Breast cancer is the most common cancer in women with a lifetime incidence of 1 in 7 women. It is the second most common cause of cancer-related death following lung cancer. It is the most common cause of death for women aged 40 to 59 years. (1) We have reported the breast cancer program in Saint Louis University in our 1999 annual report. As a follow-up report, we reported herein the epidemiological data of breast cancer care in SLU in comparison to national teaching hospital average per NCDB database for the years 2000 and 2001. Furthermore, the referral pattern and study protocol participation were analyzed to determine the future direction of improving the Breast Cancer Program at SLU.

STAGE OF BREAST CANCER

Compared with NCDB average for teaching hospitals, there were less patients with early stage breast cancer (Stage II or less) treated at SLU (SLU-82% vs. NCDB-90%) for 2000-2001 (Fig. 1). There was also a trend toward more advanced-stage breast cancer patients treated in SLU in 2003-2004 compared with 2000-2001, 22% Stage III / IV vs. 14%, respectively. The higher percentage of unknown stage for 2003-2004 (21%) compared with 2000-2001 (5%) was partly due to increased utilization of SLU Breast Center by community physicians for diagnostic testing purposes.

AGE AT DIAGNOSIS

The age distribution of breast cancer patients treated at SLU was similar to NCDB teaching hospital average (Fig. 2). There was a higher proportion of patients ≥ 60 years of age in 2003-2004 compared with 2000-2001 (47%).

TREATMENT OF BREAST CANCER

Compared with national teaching hospital average, similar pattern of treatment modality utilization was observed for SLU breast cancer care in 2000-2001 (Fig. 3). The most common type of treatment was surgery only (SLU-23%, NCDB-28%). This was the result of early detection of breast cancer. Data for SLU 2003-2004 was not mature at this time for analysis.

SURVIVAL

Survival data was available for 1995-1996. The 5-year survival rates for various stages of breast cancer at SLU were Stage 0 – 96%, Stage I – 84%, Stage II – 73%, Stage IV – 37%, and Stage IV 15%. These were similar to the NCDB database for 1995-1996, 93%, 89%, 78%, 52%, and 17%, respectively.

PARTICIPATION IN RESEARCH STUDY

Higher proportion of breast cancer patients were enrolled in research studies in 2004 compared with 2003, 47% and 26%, respectively. (Fig. 4) This was due in part to increased available research protocols for breast cancer patients from both Medical Oncology and Surgical Oncology aspects of breast cancer treatment.

REFERRAL FOR BREAST CANCER TREATMENT

Proportion of breast cancer patients referred for treatment at SLU Cancer Center from non-SLU physicians were similar for 2003 (29%) and 2004 (33%). (Fig. 5) There were more patients referred from SLU physicians for breast cancer treatment at SLU Cancer Center in 2004 (47%) compared with 2003 (32%).
CONCLUSION

Breast cancer care at SLU was comparable to NCDB national average of teaching hospitals. There was a trend toward increasing patient accrual into research studies. Referral for breast cancer care from non-SLU physicians remained unchanged from 2003 to 2004.

RECOMMENDATIONS

1. Increase community outreach efforts to enhance visibility of SLU Breast Cancer Program.
2. Encourage enrollment of breast cancer patients into research studies to improve breast cancer care at SLU.
At the heart of the St. Louis University Cancer Center’s nursing staff is the desire to accommodate patients and allow them to feel like family in a high tech environment. Navigating an academic facility is often overwhelming for patients who come from smaller towns and even the surrounding community. Even though the hospital and outpatient staff is employed by different entities, they have worked hard over the years to maintain the flow of patients from one setting to the other.

The medical oncology staff at St. Louis University Hospital has created something special in its relationship between the outpatient staff and the inpatient staff. The patients they share catalyze the staff to communicate in order to improve coordination of patient care. This relationship is fostered by the physicians and perpetuated by the managers in both care settings. The inpatient manager meets with the outpatient manager on a weekly basis to discuss concerns and issues that have occurred over the past week in an attempt to improve communication.

As a result of the weekly meetings, the managers identified specific areas of disjoint in the flow of patients from the inpatient to outpatient setting and visa versa. This information was reported to the cancer committee who adopted this quality improvement project as a priority for 2005. Consequently, an ongoing review of patients being admitted to the hospital and discharged to the outpatient setting was initiated. In the first 6 months several areas of improvement were identified. These improvements are being implemented and reevaluated. The goal of this improvement project is better coordination of patient care and improved patient satisfaction. Satisfaction scores on the medical oncology/BMT unit are consistently higher than the rest of the hospital. For the months of May/June/July the floor was commended for its 4 star consistency. And in March, one of the nurses on the unit was awarded the most prestigious commendations given to tenet staff, ???.

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Hereditary Breast and Ovarian Cancer

Suzanne Mahon, DNSc, RN, AOCN®, APNG
Clinical Professor
Division of Hematology/Oncology
Department of Internal Medicine
Saint Louis University

A number of hereditary cancer syndromes have now been identified that can be attributed to specific germ line mutations in inherited cancer susceptibility genes. The commercial availability of genetic testing for the cancer susceptibility genes associated with these hereditary cancer syndromes has greatly changed oncology practice. Cancer susceptibility genetic testing has the potential to identify whether or not a person is at increased risk for a particular cancer or cancers associated with a hereditary cancer syndrome. These tests, however, cannot predict when, where, or if the individual will be diagnosed with the cancer. One of the challenges in the communication of genetic risk information and genetic test results is that probabilities and uncertainties surround genetic information.

