Focus on IBC

November 2009

IBC Research Foundation Newsletter

ResearchMatch.org

On Tuesday, November 10, the National Institutes of Health (NIH) announced the launch of the first national research study recruitment registry designed to increase and improve the connection between potential research participants and researchers. ResearchMatch.org is a not-for-profit, disease-neutral, online volunteer recruitment registry seeking to remove the barrier unsuccessful participant recruitment presents to the completion of research studies nationwide. The site is a collaborative effort of the national network of medical research institutions affiliated with the Clinical and Translational Science Awards (CTSAs), a program led by NIH's National Center for Research Resources. The registry is designed to be user-friendly, and unlike ClinicalTrials.gov, it places the burden of connecting research volunteers to appropriate studies on the researcher, as opposed to potential participants.

Read the NIC Press Release

YEAR'S END MUSINGS FROM OUR EXECUTIVE DIRECTOR

Last month I was interviewed by fellow inflammatory breast cancer survivor Phyllis Johnson for an on-line article about the work of the Inflammatory Breast Cancer Research Foundation. ("Kitchen Table Activists")

Phyllis has been writing for HealthCentral.com as the 'resident expert' for inflammatory breast cancer (IBC), and shares on a variety of topics associated with the disease. When she first contacted me about the article, Phyllis indicated she wanted her readers to know about the "excellent work of the Foundation." Of course I was only too happy to oblige!!

Acquiring information for the piece we talked about the early days, as the Inflammatory Breast Cancer Research Foundation was just taking shape, and discussed how the organization has grown and developed over the years. As we listed the many accomplishments and projects of the Inflammatory Breast Cancer Research Foundation, I thought about all the wonderful people who have given of their time, talents and financial resources to support this important work. It is an honor to represent this organization and work with such amazing people.

In August of this year the Inflammatory Breast Cancer Research Foundation marked an important milestone, our 10th anniversary. What started out as a handful of individuals sharing their thoughts and concerns about IBC via email has grown into a non-profit organization that has gained a "seat at the table" and respect in the breast cancer research community. Phyllis' article title sums it up, "Kitchen Table Activists". We have no desire to be a multi-million dollar breast cancer organization and all the headaches that come with that designation.

Upcoming Events

Nov. 3 - FDA Transparency Task Force; Washington, DC Click here.

Nov. 4-8 - Quality Care Project LEAD; National Breast Cancer Coalition; Northern Virginia

Click here.

Nov. 5 - Advanced Breast Cancer: Living Well Through Information & Support, Part 3, Lillie D. Shockney, RN, BS, MAS, Living Fully: Making Treatment Decisions; Teleconference 7-8:15 pm ET

Click here.

Nov. 5 - National Breast Cancer Coalition Fund 14th Annual New York Gala

Click here.

Nov. 14 - The Future of Breast Cancer Care; Living Beyond Breast Cancer Annual Fall Conference; Philadelphia, PA

Click here.

Dec. 2-5 - International Project LEAD for non-US participants; Buenos Aires, Argentina Click here.

Dec. 9 - Telephone Workshop: Clinical Trials: Improving Treatment Options and Care for People Living with Cancer; Click

The Inflammatory Breast Cancer Research Foundation has a very specific niche' and purpose, to facilitate research of inflammatory breast cancer while also raising awareness of the disease through education.

The Inflammatory Breast Cancer Research Foundation has no walk-in office and operates with a dedicated group of volunteers, as well as some contract labor for a variety of services as needed. Volunteers work from their homes in an effort to keep administrative costs to a minimum. Unlike many other organizations, there is no Director of Development sending out letters asking for funds to keep the organization moving forward. Instead, the Inflammatory Breast Cancer Research Foundation has relied on the belief that people will support the work because it is important to them. Those individual donations, the fundraising efforts of various families, and a few grants have supported the various programs and services. Our heartfelt thanks to all of them! More recently, thanks to the generous collaboration of the Milburn Foundation (see the October issue of Focus On IBC), a research grant was given last month to Diane Palmieri, PhD, to study brain metastasis of IBC.

There are many worthwhile causes seeking your support and I know you can't support them all, especially in these challenging economic times. Each year my husband and I review our finances and determine where we'll make our "charitable investments." Our church is always first on the list, followed by the Inflammatory Breast Cancer Research Foundation. It is important to us to give back to an organization that uses its funds wisely and is devoted to a cause we strongly support. This year as I marked fifteen years since my diagnosis of IBC and later another birthday, I asked family and friends to make a donation to the Inflammatory Breast Cancer Research Foundation in celebration. It warmed my heart that many responded to my plea and supported this cause near and dear to my heart.

As this year draws to a close and you think about your charitable contributions for this year and next, I hope you'll be challenged to join me and my husband in support of the Inflammatory Breast Cancer Research Foundation. Your donation helps fund research, awareness, and a strong voice for the IBC community.

Thank you,

Ginny Mason, RN, BSN

Noted IBC Researcher Now at University of Nevada School of Medicine

By, Ginny Mason, RN, BSN

Executive Director, ibcRF

here or call 1-800-813-4673 to register.

Dec. 9-13 - 32nd Annual San Antonio Breast Cancer Symposium, San Antonio, TX Click here.

Dec. 15 - Pediatric Oncology Subcommittee Advisory Committee Meeting: Gaithersburg, MD Click here.

Dec. 16 - Telephone Workshop: The Latest Developments Reported at the 32nd Annual San Antonio Breast Cancer Symposium; Click here or call 1-800-813-4673 to register.

