses and breast forms.”⁷

Based on this requirement, this report details the breast cancer activities and education carried out during this period pertaining to the mandates, an evaluation of the extent to which the activities have been effective in improving the health of racial and ethnic minority groups, and what to expect in the future for the next reporting period.

Breast Cancer Educational Materials

- The *Your Right to Know* (YRTK) publication legislation dates to 1995 and has undergone updates in 2000, 2006, and 2023. The publication was mandated to provide a reference document for newly diagnosed breast cancer patients. The publication also includes information on reconstructive breast surgery and breast prosthetic options. In 2022 and 2023, *Your Right to Know* was edited by Illinois State Medical Society radiology oncologist Lauren Green, MD, and Nora Hansen, MD, the Illinois Breast and Cervical Cancer Project (IBCCP) breast health medical consultant, to include breast reconstruction and prosthetics content. The document was shared with the IDPH Center for Minority Health, which routed it to African American, Asian American, and Latino partners for their input. Their questions were answered, and content clarifications were included in the draft submitted to the Office of Women’s Health Services leadership for content review before IDPH Office of Communication’s final approval. The draft document was shared with the OWHFS deputy director, Lisa Masinter, MD, and OWHFS medical director, Maura Quinlan, MD, for additional edits. Dr. Quinlan supports the OWHFS program with clinical matters, including compliance with legislative mandates. Dr. Quinlan will coordinate future revisions to the document with clinical updates and input from the Illinois State Medical Society and Center for Minority Health. The draft received IDPH Office of

⁵ 20 ILCS 2310/2310-670

⁶ 20 ILCS 2310/2310-670

⁷ 20 ILCS 2310/2310-670

Communications approval, Spanish translation, and redesign and was uploaded to the IDPH website in June 2023. Ellen Mendelson, MD, a radiology professor, revised the Dense Breast document and the IBCCP translated and redesigned it to accompany the *Your Right to Know* document. Dr. Quinlan will also facilitate the revisions to the Dense Breast document on the same cycle as the *Your Right to Know* document and schedule it for inclusion on the IDPH website in June 2025. The English and Spanish versions of both documents, along with educational information on breast cancer, the IBCCP, and the Illinois WISEWOMAN Program (IWP), can be found on IDPH's website at <https://dph.illinois.gov/topics-services/diseases-and-conditions/diseases-a-z-list/breast-exams-mammograms.html>.

The information in *Your Right to Know* has been updated to include the law requirements. This includes information about specific requirements in federal law that mandate both public and private health plans include coverage of breast reconstruction and prostheses when insurers provide coverage for a mastectomy. Additionally, the updated version of *Your Right to Know* includes information that breast reconstruction is possible at the time of breast cancer surgery or can be delayed and that the patient may opt to delay breast reconstruction for personal reasons or after completion of all other breast cancer treatments. Also included is the patient's right to choose their breast reconstruction provider while noting that there may be restrictions on insurance coverage based on plan requirements.

Summary of Educational Activities Carried Out Pursuant to Section 670⁸

Breast (and Cervical) Health Education Activities Carried Out During Fiscal 2022 and 2023

IBCCP offers free mammograms, breast exams, pelvic exams, and pap tests to eligible Illinois residents and has been providing breast and cervical cancer screenings since 1995. During fiscal 2022 and 2023, IBCCP collaborated with Southern Illinois University School of Medicine (SIUSOM) to promote relevant training opportunities related to women's health, breast health, cancer screening, and other related topics aimed at educating and empowering Illinois providers and residents.

On September 16, 2022, IBCCP partnered with SIUSOM to hold the **20th Annual Simmons Cancer Institute Symposium: Updates on Common Cancers and the Role of the Genetics and Immunology in Cancer Care**. The audience included physicians, advanced practice providers, and other health care professionals interested in cancer prevention, diagnosis, treatment, and survivorship.

- **The Emerging Role of Clinical Genetics in Cancer Care**

⁸ 20 ILCS 2310/2310-670

Education included the importance of detailed family history in cancer care, heritable common cancers and how they present, and the emerging role of molecular genetics in cancer therapeutics.

- **Updates on the Management of Breast Cancer**
Education included recent changes in the management of breast cancer.
- **Surviving Cancer Panel Discussion: Community Resources Available for the Journey**
Education included identifying resources and incorporating navigation into daily practice.

There were 82 symposium participants. Post-symposium survey results: 81% said the education was relevant or very relative to their practice, and 41% stated they would make changes in their practice related to the education provided.

