

Together

Together We Can

Newsletter of the Joan Karnell Cancer Center at Pennsylvania Hospital

Breaking the

Code ■ Sarcoma Researchers Search for Answers

How do tumors develop and progress? That is the question researchers at Pennsylvania Hospital are trying to answer with the help of the GeneChip Microarray Technology from Affymetrix. Purchased with the help of hospital donors, the GeneChip offers a way for researchers to read every single known gene. "With this technology, we can examine the genes in tumor samples to determine how genes are expressed differently in different types of tumors," says Anne-Marie Martin, PhD, a molecular biologist with Pennsylvania Hospital.

The GeneChip consists of a small microscope glass slide encased in plastic and is manufactured using processes similar to those used for making computer microchips. Synthetic strands of DNA sequences identical to the sequence of a normal gene are applied to the surface of each chip. The chip surface can hold up to 33,000 different synthetic sequence strands representing 33,000 different genes, or all the genes of the Human Genome.

In and of itself, the GeneChip technology is fairly common. However, the patients of the Joan Karnell Cancer Center at Pennsylvania Hospital are what makes the research completed here so different from research conducted elsewhere. Drs. Lackman and Donthineni-Rao and the Joan Karnell

Cancer Center see approximately 400 sarcoma patients in any given year. Further, these patients suffer from a variety of different sarcomas, which means researchers can study a wide variety of tumor types.

"Compared to other research in this area, we have a unique resource of tissue thanks to the donations of our patients," says Dr. Martin. "Our patients are very proactive and interested in advancing knowledge about this type of cancer. Not only do they consent for tissue to be used as a part of this study but we've also had patients set up foundations to help provide the funds necessary for this type of research. Our sarcoma research wouldn't be where it is today without them."

Currently, researchers are examining several different tumor types including osteosarcoma and chondrosarcoma. While specifically examining the

(continued on page 3)

Palliative Care IS COMING

The Joan Karnell Cancer Center at Pennsylvania Hospital is pleased to announce our newest program, the Palliative Care Program. Under the direction of Dr. David Mintzer, this outpatient-based program focuses on the total care of cancer patients. This innovative program is unique in the Philadelphia area and has many goals including control of pain, psychological, social and spiritual problems. Look for more information on Palliative Care in the next issue of our newsletter. •



Joan Karnell Cancer Center at

Pennsylvania
 *Hospital*

University of Pennsylvania Health System

1-800-789-PENN

Winter 2003
Volume 2 • Issue 1

Pennsylvania Hospital is a member of the University of Pennsylvania Cancer Network

PARENT TO PARENT

& Heart to Heart

By Helen E. Grosky, MSS, LSW

As parents you protect, provide and cherish your children. But when parents and children are challenged by a diagnosis of sarcoma, this family equilibrium is disrupted. Parents often experience an array of emotions including guilt and fear. Some parents even feel that they have in some sense failed to keep their children safe; that having a child diagnosed with cancer somehow suggests they are inadequate guardians and caretakers.

It is this loss of control that accompanies a cancer diagnosis that can be most difficult for parents and often results in a crisis atmosphere at home. Parental response to this crisis is often a balancing act. None of the old coping mechanisms work and new coping strategies have not yet been developed.

Who better to help parents during this time of crisis than other parents who have experienced the same struggles? In order to help them overcome the anxiety and fear

associated with their children's sarcoma, the Joan Karnell Cancer Center at Pennsylvania Hospital offers a program to join parents whose children have completed treatment with those parents who are new to the experience. Through this network, parents offer emotional support and encouragement on a one-on-one basis. Talking to someone who can relate to your experience helps to normalize the situation and helps parents feel that they are not alone.

The network also includes sarcoma patients who are matched with newly diagnosed children. They keep in touch via the Internet and offer support and advice to one another about school issues, chemotherapy issues, and of course hair loss. Sometimes they are silly, sometimes they are serious, but the bottom line is that they are always caring and they are there when they are needed. For more information, call Helen Grosky at 215-829-5954. •



Feeling sad or worried? Need to talk to someone? Psychological counseling services are now available at Pennsylvania Hospital's Joan Karnell Cancer Center. This service is available at no charge to Cancer Center patients and psychologists are available Monday through Fridays. To make an appointment call Marylou Osterman at 215-829-6466.