At Saint Louis University Cancer Center, counseling and education services are readily available. Thanks to two generous grants from the St. Louis Affiliate of the Komen Foundation and the Missouri Foundation for Health, individuals may receive counseling and education without charge. Professionals with expertise in cancer genetics are also available to provide community and professional education on topics of cancer genetics.

Background

About 5% to 10% of cancers are related to hereditary factors. Most major hereditary cancer syndromes follow an autosomal dominant pattern of inheritance. This means that the altered gene can be transmitted by either parent to their offspring, a person only needs to inherit one altered copy of the gene to be at risk of the cancers associated with that particular genetic change, and there is a 50% chance of passing this same altered gene on to one’s children. The majority of altered genes associated with hereditary cancer syndromes act as tumor suppressor genes when they are functioning properly. Tumor suppressor genes regulate or stop the growth of damaged cells. A defective or mutated tumor suppressor gene cannot stop
cells from proliferating wildly and therefore is not able to suppress cellular changes that lead to cancer. This includes mutations of the BRCA1/2 genes which are associated with hereditary breast and/or ovarian cancer.

If a child inherits one altered copy and one normal copy of an autosomal dominant cancer predisposing gene such as BRCA1 or BRCA2, the child will be at increased risk of the cancers associated with that particular cancer predisposing gene. For example a woman who carries a BRCA1 mutation will have a lifetime (birth to age 75yrs) breast cancer risk of about 56% to 87% compared to 12% in the general population and a lifetime ovarian cancer risk of 28% to 44% compared to about 1% to 2% in the general population. Because of autosomal transmission, there is a 50% chance the mutation will be passed to the next generation.

Cancer Risk Assessment and Counseling

Central to clinical cancer genetics is the cancer risk assessment process. Without an accurate assessment, it is impossible for an individual to make good choices about genetic testing, cancer prevention practices, and cancer detection strategies. A cancer risk assessment involves obtaining a detailed patient and family history of cancer, information regarding other medical conditions, and lifestyle factors. Once information about these factors is obtained, estimates can be made regarding the risk of developing a specific cancer in a specific time period and over a lifetime, and estimates of having a hereditary cancer syndrome can be calculated. This information should be interpreted to the patient in understandable terms. Information about the risk assessment can then be used to formulate a plan for the prevention and early detection of cancer.

A detailed pedigree is a visual representation of a family history and should be constructed involving at least three generations. Obtaining information on at least three generations is critical for the accurate evaluation of family history. It is important to note the type of cancer, age of diagnosis, and age of death on the pedigree. Confirming the cancers within a pedigree with pathology reports or death certificates is important for an accurate genetic risk assessment. If a reported ovarian cancer is pathologically confirmed as uterine cancer or cervical cancer, for example, the risk calculation may change considerably.
Cancer risk assessment should also include appropriate information about individual medical risks for cancer such as menstrual history, history of cancer screening practices, exposures to environmental hazards and carcinogens. This information is important when estimating cancer risk and making recommendations for cancer risk reduction, surveillance, early detection.

All individuals need to receive an age appropriate cancer risk assessment in the primary care setting and a plan for cancer risk reduction, surveillance, and frequency of early detection tests. A small subset of those seen for cancer risk assessment will probably have a genetic predisposition for developing cancer and would benefit from education about genetic counseling and testing. There are several key indicators for identifying persons that may have a genetic predisposition for developing cancer and are at risk of hereditary breast/ovarian cancer syndromes, which are outlined in Table 1.

Not all hereditary cancers have an early age of onset and older persons are also at risk of hereditary cancer syndromes. For example, ovarian cancer at any age increases the probability of carrying a BRCA mutation. Women with a family history of breast cancer are more likely to develop the disease in middle or old age and have a 30% to 80% higher risk of being diagnosed with breast cancer compared to women without this family history. Seventy-seven percent of all cancers are diagnosed in persons age 55 and older. This risk persists even when breast cancer is diagnosed in the first-degree relative after age 65. Determining whether or not a cancer diagnosis in persons age 65 and older is related to a cancer predisposing mutation can be challenging, especially with common cancers such as breast, ovarian, and colon cancer. Genetic risk assessment can be helpful in an older patient in determining whether or not these cancers are sporadic or could be related to a hereditary cancer syndrome.

**Genetic Risk Assessment Models**

By using cancer risk models it is sometimes possible to estimate the probability of an individual having a particular cancer predisposing mutation based on their personal and family history of cancer. It is important to distinguish between whether the model is predictive of risk for developing cancer(s), or the risk of having a cancer predisposition mutation. For example, there are genetic risk assessment models that estimate the probability that a person carries an alteration in the *BRCA1* or *BRCA2* gene such as the Couch model, Shattuck-Eidens Mode, Berry Model, Frank model, and BRCAPRO. Each model has its
own strengths and weaknesses. The Claus model does not consider the family history of ovarian cancer. The Couch and Shattuck-Eidens models only predict BRCA1 risk. The Berry model has had limited testing with minority groups. The Frank model is most helpful with premenopausal women.