On October 20, 2022, IBCCP partnered with SIUSOM for the **19th Annual Women's Health Conference: Reproduction and Beyond** (virtual). The focus audience was physicians, advanced practice providers, and other health care professionals interested in women's health care.

- **Breast Cancer Screening in Survivorship**
Education included appropriate follow-up care after completing breast cancer therapy and appropriate screening strategies after completion of initial treatment for breast cancer.

There were 72 conference participants. Post-conference survey results: On a scale of 0-5, the mean score for relevance of the education was 4.6, and for practical application to practice, it was 4.5. Of the survey respondents, 68% said they would make changes to their practice based on the information provided.

Breast (and Cervical) Cancer Program Activities Carried Out During Fiscal 2022 and 2023

In 2022 and 2023, the IBCCP hosted a town hall open to the public in partnership with the SIUSOM entitled, **You've Been Diagnosed with Breast Cancer and Are Interested in Breast Reconstruction: What Questions Do You Ask?** The session was an in-person and virtual panel discussion on April 26, 2023, that focused on breast reconstruction and prosthetics. It featured Nicole Summers, MD, a plastic surgeon who specializes in breast reconstruction, an oncology nurse, and two survivors who had breast reconstruction. Breast reconstruction options, including the use of prosthetics, care coordination, insurance coverage, and clinical navigation, were discussed. The survivors shared their decision-making process for the use of prosthetics and opting for reconstruction. Additionally, an audience member shared her experience with pain after her reconstruction procedure. Participant data was collected for evaluation and improved marketing. SIUSOM reported that 32 individuals registered for the event. Ten individuals completed a post survey, and 80% stated the information was relevant or very relevant.

The IBCCP also hosted Erica Austin, an African American breast cancer survivor who opted for breast reconstruction. She shared her experience in a three-part conversation with Dr. Quinlan, where she discussed her family history with breast cancer and gynecologic cancers that led to

genetic testing and early screening, her diagnosis, treatment, and decision to pursue breast reconstruction. She also discussed her awareness activities, where she walked in a New York City fashion show and presented to community organizations on screening, early detection, treatment, and breast reconstruction. The IDPH Office of Communications produced the audio blog and shared it via IDPH’s website and IBCCP grantee listserv in recognition of Breast Cancer Awareness Month 2023.

Strength and Survival: Erica Austin - <https://youtu.be/gPLuNgVBOUg>

Erica Austin Speaks About Her Breast Cancer Diagnosis- <https://youtu.be/qiHp9Ygc-d8>

Erica Austin Explains How She Chooses Her Treatment Options - <https://youtu.be/mxazW9IZ2vl>

Erica Austin: A Survivor's Chat - https://youtu.be/NfYVX9p0_sc

Website Access

The *Your Right to Know* publication provides educational information about breast cancer diagnoses and available treatment and test options. It includes a written summary of methods used in the early detection, diagnosis, and treatment of breast cancer. The different stages of breast cancer are explained, and information about 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 IDPH data for the number of “views” to the IBCCP webpage and the English or Spanish *Your Right to Know* publications. Through additional marketing and an update of materials, number of visitors viewing and downloading the materials during the upcoming fiscal year is expected to increase.

Table 1: Number of Events (Views) for IDPH’s IBCCP Webpage and Breast Cancer Educational Materials, 2022 and 2023

Source Material	2022		2023	
	Total Views	Unique Visitors	Total Views	Unique Visitors
IBCCP Webpage	2,447	1,625	11,769	7,333
Your Right to Know (English)	14	0	56	0
Your Right to Know (Spanish)	0	0	9	0

Source: Illinois Department of Public Health

Next Steps

The Office of Women’s Health and Family Services will continue to work on the following for FY24 and FY25: (1) conduct biennial revisions to the *Your Right to Know* and dense breast publications

based on feedback from the Illinois State Medical Society and minority health advocacy organizations who will review the content for effective reach to priority populations; (2) post the documents on the IDPH website for public access; (3) partner with local organizations and academic partners to sponsor public town halls and educational opportunities that provide information on the options for breast reconstruction, prosthetics and insurance coverage; (4) continue to work with the Illinois Critical Access Hospital Network and Southern Illinois University's School of Medicine to conduct training for statewide medical providers; and, (5) monitor the number of views and visits to IDPH's website for access to the IBCCP and *Your Right to Know* publications.

Conclusion

The focus will continue 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 following biennial report will include information from FY24 and FY25 efforts.