

ICARE Initiative

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ICARE INHERITED CANCER REGISTRY



Agenda

- Overview of ICARE
 - History
 - Mission
 - Benefits
- Patient enrollment
- Website contents
- Questions

What is ICARE?

- Research initiative representing a clinical-research-community partnership between medical practitioners, researchers, and individuals facing inherited cancer risk
- Mission Statement: *To end the cycle of inherited cancer through research, education, and outreach*



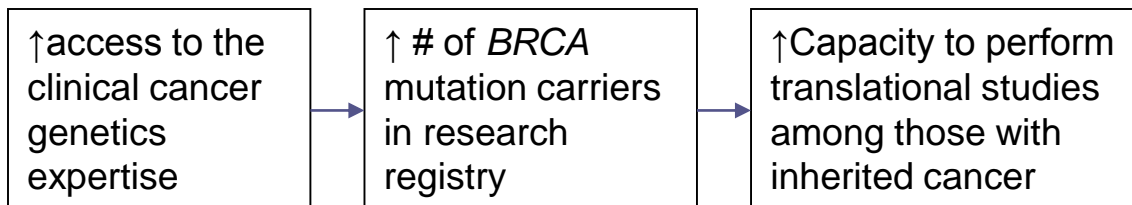
ICARE Grant - 2010

Funding: Florida Biomedical (IBG09-34198)

Grant Objectives:

1. Increase enrollment of *BRCA* mutation carriers to ICARE by 20% yearly.

Target: 1000 *BRCA* carriers by year 5



Number of ICARE Participants

2 2 2 0

Number of *BRCA* Carriers Enrolled

1 0 5 4

Explore ICARE

What is Hereditary Cancer?

Why Participate in ICARE?

Other Research Opportunities

Contact ICARE

Participant Contact Form

Provider Contact Form

www.inheritedcancer.net

ICARE Grant - 2010

Funding: Florida Biomedical (IBG09-34198)

Grant Objectives:

2. Assess adherence to cancer risk management strategies for *BRCA* carriers at the provider and patient level

✓ [Meet the Study Team](#) ✓ [Participants](#) ✓ [Providers](#) ✓ [Gene Specific Efforts](#) [Newsletters](#) ✓ [Our Research](#) ✓ [Contact Us](#)

ICARE Research

Please view the publications, abstracts, and presentations made possible by the Inherited Cancer Registry (ICARE) Initiative, its recruiting providers, and, of course, its participants. Only through these research efforts, will we be able to learn more about inherited cancer susceptibility genes, and determine how to better manage at risk family members and those with inherited cancer.



[Abstracts & Presentations](#)

[Publications](#)

www.inheritedcancer.net

2016

- Cragun et al., *Healthcare: Hereditary Cancer: Example of a Public Health Approach to Ensure Population Health Benefits of Genetic Medicine*
- Gronwald et al., *Fertility and Sterility: Treatment of infertility does not increase the risk of ovarian cancer among women with a BRCA1 or BRCA2 mutation*
- Kotsopoulos et al., *Journal of the National Cancer Institute: Bilateral Oophorectomy and Breast Cancer Risk in BRCA1 and BRCA2 Mutation Carriers*
- Cragun et al., *Genetic Testing and Molecular Biomarkers: Evolution of Hereditary Breast Cancer Genetic Services: Are Changes Reflected in the Knowledge and Clinical Practices of Florida Providers?*
- Iqbal et al., *British Journal of Cancer: The incidence of leukaemia in women with BRCA1 and BRCA2 mutations: an International Prospective Cohort Study*

Patient Participation: Eligibility

Who is eligible?

- Men and Women age 18 and older
- Anyone with an inherited cancer syndrome
- Anyone who appears high risk (hereditary) with a negative or VUS test result
- Current targeted initiatives: PALB2 and PMS2

Gene Specific Efforts:

- PALB2
 - Aim to determine the best treatment for women with a *PALB2* mutation and breast cancer
 - Part of "ICARE umbrella"
 - Commercial lab collaborations
- PMS2
 - Phenotype??