Ethnic background also needs to be considered when deciding if testing may be appropriate. Over 2% of Ashkenazi Jews are estimated to carry \textit{BRCA1} and \textit{BRCA2} mutations associated with increased risk for breast, ovarian, and prostate cancer. Another example of a key indicator is male breast cancer, as this can indicate an increased risk for carrying mutations in either \textit{BRCA1} or \textit{BRCA2}.

**Who Might Benefit from Genetic Testing?**

Deciding who is the most appropriate candidate for cancer predisposition testing requires clinical judgment due to the complexity of the issues involved. Ideally, an affected family member will be the first one to be tested. A person who has been diagnosed with a cancer within the constellation of tumors that have been clearly linked to a particular cancer syndrome will be the most informative for the rest of the family. If this relative has been tested and found to carry a deleterious mutation known to be associated with increased cancer risk, then at risk family members are likely to benefit from testing for the same mutation.

The American Society of Clinical Oncology (ASCO) recommends cancer predisposition genetic testing be offered when 1) the individual has a personal or family history of cancer suggestive of a hereditary cancer syndrome; 2) the test can be adequately interpreted, and 3) the results will influence the medical or surgical management of the patient or family members.

**Psychosocial Issues Associated With Testing**

When deciding whether to pursue cancer predisposition genetic testing, each patient and family member must weigh the options, risks, and benefits in light of their unique situation. The decision is a very personal one and for each patient the issues will be different. Just because a person has a personal or family history putting them at increased risk for carrying a genetic mutation does not mean they will wish to know their genetic status. For another person the uncertainty may be causing them great anxiety or interfering with their ability to make informed choices about their health. The physical risks of having a blood sample drawn are minimal. The real risks are associated with the psychological and psychosocial impact on the patient of knowing one’s genetic status.
There are psychosocial issues associated with cancer genetic counseling and testing that need to be recognized and addressed. Patients found to carry a cancer susceptibility mutation may experience anxiety, depression, anger, and feelings of vulnerability or guilt about possibly having passed the mutation to children. Those not found not to carry a mutation may experience guilt, known as survivor’s guilt, especially if close family members are found to carry the mutation. Individuals may also experience regrets regarding making major life decisions, such as prophylactic surgery, prior to testing. Expectations related to genetic testing may not be realistic.

Psychological issues to be considered also include fear of cancer or medical procedures, past negative experiences with cancer, unresolved loss and sorrow, feelings of guilt about passing on a mutation to children, anxiety about learning test results, and concern about the effect of results on other family members. The familial context in which genetic testing is conducted is also important for understanding how individuals react to their own test results. For these reasons, it is important for patients to know how to access additional support services such as counseling, social work, or support groups.

**Informed Consent For Genetic Testing**

The informed consent process for predisposition genetic testing needs to include both educational and decision-making components. Integral to informed, shared decision making between the patient and the health care provider is the entire education and counseling process that occurs when a patient faces a complicated decision such as whether or not to pursue predisposition genetic testing. Components of informed consent for genetic testing includes: risks, benefits, cost, accuracy, and purpose of the specific genetic test being ordered, alternatives to genetic testing, implications of a positive, negative, or uncertain test result, how results will be communicated, psychosocial implications, confidentiality issues, options for medical surveillance and risk reduction. Cancer genetic counseling and testing often requires more than one patient visit with informed consent an integral part of the counseling process.

The goal is to provide enough information to enable the patient to come to a personal informed decision about predisposition genetic testing based on adequate knowledge of the benefits and limitations of genetic testing. This information also needs to address the same concerns and benefits of genetic information as it applies to family members as well as the patient.
Communicating Test Results

Predisposition genetic tests, however, involve probabilities and uncertainties that must be interpreted to the patient in a way that is understandable. Results of cancer predisposition genetic tests generally fall into several categories. It is critical that patients understand both the issues associated with predisposition genetic testing, and all the potential test result outcomes prior to initiating the testing process.

Positive test result

A patient can have a positive test result. This occurs when the test result is positive for a mutation known to be associated with an increased risk for a particular cancer or syndrome of cancers. The patient is at increased risk of the cancers known to be associated with that mutation. If the patient has been diagnosed with cancer, a positive test result can have implications for risk of developing a second primary cancer or a cancer recurrence associated with that mutation.

Negative test result

There are two situations where a negative test can occur. The first is in a patient where there is a known mutation in the family and the patient has been tested specifically for that same mutation. The second situation is when there is no known mutation in the family and the patient is tested for one or more mutations associated with increased cancer risk.

In a patient without a cancer diagnosis when there is no known mutation in the family, there are several possible interpretations to a negative test result. The first possibility is that the cancer in the family is due to a known mutation for which the patient was tested and the patient did not inherit it. A second possibility is that the cancer in the family is due to a different gene mutation for which the patient was not tested. A third possibility is that the cancer in the family is due to environmental or other non-hereditary risk factors. Because it is not possible to know which outcome is true for the patient, it is best to first test a blood relative who has been diagnosed with cancer for a mutation known to be associated with that type of cancer.

