BERRIEN COUNTY CANCER SERVICE NEWSLETTER

www.bccancerservice.org

In honor of the committed service of Olove Colcord, R.N.

THE MISSION OF THE BERRIEN COUNTY CANCER SERVICE:

To provide free skilled home nursing services, equipment, information and supplies at cost for cancer patients and their families in Berrien County.

April 2012 **(269) 429-3281** **VOLUME XXI ISSUE IV**

The **BERRIEN COUNTY CANCER SUPPORT GROUP** is a group for patients, family members and care givers. Come share successes, feelings, fears and practical methods of coping with the physical and emotional aspects of living with the diagnosis of cancer.

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Spring Delight

Pink streaks of sun's rays before turning to gold
Fortell the day's patterns new life to unfold;
Robins so merry and blue jays so bright,
Fly springtime skies from morning to night:
Tulips in rows lift their clean faces,
And nod their acquaintance to bees in their places;
Soft gentle breezes stir buds on the trees,
Then scatter earth's perfume – the senses to please.
From dawning to sunset 'tis glorious to see
God's spectacular show and all of it free

Author: Estelle Pfetsch

United Way of Southwest Michigan

BRCA1 and BRCA2: Cancer Risk and Genetic Testing

BRCA1 and BRCA2 are human genes that belong to a class of genes known as tumor suppressors. Mutation of these genes has been linked to hereditary breast and ovarian cancer.

A woman's risk of developing breast and/or ovarian cancer is greatly increased if she inherits a deleterious (harmful) BRCA1 or BRCA2 mutation. Men with these mutations also have an increased risk of breast cancer. Both men and women who have harmful BRCA1 or BRCA2 mutations may be at increased risk of other cancers.

Genetic tests are available to check for BRCA1 and BRCA2 mutations. A blood sample is required for these tests, and genetic counseling is recommended before and after the tests.

If a harmful BRCA1 or BRCA2 mutation is found, several options are available to help a person manage their cancer risk.

Federal and state laws help ensure the privacy of a person's genetic information and provide protection against discrimination in health insurance and employment practices.

Many research studies are being conducted to find newer and better ways of detecting, treating, and preventing cancer in BRCA1 and BRCA2 mutation carriers. Additional studies are focused on improving genetic counseling methods and outcomes. Our knowledge in these areas is evolving rapidly.

What are BRCA1 and BRCA2?

BRCA1 and BRCA2 are human genes that belong to a class of genes known as tumor suppressors.

In normal cells, BRCA1 and BRCA2 help ensure the stability of the cell's genetic material (DNA) and help prevent uncontrolled cell growth. Mutation of these genes has been linked to the development of hereditary breast and ovarian cancer.

The names BRCA1 and BRCA2 stand for breast cancer susceptibility gene 1 and breast cancer susceptibility gene 2, respectively.

How do BRCA1 and BRCA2 gene mutations affect a person's risk of cancer?

Not all gene changes, or mutations, are deleterious (harmful). Some mutations may be beneficial, whereas others may have no obvious effect (neutral). Harmful mutations can increase a person's risk of developing a disease, such as cancer.

A woman's lifetime risk of developing breast and/or ovarian cancer is greatly increased if she inherits a harmful mutation in BRCA1 or BRCA2. Such a woman has an increased risk of developing breast and/or ovarian cancer at an early age (before menopause) and often has multiple, close family members who have been diagnosed with these diseases. Harmful BRCA1 mutations may also increase a woman's risk of developing cervical, uterine, pancreatic, and colon cancer. Harmful BRCA2 mutations may additionally increase the risk of pancreatic cancer, stomach cancer, gallbladder and bile duct cancer, and melanoma.

Men with harmful BRCA1 mutations also have an increased risk of breast cancer and, possibly, of pancreatic cancer, testicular cancer, and early-onset prostate cancer. However, male breast cancer, pancreatic cancer, and prostate cancer appear to be more strongly associated with BRCA2 gene mutations.

The likelihood that a breast and/or ovarian cancer is associated with a harmful mutation in BRCA1 or BRCA2 is highest in families with a history of multiple cases of breast cancer, cases of both breast and ovarian cancer, one or more family members with two primary cancers (original tumors that develop at different sites in the body), or an Ashkenazi (Central and Eastern European) Jewish background. However, not every woman in such families carries a harmful BRCA1 or BRCA2 mutation, and not every cancer in such families is linked to a harmful mutation in one of these genes.