Patient Participation: Expectations

- Patient enrollment/participation facilitated remotely
- Informed consent form
- Questionnaire(s)
 - Initial
 - Follow-up to gather updates
- Copy of genetic test results / pedigree
- Sometimes saliva sample



Provider Expectations

- Inform participant of ICARE initiative
- Obtain permission for ICARE team to contact patient
- By becoming a recruitment site, you would be offering the following to your patients:
 - The opportunity to contribute to research for the future benefit of their families and others
 - Access to new research opportunities as they become available, such as new screening tools or medications for chemoprevention
- Select a recruitment method(s) that works best for your workflow
- Brochures are available



Recruitment Options:

- Online participant contact form
- E-mail patient's information to the study team:
icare@inheritedcancer.net
- Provide patient with an online enrollment card directing them to ICARE website where they can enroll directly
- Complete a prepaid provider postcard and drop it in the mail or fax a copy to the study team's secure fax line (813-449-8403)



Provider Benefits:

ICARE Newsletter

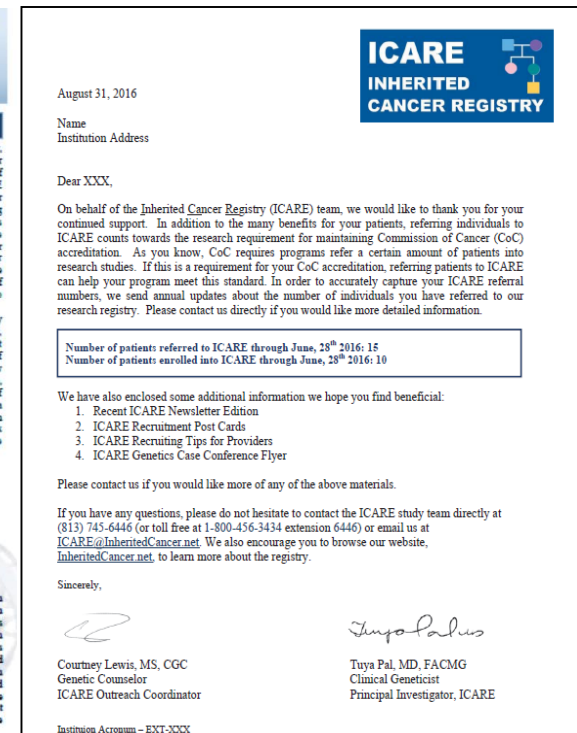
- Electronic and hard copy version

ICARE Referral Number Letters

- Count towards CoC/NAPBC requirements
- Newsletter hard copy to accompany letter

Monthly Case Conference

- Outside cases are encouraged



2017 ICARE Case Conference Schedule

Date	Time (EST)	Focus
Thursday, January 19th	9:30am – 10:30am	Complex Case
Monday, February 20th	1:30pm – 2:30pm	Complex Cases (<i>continued</i>)
Thursday, March 9th	9:30am – 10:30am	Colorectal Cancer
Monday, April 17 th	1:30pm – 2:30pm	Possible Topics include: <ul style="list-style-type: none"> • <i>PALB2</i> • Exome • <i>ATM</i>
Thursday, May 18th	9:30am – 10:30am	
Monday, June 19 th	1:30pm – 2:30pm	

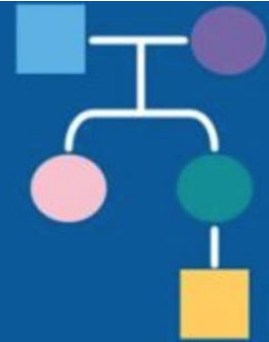
... July topics and dates to be announced!



www.inheritedcancer.net

ICARE

Inherited Cancer Registry



✓ Meet the Study Team ✓ Participants ✓ Providers ✓ Gene Specific Efforts Newsletters ✓ Our Research ✓ Contact Us

English
Español (Spanish)



Explore ICARE

What is Hereditary Cancer?

Why Participate in ICARE?

Enroll in ICARE Now!

Contact ICARE

Welcome to the Inherited Cancer Registry!