Patients Needed for **Massage Study**

Patients currently undergoing chemotherapy at the Joan Karnell Cancer Center can participate in a nursing research study on the effects of shiatsu massage on sleep. Shiatsu massage or bodywork is a form of Asian Bodywork Therapy. Shiatsu, which literally means "finger pressure," is an Asian healing art in which the practitioner applies gentle stretches and pressure to specific points on a client's body that lie along channels of energy called meridians. This energy (Qi) animates the body as it flows through the meridians. The Shiatsu practitioner's intention is to promote health and well-being by maintaining the balance of this flow of energy.

The research study is designed to determine if treatment with Shiatsu bodywork has an impact on sleep problems in patients with cancer. Patients who agree



to participate will answer questions about sleep and keep a sleep log during the four weeks they are in the study. They will undergo Shiatsu massage weekly for four weeks as part of the study. There is no cost to patients who participate in the study. For more information or to enroll, contact Marylou Osterman at 215-829-6466. •

Celebrate Life *with us* on June 8

Held in the Elm Garden at Pennsylvania Hospital, the Celebrate Life program is part of the annual National Cancer Survivor's Day. This year our cancer survivors will be celebrating life on Sunday, June 8 from 12:30 p.m. to 3:00 p.m. A cancer survivor is any patient who has been diagnosed with cancer. Join us as our physicians and patients share the challenges, obstacles and rewards of learning to live with a cancer diagnosis. We'll also supply food, entertainment and good family fun. Registration for National Cancer Survivor's Day 2003 is required. To register, call 1-800-789-PENN. •

Breaking the Code ■ Sarcoma Researchers Search for Answers

(continued from page 1)

differences between tumor types, researchers are seeking the answers to two main questions. First, what is the biology of these tumors? And second, what is happening to the chromosomes of these tumors? "By answering these questions we hope to find ways to target new therapies for cancers of the bone, cartilage and other soft tissue," said Dr. Martin. Today, treatment for sarcoma often involves radical surgery. With the findings of this and other research, doctors hope to design new treatment strategies targeted directly to each tumor type.

In the meantime, Dr. Martin anticipates that some of the results from this study will be ready for publication within the next year. "The collaboration between the different experts – surgeons, oncologists, and pathologists – you need to complete this kind of research is exceptional here at Pennsylvania Hospital. We are all very interested and very motivated to uncover the answers to these questions. Our hope is that this research will have a significant impact on the quality of life of our patients," says Dr. Martin. •



Tune in to Penn Vital Signs on WPVI 6ABC on Saturday, April 12 at 7 p.m. Witness first-hand how our doctors, nurses and the entire team at Penn care for our bone and soft tissue cancer patients and their families. See how the latest advances in neuro-orthopaedics is improving quality of life for patients who have lost mobility due to stroke, brain injury or cerebral palsy. You can also chat live with our physicians featured in the show by logging on to www.pennhealth.com during the show and for two hours after. •

Together We Can CHARITY BALL



Anne Nofer, Joe Sullivan, Susan Kruse, RN, Surgical Oncology Nurse, Susan Ley and Pam Eckardt, Pennsylvania Oncology Hematology Associates at the Together We Can Charity Ball.



Marty Weinar, RN, Cancer Risk Evaluation Nurse and Susan Hunter, CRNP, GYN Oncology Nurse are two of the newest staff members at the Joan Karnell Cancer Center.



Right: Marylou Osterman, Cancer Center coordinator, and Anna Marie Marshall at the Ball. Anna Marie Marshall chaired last Spring's Washington Square Tour, which featured the Cancer Center as a destination.

Far right: Robert Karnell, co-chair of the Together We Can Charity Ball, welcomed the supporters of Pennsylvania Hospital's Joan Karnell Cancer Center.



Thank You

Welcome

Susan Stonehouse

Susan Stonehouse, CRNP, joins the Joan Karnell Cancer Center at Pennsylvania Hospital as a nurse practitioner in orthopedic oncology. Formerly a nurse in hematology/oncology and bone marrow transplant at the Hospital of the medical center, Susan has worked as a Penn nurse for four years.

