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Attached is a proof for your review. Please pay particular attention to contact information such as phone numbers, email addresses, web addresses and mailing address.

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Thank you for helping us ensure this information is accurate.



UVA Tissue Bank News

Spring 2017 – Issue 1

Welcome! *A Letter from Dr. Moskaluk*

You are receiving this newsletter because you graciously decided to participate in Partners in Discovery for Total Cancer Care at UVA, a new tissue banking project sponsored by UVA Cancer Center. To date, over 1,100 people have chosen to participate here at UVA. We thank you warmly for volunteering for this new initiative as we seek out new ways to diagnose, treat and prevent cancer.

The purpose of this newsletter is to keep our participants informed about our latest research and undertakings. One of the challenges of tissue bank-centered research is keeping our participants informed as new projects emerge. We hope this newsletter can do just that.

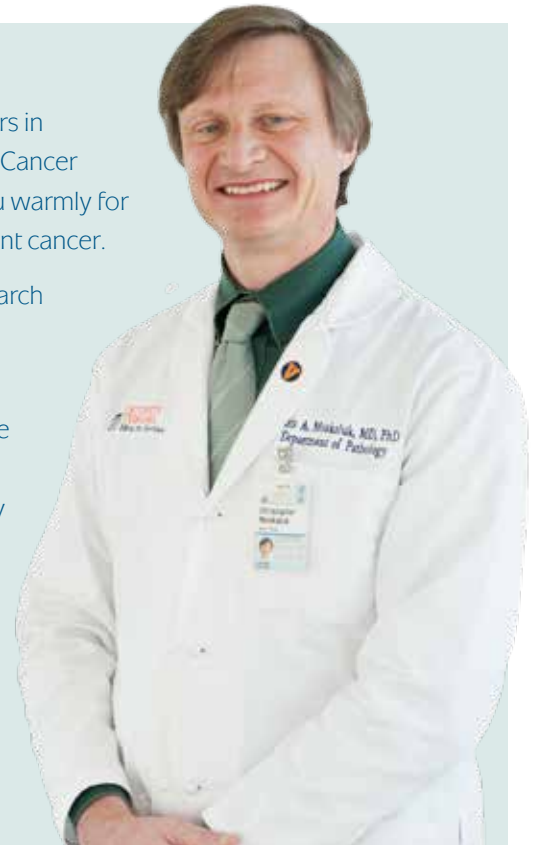
This and future editions of UVA Tissue Bank News will have articles designed to educate you about the basics of tissue banking, current developments in tissue banking and other topics that might be of interest. Your input is very important to us and we strongly encourage all of you to contact us with specific questions about this program so that we can better understand the principles and values of the people we serve.

We hope you find this newsletter informative.

Sincerely,

Chris Moskaluk, MD, PhD

Principal Investigator | Chairman, Department of Pathology



About Our Program

What is Partners in Discovery for Total Cancer Care at UVA?

Partners in Discovery for Total Cancer Care at UVA is a new research initiative through which UVA Cancer Center will build a tissue bank, also called a biorepository, of biological samples for use in current and future medical research. Samples in tissue banks are donated by participants who sign a consent form and agree to have their samples used in medical research.