"To end the cycle of inherited cancer through research, education, and outreach"

ICARE is a questionnaire-based research study established in June 2010, representing a clinical-research-community partnership among medical practitioners, researchers, and members of the general population. The goal of our research efforts is to maintain a registry of individuals interested in participating in inherited cancer research studies. Through this registry we hope to improve access to cancer genetics expertise for patients and healthcare providers. There is no cost to participate in ICARE and communications can be conducted via phone, email, or mail.

ICARE@inheritedcancer.net



What is Hereditary Cancer?

Why Participate in ICARE?

Participant Resources

Community Spotlight

Enroll in ICARE Now!

Other Research

English



Community Spotlight



Click here to read inspiring stories from our ICARE participants!

ICARE Now!

cycle of inherited cancer through research, education, and outreach

registry, please complete one of the below online Informed Consent Forms. Once you complete the Informed Consent Form, you will be automatically directed to the online questionnaire. You may choose to complete the questionnaire immediately or save and return later. If you have any questions regarding participation, or wish to complete the Informed Consent Form or Initial Questionnaire on paper, please fill out a [participant contact form](#) and a member of the study team will be in contact with you shortly.



Enroll Now (English)

To download a copy of the English Informed Consent Form for your personal records, [click here](#).

Enroll Now (Spanish)

To download a copy of the Spanish Informed Consent Form for your personal records, [click here](#).

[Meet the Study Team](#)
[Participants](#)
[Providers](#)
[Gene Specific Efforts](#)
[Newsletters](#)
[Our Research](#)
[Contact Us](#)

 English
 Español (Spanish)

[Why Recruit for ICARE?](#)
[How to Recruit to ICARE?](#)
[Provider Resources](#)

healthcare providers information and guide

ICARE **INHERITED** **CANCER REGISTRY** **REGISTRO DE CÁNCER** **HEREDITARIO**

To end the cycle of inherited cancer through research, education and outreach

Poner fin al ciclo del cáncer hereditario mediante investigación, educación y extensión a la comunidad



Email/Correo electrónico:
ICARE@inheritedcancer.net

Phone/Teléfono: (813) 745-6446

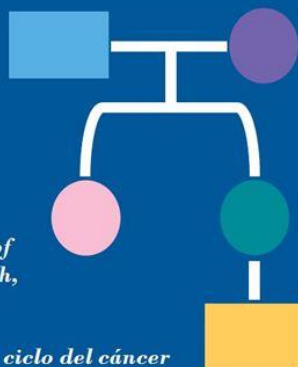
Toll-free/Línea gratuita: 1-800-456-3434 x6446

Website/Sitio web: inheritedcancer.net

ICARE **Inherited** **Cancer Registry** **Registro de cáncer** **hereditario**

"Our mission is to end the cycle of inherited cancer through research, education and outreach."

"Nuestra misión es acabar con el ciclo del cáncer hereditario mediante la investigación, educación y la divulgación."



Unique acronym on the postcards



The Inherited Cancer Registry (ICARE) Initiative represents a clinical-research-community partnership. The common goal of our efforts is to improve the lives of patients and families at risk for inherited cancer. This involves performing research in all aspects of familial cancer spanning from prevention and detection to treatment. Our participants have helped us take an important step towards achieving this goal.

If you are interested in learning more about this initiative, please complete and return this card.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (____) _____ - _____

Email: _____

Date of Birth: ____/____/____

Preferred Contact Method (please check one):

☐ Phone → Please circle: Morning or Afternoon or Evening

☐ Email

Who referred you to ICARE? _____

If you have any questions, please do not hesitate to contact the ICARE study team directly by:

Phone: (813) 745-6446

Toll free: 1-800-456-3434 ext. 6446

Fax: (813) 449-8403

Email: ICARE@moffitt.org

We invite you to visit our Website (www.Moffitt.org/ICARE) and Facebook page (www.facebook.com/ICAREatMoffitt) to learn more about us.

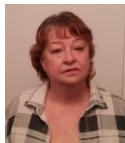
Version 10/2012

Principal Investigator: Taya Pal, MD
 Phone: (813) 745-6239
 Research Study IRB #5893

WHO ARE WE?

