



In this issue:

Contents

Informed Consent 1

Study: Finds Pregnancy Seems Safe for Breast Cancer Survivors 2

Informed...(continued) 2

2017 MCC Meetings 2

Quick News & Links:

[Cancer Disparities Infographic Available](#)

[Many Elders OK with Stopping Cancer Screening, but They Don't Always Want Life Expectancy Mentioned](#)

[Use of Community Health Workers and Patient Navigators to Improve Cancer Outcomes Among Patients Served by Federally Qualified Health Centers: A Systematic Literature Review](#)

[Publicly-Funded Cancer Trials Gained Americans 3 Million More years](#)

[MCC Calendar of Events](#)

Informed Consent – Ensuring Consent Forms Are Following the Law

Michigan Cancer Genetics Alliance

Adelyn Beil, University of Michigan School of Public Health, Genetic Counseling, 2019

Did you know that Michigan is one of only twelve states that requires written informed consent prior to pre-symptomatic or predictive genetic testing? In fact, Michigan was one of the first states to institute such a law. The enactment of this legislation signaled an important step forward for patient protections in the continuously evolving medical world, as it ensures that those who undergo genetic testing are aware of the purpose, benefits, risks, confidentiality, limitations, and future use of the sample they submit for testing. This regulation helps to enhance patient health literacy, while also safeguarding private information.

The Michigan Department of Health and Human Services (MDHHS) provides both a [model consent form and a genetic testing information pamphlet](#). Copies of the pamphlet may also be requested free of charge through an [order form](#). Recently, the Michigan Cancer Genetics Alliance (MCGA) worked with MDHHS to update the model consent form as well as the testing pamphlet in order to certify the efficacy of both for patients and providers. Due to the increased use of panel testing, it is important to remember that it is the ordering provider's responsibility to continuously confirm that the testing forms used in their clinic remain up to date and compliant with this legislation.

For those providers who are performing predictive (meaning a person has an increased chance of developing a disease) or pre-symptomatic (meaning a person will eventually develop a disease) genetic testing, the law stipulates the following six points that must be covered within each consent form:

- (a) The nature and purpose of the pre-symptomatic or predictive genetic test.
- (b) The effectiveness and limitations of the pre-symptomatic or predictive genetic test.
- (c) The implications of taking the pre-symptomatic or predictive genetic test, including, but not limited to, the medical risks and benefits.

CONTINUED ON PAGE 2



Study Finds Pregnancy Seems Safe for Breast Cancer Survivors

A study gives reassuring news for breast cancer survivors who want to have children. Those who later became pregnant were no more likely to have their cancer come back than those who did not have a baby. The results show “fairly convincingly” that women don’t have to worry, said Dr. Richard Schilsky, chief medical officer for the American Society of Clinical Oncology. The group featured the study at its annual conference last month. About 11 percent of new breast cancer cases in the U.S. are in women under 45. A big [study](#) underway now in the U.S. and other countries is taking this research one step further, testing whether it’s safe for breast cancer survivors who want to get pregnant to temporarily suspend taking the hormone-blocking drugs like tamoxifen usually recommended for five years after initial treatment.

Source: Associated Press, June 6, 2017

Informed Consent....

(continued from page 1)

(d) The future uses of the sample taken from the test subject in order to conduct the pre-symptomatic or predictive genetic test and the information obtained from the pre-symptomatic or predictive genetic test.

(e) The meaning of the pre-symptomatic or predictive genetic test results and the procedure for providing notice of the results to the test subject.

(f) Who will have access to the sample taken from the test subject and the information obtained from the test, and the test subject’s right to confidential treatment of the sample and the information.

The Michigan Cancer Genetic Alliance (MCGA) is an MCC affiliate group that strives to promote awareness and advance appropriate application of genomics to improve cancer prevention, detection and treatment throughout Michigan. Any individual with an interest in cancer genetics can become a MCGA member at no cost. [Learn more about the MCGA.](#)

To learn more about this law as well as the MCGA organization, please feel free to contact Maricar Macalincag at MacalincagM@michigan.gov.



Reminder!

The [MCC has three awards](#): Champion, Inspiration, and Spirit of Collaboration. Check them out and think about who you will nominate.

2017 MCC Meetings

Board Meetings (12 pm – 3 pm):

Wed, Sept 27

Annual Meeting (Lansing):

Wed, Nov 8

For more information: 877-588-6224

MCC Website

Be sure to visit the [MCC website](#) to find provider and patient resources