In orthopedic oncology much of Susan's time is spent helping patients deal with pre- and post-operative issues. "Our doctors are well-known for their limb sparing techniques," says Susan. "For that reason, some of our patients travel a significant distance to be treated here. I spend a lot of my time on the phone counseling and helping people deal with issues related to their cancer treatment."

Those issues range from helping patients prepare for surgery to helping patients through rehabilitation. "Most of our patients are adults," says Susan, "but we also see a fair number of children. Their needs are different, of course, but with the help of the Joan Karnell Cancer Center we can provide all of our patients and their families with the support they need. As a nurse practitioner, my most important job is helping people get to a place where their quality of life is acceptable to them."

Please join us in welcoming Susan to the Cancer Center. For more information about orthopedic oncology at the Joan Karnell Cancer Center at Pennsylvania Hospital, call 1-800-789-PENN. •

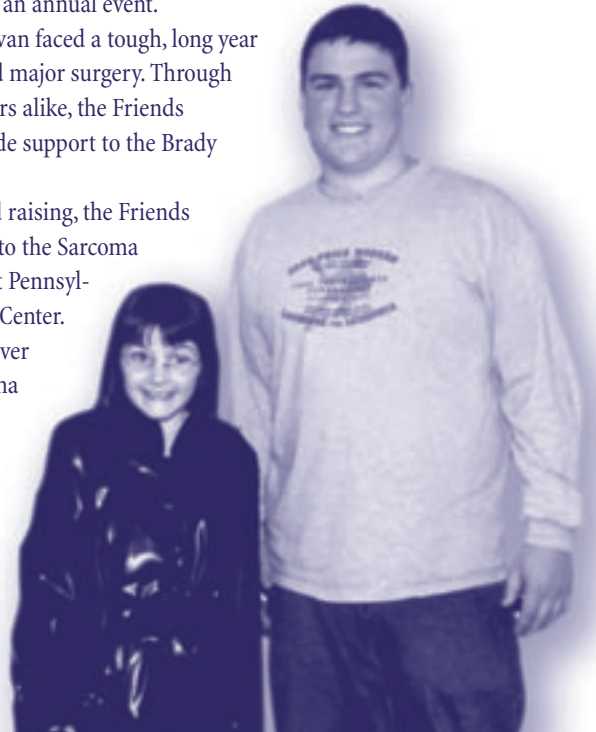
Making a Difference

Last fall, All-Star lacrosse player Evan Brady was diagnosed with osteogenic sarcoma. When friends and teammates heard about Evan's condition, they came together to establish the Friends for Evan Brady, a group committed to providing support to those in their community who deal with hardships as a result of unexpected illness. To raise funds, they established the Friends of Evan Brady Lacrosse Tournament, which has now become an annual event.

During his battle with cancer, Evan faced a tough, long year filled with intense chemotherapy and major surgery. Through the generosity of friends and strangers alike, the Friends of Evan Brady was able to help provide support to the Brady family during this difficult time.

As a result of its successful fund raising, the Friends of Evan Brady also made a donation to the Sarcoma Research Fund to support research at Pennsylvania Hospital's Joan Karnell Cancer Center. We are committed to helping to uncover new and better treatments for sarcoma and thank the Friends of Evan Brady for its support. For more information about this organization visit www.evanbrady.com. •

Evan Brady (right) and seven-year-old Melina Angelo enjoy the Friends of Evan Brady Lacrosse Tournament. Melina was diagnosed with a brain tumor at about the same time Evan was diagnosed with cancer.



Dr. Arthur Staddon accepts a check from Ed Hoag, President of the Leiomyosarcoma Foundation. Also pictured L to R, Gary Stopyra, MD, AnneMarie Martin, PhD, Michael Warhol, MD, Richard Lackman, MD and Ken Gibson, Treasurer. The Foundation was established by the friends and family of Brian Monaghan in his memory.

Supportive Care Services CALENDAR

The Joan Karnell Cancer Center at Pennsylvania Hospital offers a variety of support groups to help cancer patients and their families cope with the diagnosis of cancer. Led by trained professionals, these groups offer emotional support, education, an opportunity to learn ways of coping with uncertainty and change, and a chance to meet others who face similar issues. One-day seminars are also regularly scheduled on a variety of topics for patients and families.