- We are a group of scientists who study hereditary breast cancer
- Our research focuses on the prevention and treatment of breast cancer in women with a genetic mutation
- We have studied the treatment of breast cancer in women with a BRCA1 or BRCA2 mutation and how treatment can be personalized for these women
- We now want to understand if we should also personalize treatment for women with a PALB2 mutation who develop breast cancer
- This study is a collaboration between Women's College Hospital in Toronto (Drs. Kelly Metcalfe and Steven Narod) and Moffitt Cancer Center in Tampa, Florida (Dr. Tuya Pal)

"I had negative BRCA testing several years ago, but my strong family history of breast cancer led my breast surgeon to offer me additional genetic testing for several other inherited breast cancer genes (called multi-gene panel testing) once it became available. Through this testing, I was found to carry a PALB2 gene mutation. I have since enrolled in the Inherited Cancer Registry, as I am interested in participating in research in any way that I can to learn more about inherited cancers in people with a PALB2 mutation."



Mari-Lynn Slayton, two-time breast cancer survivor and carrier of a PALB2 mutation

FOR MORE INFORMATION ABOUT THIS RESEARCH STUDY, PLEASE CONTACT OUR STUDY TEAM:

United States: (813) 745-6446
Toll Free: 1(800) 456-3434 x6446
Canada: (416) 351-3800 x2761

Email: ICARE@InheritedCancer.net

Website:
<http://inheritedcancer.net/palb2-study/>

RESOURCES



Inherited Cancer Registry (ICARE)

ICARE's mission is to end the cycle of inherited cancer through research, education and outreach. Through ICARE, we partner with healthcare providers and patients facing inherited cancer risk to meet this goal. To learn more, visit inheritedcancer.net or contact the study team:

Email: ICARE@inheritedcancer.net
Phone: (813) 745-6446
Toll-free: 1(800) 456-3434 x6446



National Society of Genetic Counselors (NSGC)

To locate a genetic counselor near you, please visit: <http://www.nsgc.org>

PALB2

A STUDY TO BETTER UNDERSTAND
BREAST CANCER TREATMENT
AMONG WOMEN WITH A
PALB2 GENE MUTATION



 English
  Español (Spanish)



Explore ICARE

[What is Hereditary Cancer?](#)
[Why Participate in ICARE?](#)
[Enroll in ICARE Now!](#)

Contact ICARE

[Participant Contact Form](#)
[Provider Contact Form](#)

Contact Us

**OUR MISSION IS TO END THE CYCLE OF INHERITED
 CANCER THROUGH RESEARCH, EDUCATION, AND OUTREACH**

**FOR INFORMATION ABOUT ICARE
 PLEASE CONTACT OUR STUDY TEAM:**

Phone: 813-745-6446
Toll free: 1-800-456-3434 x6446
Email: ICARE@inheritedcancer.net
Fax: 813-449-8403
Mail: 12902 Magnolia Drive
MRC-CANCONT-PAL
Tampa, FL 33612