Dec. 16-17 - Oncologic Drugs Advisory Committee, Gaithersburg, MD; Click here.

Quick Links for IBC Patients and Caregivers

Previous Newsletters

ibcRF BioBank

Donate to ibcRF

1-877-STOP-IBC
1-877-786-7422

www.ibcresearch.org
email:
info@ibcresearch.org

Earlier this fall, Sanford H. Barsky, MD, joined the University of Nevada School of Medicine as professor and new chair of the Department of Pathology. In addition to these responsibilities he will also serve as chief of pathology of Nevada Cancer Institute (NVCI) in Las Vegas and an associate director of NVCI at the Reno campus. Dr. Barsky brings a strong research and clinical background to his new position having most recently served as The Donald A. Senhauser Endowed Chair of Pathology, chair of the pathology department, and chief of pathology services at The Ohio State University College of Medicine since 2004.

Dr. Barsky is a pioneer and recognized international authority in the field of inflammatory breast cancer responsible for such important milestones as Mary X, a xenograft mouse for the study of inflammatory breast cancer. He has published more than 150 peer reviewed articles and more than 200 abstracts and is known for his "out of the box" thinking bringing a creative approach to the understanding of inflammatory breast cancer.

Tumor latency is a topic of particular interest to Dr. Barsky and much of his research has focused on the unusual pattern of aggressive metastasis and dormancy seen in inflammatory breast cancer. With this move to the University of Nevada and the Nevada Cancer Institute, Dr. Barsky has the opportunity to establish an endowed professorship and eventually an endowed chair dedicated to the research of inflammatory breast cancer. Dr. Barsky has developed a presentation for potential investors detailing the importance of an inflammatory breast cancer research endowed chair to stimulate quality research and heighten awareness of this deadly form of breast cancer. For more information Click here.

In addition to his inflammatory breast cancer and other research, Dr. Barsky leads the digital pathology field and will initiate a virtual slide microscopy diagnostic consultative service throughout the state of Nevada.

To read the full press release click here.

Drug That Crosses Blood-Brain Barrier Reduces Formation of Brain Metastases in Mice

The following press release, from the National Cancer Institute posted on-line 09/29/2009, features the work of Patricia Steeg, Ph.D, and colleague Diane Palmieri, Ph.D., who was recently awarded an Inflammatory Breast Cancer Research Foundation grant to study brain metastasis in inflammatory breast cancer.

The drug vorinostat is able to cross the blood-brain barrier and reduce the development of large metastatic tumors in mice brains by 62 percent when compared to mice that did not receive the drug, according to a new study. In humans, the drug has been approved by the U.S. Food and Drug Administration for the treatment of a cancer called cutaneous T-cell lymphoma but can be used experimentally to study its effectiveness against other cancers. This research, by investigators at the National Cancer Institute (NCI), part of the National Institutes of Health, and their collaborators, appears online Sept. 29, 2009, in Clinical Cancer Research.

For people, while various therapies are improving the survival of breast cancer patients, the incidence of breast cancer spreading to the brain is increasing. Brain metastases of breast cancer have proven to be largely untreatable because the blood-brain barrier, which arises from the specialized structure of blood capillaries in the brain, severely limits drug access and many drugs are actively transported out of brain at this barrier. Consequently, the one-year survival estimate for breast cancer patients after a diagnosis of brain metastasis is only about 20 percent.

Vorinostat has been found to slow the growth of primary tumors of several different types of cancer in mice. Previous studies have suggested that the drug can be taken up by the brain, although little was known about its effects on metastatic tumors. Therefore, to study the effect of vorinostat on the formation of brain metastases, scientists used a mouse model of human breast cancer. Human breast cells were cultured in the laboratory and were injected into mice with compromised immune systems. The breast cancer cells then migrated to the brain, forming metastases.

"Drugs that can cross the blood-brain barrier and reduce the size and incidence of metastatic tumors are urgently needed," said Patricia S. Steeg, Ph.D., study author, Center for Cancer Research, NCI. The researchers found that vorinostat was absorbed readily into normal mouse brains, and accumulation of the drug was up to three-fold higher in some metastases treated with this drug when compared to surrounding brain tissue. Vorinostat also reduced the development of tiny tumors (micrometastases) in mice by 28

percent when compared with mice that did not receive this therapy.

The ability of vorinostat to reduce metastatic lesions in the brain was linked to a novel double-barreled mechanism -- the drug can cause breaks in both strands of a DNA helix and can also lower the activity of a DNA repair gene called Rad52.

In June of this year, several researchers affiliated with this study published a paper in Molecular Cancer Therapeutics showing that vorinostat could enhance the effect of radiation therapy in mice with brain cancer metastasis. Mice that received implants of human breast tumors in their brains lived the longest after treatment with both vorinostat and radiation, demonstrating that the drug enhances the sensitivity of cancer cells to radiation therapy. "Taken together with our current finding, researchers have now established a preclinical basis for testing this drug in clinical trials in humans," said Steeg.

Reference: Palmieri D, Lockman PR, et al. Vorinostat Inhibits Brain Metastatic Colonization in a Model of Triple-Negative Breast Cancer and Induces DNA Double-Strand Breaks. Clin Cancer Res. Sept. 29, 2009. Vol.15, No. 19.

NCI leads the National Cancer Program and the NIH effort to dramatically reduce the burden of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI Web site at www.cancer.gov or call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237.)

For full story Click here.