Variation of uncertain significance

A variation of uncertain significance is when the genetic test indicates a change in the gene was found, however, the cancer risk associated with that change is not yet known. This can occur when a new
mutation or variant is found, or if the variant is uncommon and there is not enough information to
determine if the variant is a deleterious mutation (associated with an increased cancer risk) or a harmless
variant. Some genes, such as \textit{BRCA1} and \textit{BRCA2}, are very large genes with hundreds of known deleterious
mutations. Not all gene changes or variants are deleterious and it is possible for a gene change to be present
which does not interfere with protein function and therefore does not increase cancer risk.

The patient will need to be informed that the significance of the mutation found is not yet known.
A patient with this test result may experience disappointment, anxiety, anger, or depression because the test
result did not give them the information they expected. They may also feel confused and uncertain about
how to make health care decisions regarding cancer surveillance. Until a number of families with the same
mutation have been studied, it is not possible to know if an increased cancer risk may be associated with
the mutation found. This can be a difficult situation for some patients because of the uncertainty. It may be
helpful to test more family members to find out if the mutation is found only in the affected persons, but
this will not give concrete answers. Another option is to encourage the patient to become part of a research
study or confidential registry for persons who carry genetic variants in hopes that more information about
the particular variant will be known as more people are tested. The patient needs to be informed that as
more information about specific variants becomes available, it may be possible to determine if the
particular variant for which they tested positive is deleterious or not. In this situation it is helpful to suggest
the patient schedule a follow up visit in a year to discuss any additional information available at that time.

Decisions about cancer surveillance, early detection, and risk reduction are based on the patient’s personal
and family history of cancer and nonhereditary cancer risk factors.

\textbf{Confidentiality of Genetic Information}

Given the sensitivity of genetic information, patients need to know that their genetic information will not be
released to any third party without their specific written informed consent. Genetic discrimination occurs
when an individual experiences workplace or insurance discrimination based on information about their
genetic make up. Persons found to have a positive genetic test are at risk for genetic discrimination based
solely on their genotype. Individuals who are asymptomatic but have a positive presymptomatic or
predisposition genetic test are at the greatest risk for genetic discrimination.
The most significant federal legislation to date pertaining to protection of genetic information is the Health Insurance Portability and Accountability Act of 1996 (HIPPA). A key provision of this legislation is that genetic information may not be treated as a preexisting condition in the absence of a diagnosis of the condition related to such information. Another key provision is that genetic information cannot be used to deny, cancel, or refuse to renew, coverage. This provision applies to an individual’s eligibility for insurance under a group health plan offered by an employer. HIPPA only applies to health insurance, not disability or life insurance. Also, individuals who are self-employed or who work for companies with very few employees may not be covered.

Managing Persons With BRCA1/2 Mutations

Disclosing predisposition test results to patients requires the clinical background and knowledge to help the patient understand the complexities associated with genetic testing. Equally important is the clinician’s sensitivity to the emotional impact of genetic information and ability to support the patient and family through this process.

The patient needs to understand that a positive predisposition genetic test result does not necessarily mean the patient will get cancer and a negative test result does not mean the patient is free from cancer risk. There is no way to predict when or if an unaffected patient will be diagnosed with cancer, or when or if an affected patient will be diagnosed with a different cancer. Predisposition genetic testing can sometimes help us determine how high the probability is that a patient may be diagnosed with a certain cancer or cancers in the future.

Increased surveillance may lead to earlier detection or prophylactic surgery may reduce the risk for certain cancers. It is important to discuss with the patient options for cancer surveillance, screening, and risk reduction. Equally important is a discussion of the known risks and benefits as well as the uncertainties associated with the use of increased surveillance, chemoprevention, and prophylactic surgery in affected mutation carriers. Published surveillance guidelines can be helpful in this process.

Screening recommendations for those with a mutation in BRCA1/2 may include breast self-examination to begin at age 20. Ideally women should be taught how to perform a self-exam, not just instructed to do so. Mammography usually begins at about age 25 and needs to be performed in a setting where the radiologist is comfortable interpreting the films of young women with dense breasts, who are at
higher risk for developing the disease. A professional examination of the breasts is also indicated twice a year. In terms of ovarian cancer screening, women should be offered a biannual gynecologic exam and consider ultrasound and CA-125 testing. Most importantly, women need to be informed that there is not a reliable method that consistently detects ovarian cancer early when it is most easily treated.

Chemoprevention is discussed with some BRCA1/2 carriers, although it remains a controversial topic. While Tamoxifen has been shown to reduce the risk of breast cancer by 45% in women at risk for breast cancer, its effectiveness in women with a BRCA1/2 mutation is less clear. Tamoxifen has been shown to reduce breast cancer incidence among healthy BRCA2 carriers by 62%, similar to the reduction in incidence of ER-positive breast cancer among all women in the Breast Cancer Prevention Trial. In contrast, tamoxifen use beginning at age 35 years or older did not reduce breast cancer incidence among healthy women with inherited BRCA1 mutations. Whether tamoxifen use at a younger age would reduce breast cancer incidence among healthy women with BRCA1 mutations remains unknown.

A bilateral prophylactic mastectomy can significantly reduce breast cancer risk in women with BRCA1/2 gene mutations. It may reduce the risk by as much as 90%. This is however, a major surgery with many psychosocial implications. Women with mutations need to carefully consider the risks and benefits of this procedure.