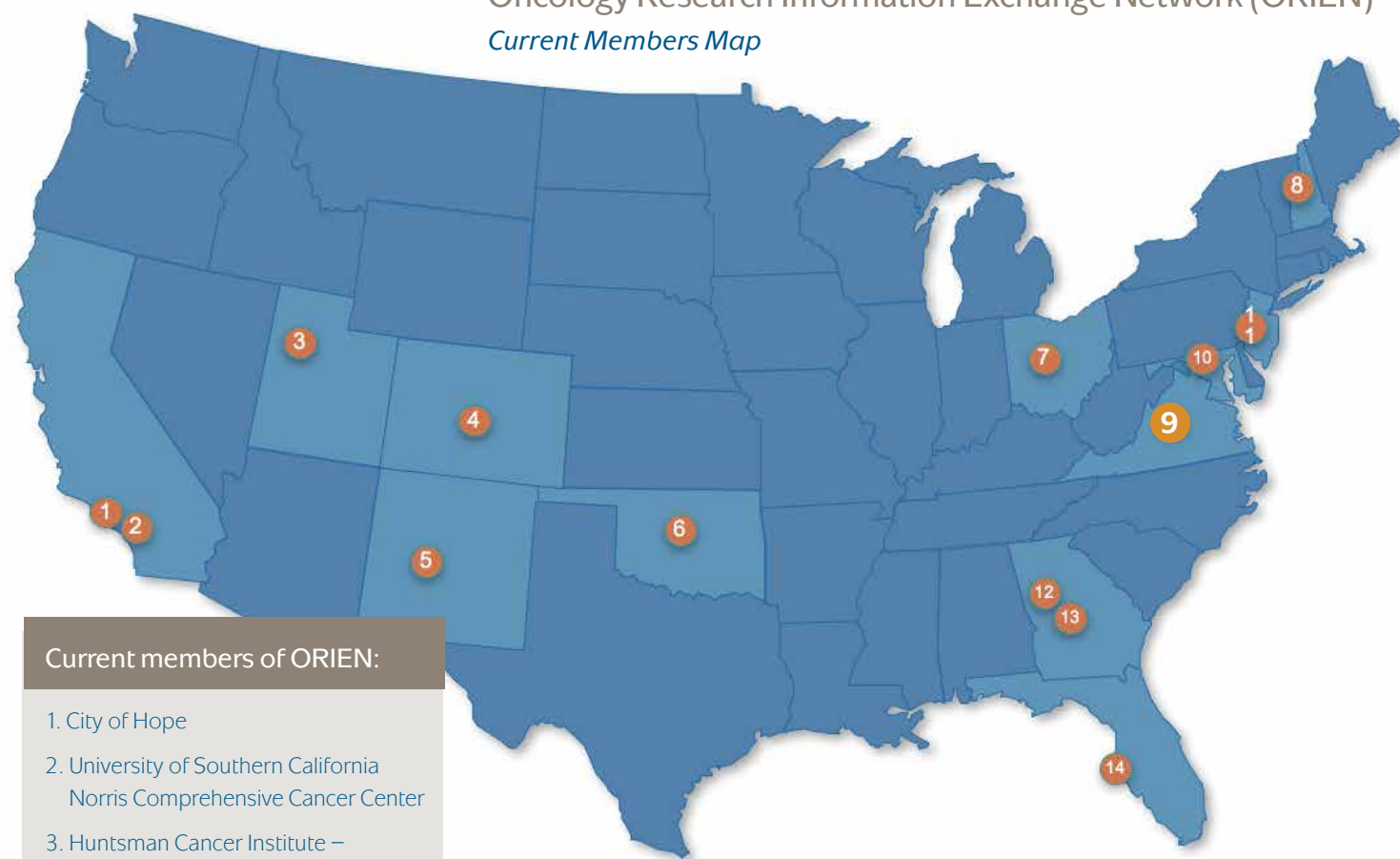
By becoming a participant in Partners for Discovery, you joined a dynamic new research initiative and gave permission for your samples to be used in ongoing medical research conducted at UVA and across the Oncology Research Information Exchange Network (ORIEN).

What is ORIEN?

ORIEN is a network of some of North America's top cancer centers, all of which recognize that collaboration and access

to data are the keys to advancing cancer research. By providing a standard system for tracking participant samples and data, ORIEN provides its members with access to one of the world's largest cancer tissue and data repositories from more than 130,000 participants across the country. By participating in this initiative, UVA will also have access to this shared resource.

Oncology Research Information Exchange Network (ORIEN) Current Members Map



Current members of ORIEN:

1. City of Hope
2. University of Southern California
Norris Comprehensive Cancer Center
3. Huntsman Cancer Institute –
University of Utah
4. University of Colorado Cancer Center
5. University of New Mexico
Comprehensive Cancer Center
6. Stephenson Cancer Center
7. The James – The Ohio State University
Comprehensive Cancer Center
8. Dartmouth-Hitchcock Norris
Cotton Cancer Center
9. **UVA Cancer Center**
10. Henry M. Jackson Foundation
for the Advancement of
Military Medicine
11. Rutgers Cancer Institute of
New Jersey
12. Morehouse School of Medicine
13. Winship Cancer Institute –
Emory University
14. Moffitt Cancer Center

Who was asked to participate?

You were asked to participate in Partners for Discovery if:

- You are 18 years of age or older
- You are or have been a patient at UVA Health System
- You either had cancer previously, have a current cancer diagnosis, are at high-risk for developing cancer down the road or have been evaluated for cancer

What does your participation allow us to do?

- Collect an extra sample of blood during a regularly scheduled lab draw (about four teaspoons)
- Collect and store leftover tissues from previous or future medical procedures
- Review your medical records and share information regarding your diagnosis
- Contact you in the future if we find other studies that you might be interested in

Going forward, we may ask patients if they are willing to provide additional blood samples and cheek cell samples as needed for research purposes.

Learn More: Tissue Banks, Genetic Sequencing and Cancer Research

What is a tissue bank?