Look Good, Feel Better

To gain control over the cosmetic effects of cancer treatment, the American Cancer Society and experts from the cosmetic industry offer a special program for patients while they are being treated. This group is led by a registered cosmetic advisor who addresses hair and skin care issues and provides various make-up tips.

Nutrition Well Being

This workshop is designed for individuals with cancer and their loved ones to enhance nutrition knowledge and to provide skills that emphasize the role that healthy eating plays in cancer treatment and recovery.

Fatigue Day

Several workshops are held throughout the year to help patients learn how to manage cancer-related fatigue by addressing the medical aspects of fatigue, energy conservation, relaxation, exercise and nutrition.

I Can Cope

During four weekly sessions, healthcare professionals provide factual, straightforward information and answers about the day-to-day issues of living with cancer. Learn about diagnosis, treatment, side effects, emotions, self-esteem and community resources. The workshops are led by Pennsylvania Hospital professionals in cooperation with the American Cancer Society.

Strength for Caring

A one-day seminar of education and psychosocial support for caregivers of cancer patients is offered periodically during the year. This program focuses on the needs of the caregiver, including education about cancer and its treatment, how to talk to the doctor, how to deal with common emotional issues such as anger and depression, time management skills, and community resources.

National Cancer Survivors Day

Help celebrate life with National Cancer Survivors Day. Joan Karnell Cancer Center staff and patients (former and current) join together to honor cancer survivors and those who support them. The event highlights how cancer survivors can live active, productive lives despite the challenges they may face.

ICE: Improving the Chemotherapy Experience

Recommended for patients who are about to begin chemotherapy, this program introduces patients and family members to the basic concepts of chemotherapy, including side effects and symptom management. The Cancer Center staff will also explain its role in improving your chemotherapy experience.

FACING FORWARD: BREAST CANCER

Support and Information
3rd Tuesday of each month
5:30 pm – 7:30 pm
Tuesday, January 21
Tuesday, February 18
Tuesday, March 18
Tuesday, April 15
Tuesday, May 20

PERSON TO PERSON

Last Thursday of each month
5:30 pm – 7:00 pm
Thursday, January 30
Thursday, February 27
Thursday, March 27
Thursday, April 24
Thursday, May 29

ICE

*Improving the
Chemotherapy Experience*
**1st Tuesday and 3rd
Thursday of each month**
2:30 pm – 3:30 pm
Thursday, January 16
Tuesday, February 4
Thursday, February 20
Tuesday, March 4
Thursday, March 20
Tuesday, April 1
Thursday, April 17
Tuesday, May 6
Thursday, May 15

LOOK GOOD, FEEL BETTER

Monday, April 14
9:30 am – 11:30 am

MOVING ON

*A meeting for patients who have
recently completed treatment*
**3rd Wednesday of every
other month**
1:30 pm – 3:00 pm
Wednesday, January 15
Wednesday, March 19
Wednesday, May 21

LEUKEMIA AND LYMPHOMA SUPPORT GROUP

Quarterly Meeting
5:30 pm – 7:00 pm
Thursday, March 6
Thursday, June 5
Thursday, September 4

GYN CANCER SUPPORT GROUP

4:00 pm – 6:00 pm
Monday, January 13
Monday, February 10
Monday, March 10
Monday, April 14
Monday, May 12

NUTRITION WELL BEING

*The first session is for patients
currently in treatment; the second
is for patients who have completed
treatment.*
Tuesday, January 28
1:30 pm – 3:30 pm
Tuesday, February 4
1:30 pm – 3:30 pm
Tuesday, May 6
5:00 pm – 7:00 pm
Tuesday May 13
5:00 pm – 7:00 pm

*Meetings are held in the
Conference Room, Farm Journal
Building, 2nd Floor, 230 West
Washington Square. Registration
is required. For more informa-
tion, call 215-829-6466.*

*Supportive Care Services
programs are offered throughout
the year. Please be aware that
this is only a partial listing. Dates
may be subject to change due to
scheduling conflicts or inclement
weather.*

Pennsylvania Hospital is a member of the

University of Pennsylvania
CANCER NETWORK
University of Pennsylvania Health System



The future of medicine.®

1-800-789-PENN
www.pahosp.com