The benefits from prophylactic oophorectomy merit consideration. It is often recommended to women between age 35 and 45 who are known mutation carriers and have completed childbearing. It offers an 85 to 95% reduction in the risk for developing ovarian cancer. It also may also offer up to a 50% reduction in the risk for developing breast cancer. There are also no data to address the optimal age at which to perform the surgical procedure, although there appears to be a greater preventive benefit when the procedure is performed at earlier ages. Because the fallopian tubes of mutation carriers have been shown to harbor dysplastic changes and these patients have a higher risk of developing tubal cancer the prophylactic surgical procedure of choice for risk reduction is salpingo-oophorectomy.

**Conclusion**

As the understanding of BRCA1/2 mutations evolves, individuals with known mutations will need new information. Options for participating in research studies need to be offered to further scientific developments. Genetic counseling and testing occur at one point in time, however, the impact of receiving
predisposition genetic test results can last a lifetime. Patients with positive test results will receive long-term clinical services for cancer surveillance, screening, and risk reduction. Little is known about the long-term follow up needs of patients after they have been through predisposition genetic testing, although their need for ongoing emotional support and health education is clear.

*For further information about cancer genetics education please contact Suzanne Mahon RN DNSc AOCN APNG at 314-577-8854*
References


12. Frank TS: Laboratory determination of hereditary susceptibility to breast and ovarian cancer. Archives of Pathology & Laboratory Medicine 123:1023, 1999


\textbf{Table 1}

\textit{Key Indicators of Hereditary Breast/Ovarian Cancer Syndrome}

- Several relatives with same or related cancer. In general the pedigree will show two or more first-degree relatives who have developed breast and ovarian cancer.
- Cancers are diagnosed at an age that is younger than seen in the general population. Often this is ten to fifteen years earlier than if it were a sporadic cancer (less than age 50 for breast cancer).
- A pattern of autosomal dominant transmission is evident. Usually the cancer(s) are seen in more than one generation and there is evidence of vertical transmission. This means that if a person carries a genetic alteration that predisposes them to cancer, there is a 50 percent chance of passing this same genetic alteration on to their children.
- There may be unique tumor site combinations. Individuals with a mutation in one of the BRCA genes may have a history of both breast and ovarian cancer.
- There can be an excess of multifocal or bilateral cancers. This can include more than one cancer in the same organ or cancers that occur in both paired organs. For example bilateral breast cancer that involves both breasts.
- There can be an excess of multiple primary tumors. After successful treatment of one cancer, individuals from these families might go on to develop a completely new cancer, such as ovarian cancer after breast cancer.
- The lifestyle history excludes a history of environmental risk factors.
Grand Vision Cancer Information Center

Knowledge is one of the keys in the fight against cancer. The staff members of the Grand Vision Cancer Information Center continue to evaluate existing programs and offer new learning opportunities.

Meet the Experts

In 2004, the Information Center introduced a lecture series called “Meet the Experts.” The major focuses of these talks are prevention, screening, and early detection of cancer, as well as the many innovative imaging and treatment technologies available at the Saint Louis University Cancer Center. Topics have also included cancer genetics and disparities in cancer treatment.

The first Meet the Experts program in March 2004 highlighted colon cancer awareness month. The program was very well received, and subsequent months have featured presentations on breast, prostate, and skin cancer. Held in the Cancer Center atrium during the lunch hour, the format is a 45-minute lecture followed by 15 minutes for questions. Thirty-seven people attended the first session, but the series has grown in popularity and now draws over 75 people, including employees from both Saint Louis University campuses, as well as Saint Louis University Hospital employees.

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<td>Erik Grossmann, MD</td>
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<td>Suzanne Mahon, RN, DNSc</td>
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<td>September 2004</td>
<td>Prostate Cancer Health Disparities and Needs Assessment in the St. Louis African-American Community</td>
<td>James Cummings, MD</td>
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<td>Ricardo Wray, PhD</td>
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<tr>
<td>October 2004</td>
<td>Treatment of Breast Cancer Hereditary Risk for Breast Cancer</td>
<td>Eddy Hsueh, MD</td>
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<td>Suzanne Mahon, RN, DNS</td>
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<td>November 2004</td>
<td>Lung Cancer Updates</td>
<td>William Sasser, MD</td>
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<td>Hans-Joachim Reimers, MD</td>
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<td>PhD</td>
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<td>Bruce Walz, MD</td>
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<td>January 2005</td>
<td>Healthy Lifestyle and Cancer Prevention</td>
<td>Rebecca Johnson, MSW, LCSW</td>
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<td>Christina Popp, RD, LD</td>
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<td>January 2005</td>
<td>Cervical Cancer</td>
<td>Thomas Buekers, MD</td>
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<td>March 2005</td>
<td>Advances in the Diagnosis</td>
<td>Medhat Osman, MD</td>
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Support Groups

Support programs continue to be a major focus for the Grand Vision Cancer Information Center. The cancer journey is an ongoing learning process that may at times feel overwhelming to patients and their caregivers. The goal of the Information Center is to make this journey easier. Teresa Dunleavy, RN, BSN, OCN and Cathy Turcotte, RN, MSN are always available to assist with educational and support needs. Reading and audiovisual materials are available for use in the Information Center.
SUPPORT GROUPS AND SERVICES PROVIDED BY THE GRAND VISION CANCER INFORMATION CENTER

CANCER TREATMENT CLASS
Patients and their caregivers learn about what to expect during radiation and chemotherapy treatments. Each patient receives a personalized binder containing information on how to recognize, manage, and record treatment side effects.
   Every Thursday
   10:00 a.m. – Noon

BREAST CANCER SUPPORT GROUP
3rd Friday of every month
Noon – 1:00 p.m.