A tissue bank is a collection of patient samples that may include blood, tissue or cheek cell samples that are stored for future research. By having access to samples in a tissue bank, researchers can rapidly learn more about the human body and the diseases that affect it. Tissue banks are particularly important in pharmacogenomics, the study of how an individual's genes affect their response to certain therapies.

Additionally, researchers conducting large-scale genome sequencing — the identification of a person's genes — can use tissue banks to obtain access to a wide variety of human samples. Genetic sequencing research in particular may one day allow for treatments that are more tailored to specific individuals.

What is genetic sequencing?

There are many factors that make you a unique person. Your biological traits and the environment in which you live both play important roles in making you the person that you are today. We know that many biological traits are passed down to us from our parents through genes. Genes are the units of information that you inherit from your parents that helped to give you many of the traits that you have, including your eye and hair color, for example.

We know that genes are made up of a substance called deoxyribonucleic acid, or DNA for short. DNA can be thought of as a long string or chain of molecules known as nucleotides. The specific order of the nucleotides on the chain — also known as the sequence — makes up a person's genetic information. This genetic information contributes to a person's

growth, development, function, cellular processes and reproduction.

The process of determining the exact order of nucleotides in a person's DNA is called genetic sequencing. Genetic sequencing is important for medical research because some diseases can be passed to you from your parents through your genes, or from changes to your genetic information that have been caused by your environment. Determining a person's genetic sequence allows scientists to identify specific genes that might contribute to a person's sickness. With this information, researchers might someday be able to create more personalized treatment plans that tailor therapies to an individual's unique genetic profile.

Additionally, some genes might not specifically make you sick, but they might increase or decrease the chance of you developing certain diseases. For example, we know that changes in the genes BRCA1 and BRCA2 are likely to increase a person's risk of developing breast cancer. Changes in these genes stop them from working the way that they are supposed to. Because everyone's genes are different, researchers want to find out more about why some people are more likely to get cancer and other people are not by learning more about changes in genes in people with different types of cancer.

Why is genetic sequencing important for cancer research?

It is now known that the major cause of cancer is the mutation, or changes, of specific genes in some cells in the body. The vast majority of these cancer-causing changes are not inherited, but occur due to exposure to chemicals or damage that

happens to the DNA in some cells during the lifetime of an individual. It takes many such events to create mutations in enough genes to cause a cell to start acting like a cancer cell. But when this occurs, the damaged cell usually starts reproducing itself uncontrollably to form a tumor composed of millions or billions of cells.

Scientists and doctors are still learning about all of the genes and all of the types of mutations that cause specific types of cancers, so the donation of a tissue sample from every tumor is valuable. In some cases, enough research has been done to develop therapies for tumors with specific types of mutations. DNA sequencing of the tumors is then required to determine if these personalized therapies can be used for that patient.

A New Tissue Bank Research Project

Two companies, Takeda Pharmaceutical Company Limited and Celgene, have partnered with ORIEN through the ORIEN Avatar™ Research Program to generate genetic data from select ORIEN participants based on stage and current status of their disease. Understanding and mapping genetic data from participants with various types of cancer has the potential to speed up new cancer research not only here at UVA, but across the United States. Through the agreement, these companies will have access to de-identified genetic information generated by the ORIEN network. De-identified means a person's identity is not connected with the genetic information.

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Electronic Newsletter

Learn more at our website:

cancer.uvahealth.com/totalcancercare

We would like to hear from you. Please email us with your questions, comments and concerns at ORIEN@virginia.edu.

Opt Out of the Newsletter

To opt out of receiving the newsletter, please send an email with your request and full name to ORIEN@virginia.edu.

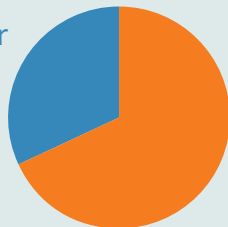
Withdrawal from the Program

If you decide that you would like to withdraw from the program, you may do so at any time without any effect on your care at UVA Cancer Center. Please send an email to ORIEN@virginia.edu or a written letter to:

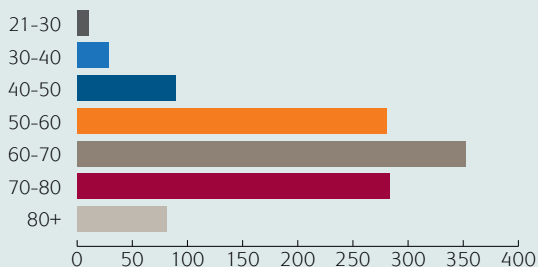
ORIENT Program, c/o Joyce Miller
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Enrollment by Gender

Female 767
Male 358



Enrollment by Age Group



Enrollment by Disease Site