Furthermore, not every woman who has a harmful BRCA1 or BRCA2 mutation will develop breast and/or ovarian cancer.

According to estimates of lifetime risk, about 12.0 percent of women (120 out of 1,000) in the general population will develop breast cancer sometime during their lives compared with about 60 percent of women (600 out of 1,000) who have inherited a harmful mutation in BRCA1 or BRCA2.

In other words, a woman who has inherited a harmful mutation in BRCA1 or BRCA2 is about five times more likely to develop breast cancer than a woman who does not have such a mutation.

Lifetime risk estimates for ovarian cancer among women in the general population indicate that 1.4 percent (14 out of 1,000) will be diagnosed with ovarian cancer compared with 15 to 40 percent of women (150–400 out of 1,000) who have a harmful BRCA1 or BRCA2 mutation.

It is important to note, however, that most research related to BRCA1 and BRCA2 has been done on large families with many individuals affected by cancer. Estimates of breast and ovarian cancer risk associated with BRCA1 and BRCA2 mutations have been calculated from studies of these families. Because family members share a proportion of their genes and, often, their environment, it is possible that the large number of cancer cases seen in these families may be due in part to other genetic or environmental factors. Therefore, risk estimates that are based on families with many affected members may not accurately reflect the levels of risk for BRCA1 and BRCA2 mutation carriers in the general population. In

addition, no data are available from long-term studies of the general population comparing cancer risk in women who have harmful BRCA1 or BRCA2 mutations with women who do not have such mutations. Therefore, the percentages given above are estimates that may change as more data become available.

1. **Do inherited mutations in other genes increase the risk of breast and/or ovarian tumors**?

Yes. However, the majority of hereditary breast cancers can be accounted for by inherited mutations in BRCA1 and BRCA2. Overall, it has been estimated that inherited BRCA1 and BRCA2 mutations account for 5 to 10 percent of breast cancers and 10 to 15 percent of ovarian cancers among white women in the United States.

2. Are specific mutations in BRCA1 and BRCA2 more common in certain populations?

Yes. For example, three specific mutations, two in the BRCA1 gene and one in the BRCA2 gene, are the most common mutations found in these genes in the Ashkenazi Jewish population. In one study, 2.3 percent of participants (120 out of 5,318) carried one of these three mutations

This frequency is about five times higher than that found in the general population. It is not known whether the increased frequency of these mutations is responsible for the increased risk of breast cancer in Jewish populations compared with non-Jewish populations.

Other ethnic and geographic populations around the world, such as the Norwegian, Dutch, and Icelandic peoples, also have higher frequencies of specific BRCA1 and BRCA2 mutations.

In addition, limited data indicate that the frequencies of specific BRCA1 and BRCA2 mutations may vary among individual racial and ethnic groups in the United States, including African Americans, Hispanics, Asian Americans, and non-Hispanic whites.

This information about genetic differences between racial and ethnic groups may help health care providers in selecting the most appropriate genetic test(s).

3. Are genetic tests available to detect BRCA1 and BRCA2 mutations, and how are they performed?

Yes. Several methods are available to test for BRCA1 and BRCA2 mutations. Most of these methods look for changes in BRCA1 and BRCA2 DNA. At least one method looks for changes in the proteins produced by these genes. Frequently, a combination of methods is used.

A blood sample is needed for these tests. The blood is drawn in a laboratory, doctor's office, hospital, or clinic and then sent to a laboratory that specializes in the tests. It usually takes several weeks or longer to get the test results. Individuals who decide to get tested should check with their health care provider to find out when their test results might be available.

Genetic counseling is generally recommended before and after a genetic test. This counseling should be performed by a health care professional who is experienced in cancer genetics . Genetic counseling usually involves a risk assessment based on the individual's personal and family medical history and discussions about the appropriateness of genetic testing, the specific test(s) that might be used and the technical accuracy of the test(s), the medical implications of a positive or a negative test result, the possibility that a test result might not be informative, the psychological risks and benefits of genetic test results, and the risk of passing a mutation to children.