LEUKEMIA, LYMPHOMA, AND MULTIPLE MYELOMA SUPPORT GROUP
The Leukemia & Lymphoma Society and Saint Louis University Cancer Center’s family support group
   2nd Monday of every month
   11:30 a.m. – 1:00 p.m.

HEAD, NECK, AND LUNG CANCER SUPPORT GROUP
4th Friday of every month
10:00 a.m. – Noon

PROSTATE CANCER SUPPORT GROUP
“Man to Man,” the American Cancer Society and Saint Louis University Cancer Center’s prostate cancer education and support group
   2nd Thursday of every month
   6:30 p.m. – 8:00 p.m.

YOGA
The Saint Louis University Cancer Center and the Wellness Community offer free yoga classes designed especially for cancer patients, survivors, and their caregivers. Led by a certified yoga instructor, these classes teach rhythmic breathing, gentle stretching, and mental focus to help participants learn how to ease physical and emotional stress.
   Every Wednesday
   Noon – 1:00 p.m.

LOOK GOOD…FEEL BETTER
Look Good…Feel Better is the American Cancer Society’s free program to help women undergoing cancer treatment learn to cope with the appearance-related side effects of treatment and regain a sense of self-confidence and control over their lives.
   4th Wednesday of every month
   10:00 a.m. – Noon

STOP SMOKING HELP
Freedom from Smoking, the American Lung Association’s eight-week behavior modification smoking cessation program, is offered four times a year. Personalized stop smoking consults are available.

WIGS
Free wigs supplied by the American Cancer Society are available in the Cancer Information Center.

BRAS AND BREAST PROSTHESES

For more information, please call the
Survivors’ Day
The Saint Louis University Cancer Center hosted our annual Cancer Survivor’s Day on October 17, 2004.

Cancer patients, their caregivers, and health professionals were treated to an afternoon of fun and fellowship in celebration of life. Participants created quilt squares signifying their feelings of hope and love. The day concluded as the crowd of cancer survivors, family members, friends, and healthcare professionals gathered to watch the releasing of doves into the bright blue sky.

Hope for Survivors and Caregivers
Rebecca Johnson, MSW, LCSW
Social Worker
Saint Louis University Cancer Center

New Hope through Research
James Hardin, PhD
Interim Director
Saint Louis University Cancer Center

Hope for Family Caregivers
Kelley Patterson
Senior Human Resources Specialist
Saint Louis University

Registration & Quilt Square Creation
The Cancer Center – Creating Hope
James Hardin, PhD
Interim Director
Saint Louis University Cancer Center

Keeping Hope in a Stressful Career
Teri McCarthy, RN, LCSW
Director, Employee Assistance Program
Saint Louis University

Providing Hope While Delivering Bad News
Rebecca Johnson, MSW, LCSW
Social Worker
Saint Louis University Cancer Center

Hope – From Trauma to Triumph
Edward Leigh, MA
Colon Cancer Survivor and Motivational Speaker
The Message of the Dove
Rev. Rob Hartmann, MDiv, RN
Oncology Chaplain
Saint Louis University Hospital

Dove Release
Survivor, Caregiver, and Healthcare Professional
Community Education

Educating and increasing the awareness in our community about cancer prevention, early detection, and treatment continue to be major objectives of the Grand Vision Cancer Information Center. More and more members of the community are benefiting from the efforts of the Information Center’s staff, through health fairs and public speaking engagements. In 2004, approximately 1,775 community members received services from the Information Center, an increase of 500 over the previous year.

We also continue to see growth in the volume of patient and caregiver requests for information about cancer and about community resources that are available. From July 2003 through July 2004, the Information Center received 2,311 requests for information, which increased to 3,530 requests for the time period from July 2004 through July 2005.
Grand Vision Cancer Information Center: Comparison of the Number of Subjects Requesting Information

- July 2003 - July 2004
- July 2004 - July 2005

Number of Requests

- Patients
- Caregivers
- Phone/emails
- Returns
The use of cancer registry information is essential to the prevention and control of cancer. The cancer program at Saint Louis University Hospital makes accurate data collection a priority. We do this by coordinating the collection, management, analysis, follow-up and dissemination of tumor registry data in keeping with the guidelines set forth through the American College of Surgeons Commission on Cancer and the Missouri State Cancer Registry guidelines. Analysis of registry data provides insight into referral trends and treatment patterns. Through the use of registry data we are able to compare institutional data to nationally published data, assuring currency of treatment. Follow-up of cancer patients allows us to learn more about treatment outcomes and future treatment considerations.

