

the INHERITED CANCER REGISTRY

at the Moffitt Cancer Center

SPRING 2011

Welcome Message

What's Inside?

Welcome Message.....	1
Introducing the ICARE logo.....	1
Recruitment and Participation....	1
Research Corner.....	2
Ask the Investigator.....	2
Upcoming Events.....	2
Welcome to family members.....	2
ICARE on the Web.....	2
Why do you CARE about ICARE?.....	2

Introducing the ICARE Logo

The ICARE team worked hard in 2010 and with a great deal of care and thought to create a logo.



We decided upon a pedigree symbol, incorporating different colors representing various cancers (including pink for breast cancer and teal for ovarian cancer, among others) that may be experienced by families at risk for hereditary cancer.

I am excited to share more about our recently launched **Inherited Cancer Registry (ICARE)** Initiative, the goal of which is to 'End the cycle of inherited cancer through research, education, and outreach', as reflected by our mission statement. Through the ICARE initiative, we form a research partnership with families at risk for hereditary cancer. ICARE participation involves giving consent to be included in this research registry and completing a questionnaire. Benefits of participation may include learning about new treatments or other open research studies for which an individual may be eligible, as well as taking part in the larger research mission to advance knowledge in the field. As part of ICARE, we also reach out to practitioners who treat individuals with hereditary cancer predisposition, for the purposes of: 1) understanding their needs to provide the best care and 2) providing them with educational resources.

We are excited to introduce Christina Bittner, a board certified

genetic counselor who serves as the outreach and education coordinator for ICARE. Ms. Bittner actively recruits registry participants and works with practitioners partnering with ICARE.

We greatly appreciate the efforts from all those who have taken the time to participate, and welcome any others who may be interested in finding out more about our registry. We plan to send a newsletter three times a year, to keep participants informed about the following: 1) registry growth, 2) additional registry initiatives that may be of interest to you (e.g., upcoming events and website development) and 3) research updates, including a forum where experts can address research questions. Please contact us for more information or inquiries. We look forward to hearing from you!

Sincerely,

Tuya Pal, MD, FABMG
Principal Investigator,
ICARE Initiative

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Recruitment and Participation

Within less than a year, the ICARE registry has gained the support of nearly twenty Florida-based hospitals and cancer treatment centers. This number continues to grow as more doctors and health services providers recognize the benefits of an inherited cancer registry and refer their patients to ICARE. ICARE participants are not only referred through medical/research facilities; many individuals learn about the benefits of being part of a registry through outreach services (such as FORCE, www.facingourrisk.org). People who are interested in learning more about the registry can contact ICARE via email at ICARE@moffitt.org or phone at 813-745-6446 (toll free at 1-800-456-3434 x6446).

Research Corner

Dr. Robert Wenham, a gynecologic oncologist at the Moffitt Cancer Center, recently presented preliminary data on the first human study of PARP inhibitors in the treatment of ovarian cancer. PARP-inhibitors disrupt repair of cancer cells damaged by chemotherapy, and are therefore believed to make cancer cells more sensitive to chemotherapy treatment. These results were revealed at the Society of Gynecologic Oncologists 42nd Annual Meeting on Women's Cancer in March of this year. The data from this phase I trial (initial human-based trial used to assess safety, side-effects, dosage, etc) indicate potential clinical benefits for using PARP-inhibitors in heavily pretreated (before chemotherapy) ovarian cancer patients. Those ovarian cancer patients in the study who were known to be positive for having inherited a *BRCA*-mutation appeared to have an even stronger benefit from using the PARP-inhibitor. The basic repair process of DNA in cells with *BRCA*-mutations has been shown to be dysfunctional. It appears that the use of PARP-inhibitors in cells already with dysfunctional repair increases the chances of cell death after chemotherapy treatment.

These results have not yet been published in a peer reviewed scientific journal and the phase I trial continues. However, these results show exciting promise for the use of PARP inhibitors in the treatment of ovarian cancer, particularly in patients who carry *BRCA*-mutations.

Reference: *Wenham RM, et al. "First in human trial of poly(ADP)-ribose polymerase (PARP) inhibitor MK-4827 in advanced cancer patients with antitumor activity in BRCA-deficient and sporadic ovarian cancers" SGO 2011; Abstract 8.*

Ask the Research Investigator

Through each newsletter, we plan to give our participants an opportunity to have their genetics and research questions answered by members of our research team. Please send your questions to ICARE@Moffitt.org. We are excited to learn what questions you have for us! We are fortunate to have Dr. Alvaro Monteiro, who is a molecular geneticist and expert on the *BRCA1* and *BRCA2* genes, as a member of our team. For our first ICARE newsletter, Dr. Monteiro teaches us about Variants of Uncertain Significance.

"What is a Variant of Uncertain Significance (VUS) test result? How do researchers learn more information about variants?"

A variant of uncertain significance test result is when a change is found in the tested DNA for which there is no clear answer to determine if the change leads to an increased risk of developing cancer. To determine whether a particular variant is linked to increased cancer risk, researchers use a series of tools that include studying families with the variant (to determine whether the variant tracks with cancer), comparing the gene code in different species (for example dog, mouse, chicken and fish) to determine the importance of this particular area in the gene (important areas of the gene stay the same with different species), computer programs, and functional tests that study how the gene may work (or not work) with the variant.

Closing Statement

Thank you for being a member of ICARE and the research family we are building. We want to form a working partnership with all our participants to fulfill the mission to *"End the cycle of inherited cancer through research, education, and outreach."*

Upcoming Events

The ICARE study team will be at the annual FORCE conference on June 23-25, 2011! We will be providing information about the registry, enrolling people for the study, and touching base with those who joined ICARE at the 2010 conference to complete any additional information needed. Please stop by the ICARE table to learn more about what's new with the study and for those who are already ICARE participants, provide us with any updates in your medical or family history. We hope to see you there!

ICARE Welcomes Family Members

Since genes and cancer risk are shared within families, family members are at risk for inheriting genetic mutations already identified within a family. Please invite your at risk family members to join ICARE. If your family members are interested in learning more, they can contact us by email ICARE@moffitt.org or phone 813-745-6446 (toll free at 800-456-3434 x6446).

ICARE website and Facebook page

Now, learning about ICARE is just a few mouse clicks away! Meet the ICARE team, discover the goals of the registry, and find valuable resources by visiting our webpage, www.moffitt.org/ICARE.

We need your "Likes"! You can "like" the ICARE Facebook page by visiting www.facebook.com/ICAREatMoffitt. We will use Facebook to inform users of any upcoming events, updates to the registry, and recent publications.

Tell us why you CARE about ICARE

ICARE is looking for current participants who would be interested in sharing their reason for joining the ICARE registry for a promotional video that will be posted on our website and Facebook. Please contact us by email ICARE@moffitt.org or phone 813-745-6446 (toll free at 1-800-456-3434 x6446) to learn more!