How do people know if they should consider genetic testing for BRCA1 and BRCA2 mutations?

Currently, there are no standard criteria for recommending or referring someone for BRCA1 or BRCA2 mutation testing.

In a family with a history of breast and/or ovarian cancer, it may be most informative to first test a family member who has breast or ovarian cancer. If that person is found to have a harmful BRCA1 or BRCA2 mutation, then other family members can be tested to see if they also have the mutation.

Regardless, women who have a relative with a harmful BRCA1 or BRCA2 mutation and women who appear to be at increased risk of breast and/or ovarian cancer because of their family history should consider genetic counseling to learn more about their potential risks and about BRCA1 and BRCA2 genetic tests.

The likelihood of a harmful mutation in BRCA1 or BRCA2 is increased with certain familial patterns of cancer. These patterns include the following:

How much does BRCA1 and BRCA2 mutation testing cost?

The cost for BRCA1 and BRCA2 mutation testing usually ranges from several hundred to several thousand dollars. Insurance policies vary with regard to whether or not the cost of testing is covered. People who are considering BRCA1 and BRCA2 mutation testing may want to find out about their insurance company's policies regarding genetic tests.

What does a positive BRCA1 or BRCA2 test result mean?

A positive test result generally indicates that a person has inherited a known harmful mutation in BRCA1 or BRCA2 and, therefore, has an increased risk of developing certain cancers, as described above. However, a positive test result provides information only about a person's risk of developing cancer. It cannot tell whether an individual will actually develop cancer or when. Not all women who inherit a harmful BRCA1 or BRCA2 mutation will develop breast or ovarian cancer.

A positive genetic test result may have important health and social implications for family members, including future generations. Unlike most other medical tests, genetic tests can reveal information not only about the person being tested but also about that person's relatives.

Both men and women who inherit harmful BRCA1 or BRCA2 mutations, whether they develop cancer themselves or not, may pass the mutations on to their sons and daughters. However, not all children of people who have a harmful mutation will inherit the mutation.

What does a negative BRCA1 or BRCA2 test result mean?

How a negative test result will be interpreted depends on whether or not someone in the tested person's family is known to carry a harmful BRCA1 or BRCA2 mutation. If someone in the family has a known mutation, testing other family members for the same mutation can provide information about their cancer risk. If a person tests negative for a known mutation in his or her family, it is unlikely that they have an inherited susceptibility to cancer associated with BRCA1 or BRCA2. Such a test result is called a "true negative." Having a true negative test result does not mean that a person will not develop cancer; it means that the person's risk of cancer is probably the same as that of people in the general population.

In cases in which a family has a history of breast and/or ovarian cancer and no known mutation in BRCA1 or BRCA2 has been previously identified, a negative test result is not informative. It is not possible to tell whether an individual has a harmful BRCA1 or BRCA2 mutation that was not detected by testing (a "false negative") or whether the result is a true negative. In addition, it is possible for people to have a mutation in a gene other than BRCA1 or BRCA2 that increases their cancer risk but is not detectable by the test(s) used.

What does an ambiguous BRCA1 or BRCA2 test result mean?

If genetic testing shows a change in BRCA1 or BRCA2 that has not been previously associated with cancer in other people, the person's test result may be interpreted as "ambiguous" (uncertain). One study found that 10 percent of women who underwent BRCA1 and BRCA2 mutation testing had this type of ambiguous result.

Because everyone has genetic differences that are not associated with an increased risk of disease, it is sometimes not known whether a specific DNA change affects a person's risk of developing cancer. As more research is conducted and more people are tested for BRCA1 or BRCA2 changes, scientists will learn more about these changes and cancer risk.

What are the options for a person who has a positive test result?

Several options are available for managing cancer risk in individuals who have a harmful BRCA1 or BRCA2 mutation. However, high-quality data on the effectiveness of these options are limited.

Surveillance—Surveillance means cancer screening, or a way of detecting the disease early. Screening does not, however, change the risk of developing cancer. The goal is to find cancer early, when it may be most treatable.