The Tumor Registry at Saint Louis University Hospital is overseen by the Cancer Committee, presently chaired by Eddy Hsueh M.D., Associate Professor of Surgery. The Tumor Registry is under the direction of Debra Wilderman, RHIT, Director of Health Information Management, and is staffed by 2 full time certified registrars and one technician - Melissa Cage, Tumor Registry Technician, Paula Carr, RHIT, CTR, and Pam Melton, LPN. CTR serves as the Oncology Data Services Coordinator and has been trained as an Independent Cancer Program Consultant by the American College of Surgeons.

The Registrars attend local, regional, state and national educational programs to stay updated on the latest advances in cancer data management, cancer care and the requirements of both the American College of Surgeons Commission on Cancer and the Missouri Cancer Registry. The registrars also remain active in their professional associations, including Missouri Cancer Registry Association (MoSTRA), Bistate Tumor Registry Association (BiSTRA) and National Cancer Registry Association (NCRA).

The computerized cancer registry database at Saint Louis University Hospital uses a reference date of January 1, 1997. Confidentiality of patient identifying information is strictly maintained. Aggregate data are analyzed and published without any patient identifiers. During 2004, 835 patients (Table 1) were seen at Saint Louis University Hospital with a diagnosis of cancer, 707 of them with a new cancer diagnosis. The remaining 128 were seen for the first time with a recurrence, relapse, pediatric radiation oncology cases or meningiomas. The registry submits data to the Missouri Cancer Registry on a monthly basis. Data is submitted to the National Cancer Database annually. The registry received commendation on 2004 submission for submitting data error free.

In addition to collecting cancer data on patients diagnosed and/or treated at Saint Louis University Hospital, the registry conducts annual follow-up on all analytic* cases. Accumulatively, the registry Maintains a follow-up rate of 80 percent or higher for all analytic patients since the reference date. 90 percent follow-up rate is maintained for all analytic patients diagnosed within the last five years, or from the registry reference date, whichever is shorter.

Table 2. Displays the 10 most frequent new cancer diagnoses in 2004 at Saint Louis University Hospital.
Table 1. ANALYSIS OF CANCER CASES, SAINT LOUIS UNIVERSITY HOSPITAL, 2004

Total Number of Cases Accessioned 2004: 835

<table>
<thead>
<tr>
<th>Category</th>
<th>Cases</th>
<th>Percent of Accessions</th>
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<tbody>
<tr>
<td>Analytic:</td>
<td>707</td>
<td>85%</td>
</tr>
<tr>
<td>Nonanalytic:</td>
<td>128</td>
<td>15%</td>
</tr>
</tbody>
</table>

*Analytic Cases:* Refers to patients who are first diagnosed and/or have received all or part of the first course of their treatment at Saint Louis University Hospital.

Nonanalytic Cases: Patients who are first seen at Saint Louis University Hospital after a full course of therapy has been completed at another facility/or those first diagnosed at autopsy as having had an unsuspected malignancy.

First Course of Therapy: In most instances, first course of treatment defines the initial tumor-directed treatment or series of treatments initiated within four months after diagnosis.

Table 2. Ten Most Frequent New Cancer Diagnoses – 2004

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Cases</th>
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<tr>
<td>Lung</td>
<td>114</td>
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<tr>
<td>Pancreas</td>
<td>61</td>
</tr>
<tr>
<td>Melanoma</td>
<td>48</td>
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<tr>
<td>Brain</td>
<td>46</td>
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<tr>
<td>Liver/Biliary</td>
<td>46</td>
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<tr>
<td>Breast</td>
<td>36</td>
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<tr>
<td>Kidney</td>
<td>33</td>
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<tr>
<td>Colon</td>
<td>33</td>
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<tr>
<td>Hematopoietic Diseases</td>
<td>31</td>
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<tr>
<td>Prostate</td>
<td>29</td>
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The CyberKnife system is used to deliver localized high doses of radiation to target areas in the body.

A reference system in 3-D space is used. The CyberKnife, manufactured by Accuray, consists of a compact 6 MV linear accelerator mounted on a computer-controlled robotic arm. Using image guidance technology, the CyberKnife is able to track the target during treatment delivery, thus providing a dose of radiation which conforms to the tumor yet reduced the radiation dose delivered to adjacent critical structures and normal tissue.

The CyberKnife began installation in March 2004. Commissioning was completed on June 8, 2004, and the first patient was treated on June 16, 2004. Technical and clinical training for registered radiation technologists (RRT’s, the actual operators), medical physicists, radiation oncologists and surgeons was provided by Accuray. It consisted of on site and off site training, both at Accuray’s headquarters in Sunnyvale, CA and visits to Cyberknife sites in Stanford, Georgetown and Boulder.

The CyberKnife program involves an entire team. From the Department of Radiation Oncology, the team includes radiation oncologists MacDonald Logie, M.D., F.A.C.R. and Bruce Walz, M.D., F.A.C.R., Director of the Department; medical physicists Julie Dawson, Ph.D, F.A.A.P.M., MBA, Chief Medical Physicist and Robert McDonald M.S.; radiation therapists Sally Pallazollo, RTT and Julie Kulage, RTT, and nurse coordinator Kathleen Klebert, R.N. From the Department of Surgery, Richard Bucholz, M.D., F.A.C.S., Chief of Neurological Surgery, was a founding member of the team. Keith Naunheim, M.D., F.A.C.S., Chief of Thoracic Surgery, is an active participant in the lung program. Recently, Anthony Mikulec, M.D.; Eddy Hsueh, M.D.; and Ann Marie Flannery, M.D. have joined the team. Sami Nassif, M.D. and Kirke
Bieneman, M.D. represent Interventional Radiology. Medhat Osman, M.D., Ph.D., from Nuclear Medicine and his team of nuclear medicine physicians are heavily involved. Dana Oliver, M.P.H., coordinates data collection and retrieval. Simon Abrahms, M.B.A. is the team’s lead administrative member. James Hardin, Ph.D. was instrumental in our acquiring the CyberKnife and provides Cancer Center support and research expertise. Harvey Solomon, M.D., transplant and hepatobiliary surgeon, and Carl Kaplan, M.D., pulmonologist and internist, are joining the team.