**TO MAKE AN APPOINTMENT FOR
 GENETIC COUNSELING, PLEASE CALL:**

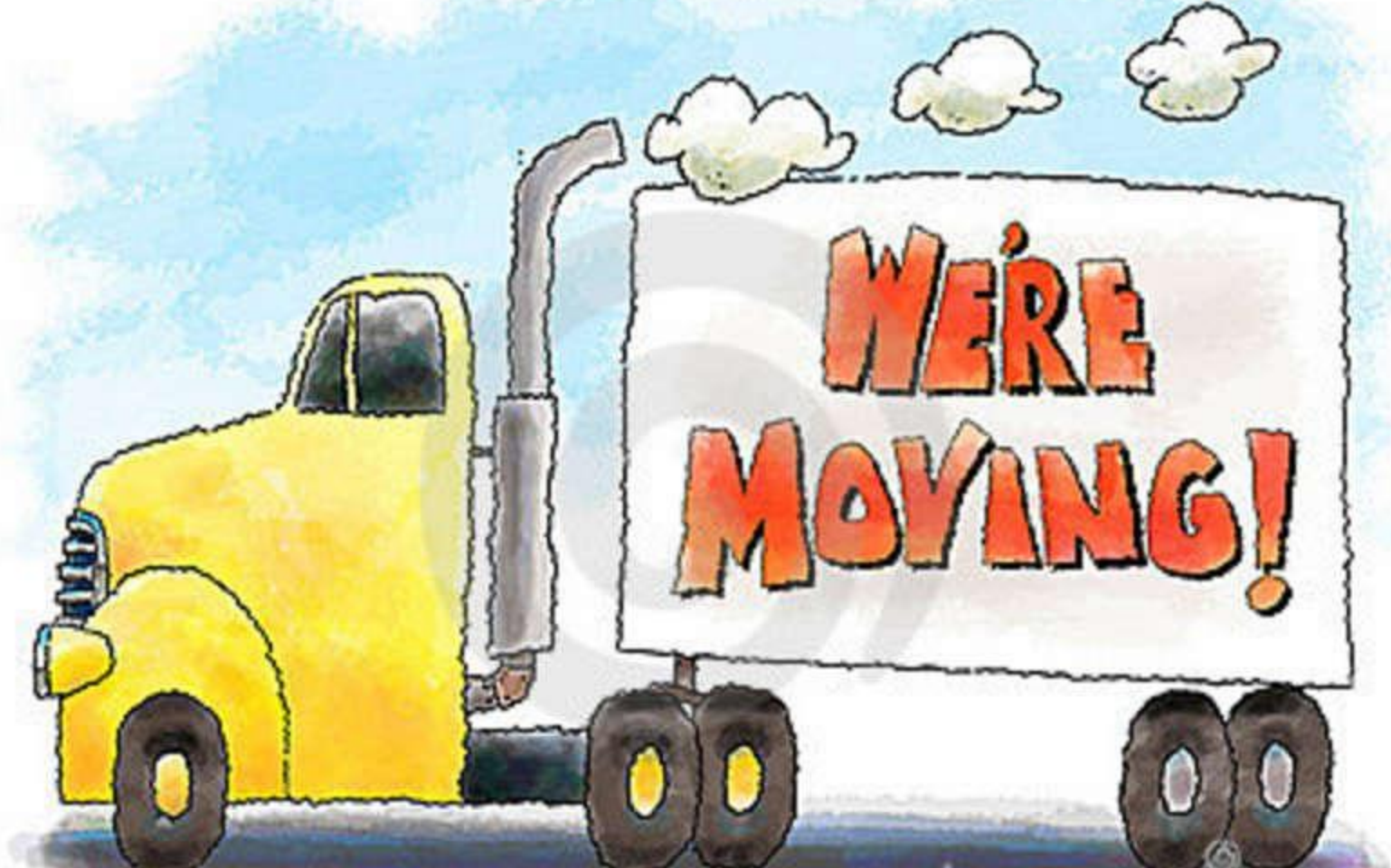
Phone: 813-745-6769
Toll free: 1-800-456-3434 x6769



If you are interested in participating in ICARE, please fill out a [participant contact form](#).
 If you are a provider interested in recruiting for ICARE, please fill out a [provider contact form](#).

[Participant Contact Form](#)
[Provider Contact Form](#)
[Materials Request Form](#)

ICARE Case Conference will be moving to Vanderbilt



Please direct all e-mails to ICARE@inheritedcancer.net
during the transition period

ICARE Benefits

- Generates information to guide the identification and management of individuals at-risk for developing inherited cancers

Provider
<ul style="list-style-type: none">Regular updates through newslettersEducation/Outreach, including monthly virtual case conferences

Patient
<ul style="list-style-type: none">Ongoing contact about other research opportunitiesReceive up-to-date info through periodic newsletters

Center
<ul style="list-style-type: none">Referring patients counts towards COC goals



To request a starter kit:

Email: ICARE@inheritedcancer.net

Phone: (813) 745-6446

Website: www.inheritedcancer.net

Questions?