Surveillance methods for breast cancer may include mammography and clinical breast exams. Studies are currently under way to test the effectiveness of other breast cancer screening methods, such as magnetic resonance imaging (MRI), in women with BRCA1 or BRCA2 mutations. With careful surveillance, many breast cancers will be diagnosed early enough to be successfully treated.

For ovarian cancer, surveillance methods may include transvaginal ultrasound, blood tests for CA–125 antigen, and clinical exams. Surveillance can sometimes find ovarian cancer at an early stage, but it is uncertain whether these methods can help reduce a woman's chance of dying from this disease.

Prophylactic Surgery—This type of surgery involves removing as much of the "at-risk" tissue as possible in order to reduce the chance of developing cancer. Bilateral prophylactic mastectomy (removal of healthy breasts) and prophylactic salpingo-oophorectomy (removal of healthy fallopian tubes and ovaries) do not, however, offer a guarantee against developing cancer. Because not all at-risk tissue can be removed by these procedures, some women have developed breast cancer, ovarian cancer, or primary peritoneal carcinomatosis (a type of cancer similar to ovarian cancer) even after prophylactic surgery. In addition, some evidence suggests that the amount of protection salpingo-oophorectomy provides against the development of breast and ovarian cancer may differ between carriers of BRCA1 and BRCA2 mutations.

Risk Avoidance—Certain behaviors have been associated with breast and ovarian cancer risk in the general population. Research results on the benefits of modifying individual behaviors to reduce the risk of developing cancer among BRCA1 or BRCA2 mutation carriers are limited.

Chemoprevention—This approach involves the use of natural or synthetic substances to reduce the risk of developing cancer or to reduce the chance that cancer will come back. For example, the drug tamoxifen has been shown in numerous clinical studies to reduce the risk of developing breast cancer by about 50 percent in women who are at increased risk of this disease and to reduce the recurrence of breast cancer in women undergoing treatment for a previously diagnosed breast tumor.

As a result, tamoxifen was approved by the U.S. Food and Drug Administration (FDA) as a breast cancer treatment and to reduce the risk of breast cancer development in premenopausal and postmenopausal women who are at increased risk of this disease. Few studies, however, have evaluated the effectiveness of tamoxifen in women with BRCA1 or BRCA2 mutations. Data from three studies

suggest that tamoxifen may be able to help lower the risk of breast cancer in BRCA1 and BRCA2 mutation carriers (18–20). Two of these studies examined the effectiveness of tamoxifen in helping to reduce the development of cancer in the opposite breast of women undergoing treatment for an initial breast cancer.

Another drug, raloxifene, was shown in a large clinical trial sponsored by the National Cancer Institute (NCI) to reduce the risk of developing invasive breast cancer in postmenopausal women at increased risk of this disease by about the same amount as tamoxifen. As a result, raloxifene was approved by the FDA for breast cancer risk reduction in postmenopausal women. Since tamoxifen and raloxifene inhibit the growth of breast cancer cells in similar ways, raloxifene may be able to help reduce breast cancer risk in postmenopausal BRCA1 and BRCA2 mutation carriers. However, this has not been studied directly.

What are some of the benefits of genetic testing for breast and ovarian cancer risk?

There can be benefits to genetic testing, whether a person receives a positive or a negative result. The potential benefits of a negative result include a sense of relief and the possibility that special preventive checkups, tests, or surgeries may not be needed. A positive test result can bring relief from uncertainty and allow people to make informed decisions about their future, including taking steps to reduce their cancer risk. In addition, many people who have a positive test result may be able to participate in medical research that could, in the long run, help reduce deaths from breast cancer.

What are some of the risks of genetic testing for breast and ovarian cancer risk?

The direct medical risks, or harms, of genetic testing are very small, but test results may have an effect on a person's emotions, social relationships, finances, and medical choices.

People who receive a positive test result may feel anxious, depressed, or angry. They may choose to undergo preventive measures, such as prophylactic surgery, that have serious long-term implications and whose effectiveness is uncertain.

People who receive a negative test result may experience "survivor guilt," caused by the Knowledge that they likely do not have an increased risk of developing a disease that affects one or more loved ones.

Because genetic testing can reveal information about more than one family member, the emotions caused by test results can create tension within families. Test results can also affect personal choices, such as marriage and childbearing. Issues surrounding the privacy and confidentiality of genetic test results are additional potential risks (see below).