The CyberKnife process begins with a referral. A radiation oncologist and a surgeon see the patient. If after review of records and examination, the patient is deemed likely to benefit by CyberKnife treatment, preparation is made for the treatment. Informed consent is obtained and if the lesion is intracranial, a CT scan in treatment position (using immobilization device) and an MRI are obtained. If the tumor is outside the skull, gold fiducial markers, that is, the interventional radiologist must place radiopaque gold seeds. About one week after fiducial marker placement, imaging studies are obtained including a CT scan, MRI or PET-CT (in treatment position, with immobilization device). The week interval allows resolution of post fiducial marker placement.

The information from diagnostic planning studies is downloaded to the Accuray treatment planning computer located in Radiation Oncology. The responsible surgeon and radiation oncologist outline the target volume and other areas of interest on the axial CT slice by slice, including critical dose limiting structures. After the physicians specify the target dose and define the dose limits to adjacent critical structures, a medical physicist performs the dosimetry calculations using Accuray’s inverse planning software. There are up to 1200 different beams available to treat the tumor. Where all the beams cross the radiation dose is high enough to be therapeutic. Outside the overlap area the dose is low and normal tissue is spared. The treatment planning software determines an array of beam positions and the doses to be delivered from each beam, thus creating the desired dose distribution pattern. Once the surgeon and radiation oncologist approve the dosimetry plan, a medical physicist transfers the plan to the treatment planning/delivery workstation. In this computer the fine grid calculations required for treatment are completed. As a reference, digitally reconstructed radiographs (DRR’s) are created. These DRR’s look like x-ray pictures, but
are a synthetic creation from the CT information. They look as if an x-ray picture had been made at some specific angle and orientation and are used to compare to the CK target. Printed copies of the treatment plan parameters are printed and reviewed for QA purposes. This computer provides 3D displays, manages the treatment, controls the accelerator and robotic arm, records the treatment and monitors the equipment for patient safety, all under the watchful eye of the RTT operator. An extensive QA program including dosimetry measurements and tests to ensure alignment is implemented and reviewed for each patient.

During treatment, the patient lies on a special table that has 6 degrees of freedom including angular rotation, up, down and back and forth. Stereoscopic bi-plane x-rays are made using a system consisting of two diagnostic type x-ray tubes mounted on the walls and two amorphous silica receptors adjacent to the treatment couch that act like a digital radiographic “film”. The actual check films are compared to the DRR’s, the synthetic images created after planning and their superposition are displayed on the treatment workstation. The computer software compares the superposition to detect any misalignment (treatment position vs. planning position); small corrections can be done automatically, larger errors require the radiation therapist (operator) to adjust the position manually and repeat the process. The table makes sub-millimeter adjustments in the patient’s position. If the tumor is one that will move with respiration, that is, a tumor in the chest or abdomen, a vest with light-emitting diodes is placed on the patient’s chest. The patient breathes normally, and a series of x-rays are made, and the computer “learns” the relationship of the respiratory cycle to the fiducial marks.

When the patient is aligned, and usually alignments are done with accuracy that is of few tenths of 1 millimeter, and a few tenths of degrees of rotation, a physician (radiation oncologist or surgeon) approve the alignment and the radiation therapists are authorized to turn the radiation beam on and proceed with the treatment. During treatment, the computer moves the linear accelerator over the patient to a series of “nodes”. These nodes are treatment positions, which are distributed around what is more or less a hemisphere above the patient. A portion of the radiation treatment is given from each beam, up to 1200 different beams. Again, where all these beams cross, there is a high dose, and the
therapeutic affect is achieved, and where the beams do not cross, there is a low dose, and thus normal tissue does not suffer significant damage.

Since the CyberKnife allows us to conform the high dose so tightly and precisely, we are able to re-treat lesions in areas that previously have been heavily irradiated. As always, the limiting factor in radiation treatments is the tolerance of normal tissue and since the beams are so tightly and accurately focussed, and the areas outside the beams receive low dose, it is possible to administer treatment with a high-degree of safety. To date, we have treated a variety of patients, see table 1.

After treatment patients are followed-up and virtually all patients are available for research analysis. The CyberKnife represents a unique tool to treat cancer patients, particularly many patients who could simply not be treated before. Saint Louis University is a leader in the multimodality treatment of cancer using a team approach, and we look forward to benefitting many, many more patients in the future, as well as expanding the CyberKnife team.
Diagnosis of patients referred to Saint Louis University Cancer Center for treatment with stereotactic surgery between June, 2004 and June, 2005.