What can happen when genetic test results are placed in medical records?

Clinical test results are normally included in a person's medical records. Consequently, individuals considering genetic testing must understand that their results might not be kept private.

Because a person's genetic information is considered health information, it is covered by the Privacy Rule of the Health Information Portability and Accountability Act (HIPAA) of 1996. The Privacy Rule requires that health care providers and others protect the privacy of health information, sets boundaries on the use and release of health records, and empowers individuals to control certain uses and disclosures of their health-related information. Many states also have laws to protect the privacy and limit the release of genetic and other health information.

In 2008, the Genetic Information Nondiscrimination Act (GINA) became Federal law. GINA prohibits discrimination based on genetic information in relation to health insurance and employment, but the law does not cover life insurance, disability insurance, and long-term care insurance. When applying for these types of insurance, people may be asked to sign forms that give an insurance company permission to access their medical records. The insurance company may take genetic test results into account when making decisions about coverage.

Some physicians keep genetic test results out of medical records. However, even if such results are not included in a person's medical records, information about a person's genetic profile can sometimes be gathered from that person's family medical history.

In Loving Memory

During February 2012, Memorial Donations were generously made by and for the following people:

In Memory of Howard Bailey
Daryl & Zena Benjamin, Niles
Sandra J. Myers, Edwardsburg

In Memory of David Bergman
Frank Nehring, St. Joseph

In Memory of Linda Boelcke
Louise E. Boelcke, Stevensville
Harold & Dorothy Curtis, St. Joseph
Richard & Diana Eberhardt, St. Joseph
Ken Jesswein, Stevensville
Dwayne Krueger, Stevensville
Ruthann Miller, Stevensville
Donald Skibbe, Berrien Springs
Virginia & G. Skibbe, Eau Claire
Tim & Cyndy Swift, Covert
Terri Traxler, Grand Rapids

In Memory James C. Bower
Linda (Bower) Brant, Hillsboro OR
Diane & Camille Curtis, Stevensville
Carol & Roger Dinges, Baroda
Jeanette Reynolds, Lawton
Pat Snow, Coloma

In Memory of Tina Cupani
Anna Stelter, Stevensville

In Memory of Robert Cupani Sr.
Anna Stelter, Stevensville

In Memory of Louise Huff
Adeline Hackel, Berrien Springs

In Memory of Cora Littke
Julia & Jodi Ballard, Benton Harbor
George & Helen Craven, Coloma
Bob & Anita Flippo, St. Joseph
Sharron & Rodney Krieger, Coloma
Nathan & Julie Nitz, Baroda
Jean McNees & Sandy Snodgrass, Stevensville
The Chemosabies, St. Joseph

In Memory of Harlan Mettler
Berrien County Sheriff Reserve Unit, St. Joseph
Karen Klug, Baroda
Joy T. & Creighton Klute, Stevensville
Joyce Toms, Port Orchard, WA
Kent Weinberg, Decatur

In Memory of Mary E. Miller
Rita Crabtree, Coloma
Brian T. Dargus, Buchanan
Pamela Evans, Berrien Springs
Elaine Jotzat, Bridgman
Donna & Dave Kirshbaum, St. Joseph
Mary Lavery, Buchanan
Gerald Levi, Stevensville
Paul W. Miller, Stevensville
Christopher & Joy Miller, Sawyer
Marilyn R. Nelson, Stevensville
Scott Romszewicz, Stevensville
% Kami Holt
Greg & Shirley Romszewisz, Stevensville
Schaffer & Layher, PLLC, St. Joseph
Mike & Ellen Seidler, St. Joseph
Phyllis Skorupa, Sawyer
Lynne Wieferich, Niles

In Memory of LaVern D. Noble
Debbie McCartney, Sodus

In Memory of Suzanne E. Smith
Joyce Stockman, St. Joseph
% & Dawn Berriman

In Memory of Jerry Toffelmire
Square Deal Auto Salvage, Benton Harbor
Jan & John Street, Berrien Springs
Perry & Susan Weikel, Sawyer

Berrien County Cancer Service sends our sincere sympathy to all those who have recently lost loved ones. We thank all of our generous donors. Your donations are very much appreciated and will help cancer patients in Berrien County. Thank you.

In Your Honor

In February 2012 donations were made by and in honor of the following:

In Honor of Hannah Nobel
Debbie McCartney, Sodus

Looking Ahead

BCCS SUPPORT GROUP – Stevensville
April 3 & 17 – 1:30 p.m.
May 1 & 15 – 1:30 p.m.

BCCS SUPPORT GROUP – Niles
April 10 & 24 – 1:30 p.m.
May 8 & 22 – 1:30 p.m.

OSTOMY SUPPORT GROUP – Stevensville
April 17 – 1:30 p.m.
May 15 – 1:30 p.m.

RAINBOWS OF HOPE– St. Joseph
Marie Yeager Cancer Center
April 12 – 5:30 p.m.
May10 – 5:30 p.m.

Ostomy Support Group
Lakeland Regional Medical Center
April 12– 6:00 p.m.
May 10 – 6:00 p.m.

Man to Man – Prostate Support Group
Trinity Center, St. Joseph
April 17– 6:30 p.m.
May 15 – 6:30 p.m.

DATES TO REMEMBER IN APRIL
April 1 – April's Fool Day
April 2 – World Autism Day
April 4 – National Day of Hope
April 6 – Good Friday
April 10 – National Farm Animals Day
April 15 – That Sucks Day
April 20 - Husband Appreciation Day
April 22 – Earth Day
April 25 – Administration Assistant's Day
April 30 – World Healing Day

Newsletters available online
Our newsletters are available on our website: *www.bccancerservice.org*. If you would like to be removed from this mailing list, please call our office at 269-429-3281 or send us an e-mail: *staff@bccancerservice.org*.

Please Consider...

Berrien County Cancer Service, Inc., is a non-profit organization funded primarily by the United Way, private donations and fund-raisers. We receive no Medicare, Medicaid or other insurance payments. To continue our free services to Berrien County cancer patients, we need your help. Any donation is greatly appreciated.

Donations to our General Fund will help balance our current budget. Donations to our Endowment Fund will help guarantee that the Cancer Service will be available for as long as needed. Your contribution to our non-profit 501(c)(3) corporation is tax deductible – an acknowledgment and receipt for tax purposes will be sent.

Donations can be made in honor of someone or in memory of a loved one. In these instances, we would also like to send acknowledgment to the honoree or next-of-kin so please provide that information when making your donation.

_____ General Fund _____Endowment Fund

Your Name _____

Your Address _____

City/State/Zip_____

_____

Donation Amount $ _____

_____

OR

In Memory of _____

Please send notification of my gift to:

Name_____

Address_____

City/State/Zip_____

Thank you for your generosity!

Berrien County Cancer Service, Inc.
7301 Red Arrow Highway
Stevensville, MI 49127

RETURN SERVICE REQUESTED

NONPROFIT ORGANIZATION
U.S. POSTAGE PAID
STEVENSVILLE, MI
PERMIT NO. 129

CANCER SUPPORT GROUP – Stevensville Office
1st and 3rd Tuesday of each month - 1:30 p.m.
Berrien County Cancer Service, Inc.
7301 Red Arrow Highway
Stevensville, MI 49127
Phone: (269) 429-3281 or (269) 465-5257

CANCER SUPPORT GROUP – Niles
2nd and 4th Tuesday of each month – 1:30 p.m.
Niles Senior Center
1109 Bell Road
Niles, MI 49120
Phone: (269) 429-3281

RAINBOWS OF HOPE GROUP- St. Joseph
2nd Thursday of each month – 5:30 p.m.
Marie Yeager Cancer Center
Ward and Kinney Room
3900 Hollywood Rd.
St. Joseph, MI 49085
Phone: (269) 556-7114

OSTOMY SUPPORT GROUP
2nd Thursday of each month- 6:00 p.m.
Lakeland Regional Medical Center
Community Room
1234 Napier Ave
St. Joseph, MI 49085
Phone: (269) 983-8804

MAN TO MAN – Prostate Support Group
3rd Tuesday of each month – 6:30 p.m.
Trinity Center
619 Main Street (use Main entrance)
St. Joseph, MI 49085
Phone: (800) 465-5244

Printing Courtesy of Lakeland Community Benefit