Platinum Study Newsletter

VOLUME I, ISSUE I SUMMER/FALL 2014

SPECIAL POINTS OF INTEREST:

- We learn about the purpose of the Pt study
- Dr. L. Einhorn shares important insights
- We discuss why genes are so important
- We introduce the research coordinators you see in clinic

INSIDE THIS ISSUE:

About the Study

The Platinum Study is a research study designed to gain new information that can benefit future testicular cancer patients. The purpose of this study is to look at the long term health of men who have been treated for a specific type of cancer with cisplatin chemotherapy. This study is being conducted at a number of cancer centers located in the United States and Canada. We expect approximately 4,000 men to participate in this study at all the institutions combined. This study is funded by the National Institutes of Health in the United States.

You qualified for this study because you were treated for a 'germ cell' cancer with chemotherapy that included a medicine named cisplatin. By signing a consent form and completing all study associated procedures, we believe you are contributing to helping future patients.

This study required you to complete a number of tasks that would give researchers valuable information:

- Completing a confidential questionnaire
- Allowing us to record your vital signs (i.e. height, weight, blood pressure, etc.)
- Giving a blood sample
- Completing a hearing exam
- Allowing us to review your medical records

Once we have collected this data, we will synthesize it and distribute our findings to the medical community. Learning more about you and what we can do in the future to improve your life is our top priority.

We appreciate your participation in the study as we could not complete this research without you. We also look forward to many more years of working with you and appreciate any feedback that you might have on this letter and how we can better serve you.

Important TERMS

Germ Cells: reproductive cells that develop into sperm in males and eggs in females.

(from cancer.gov)

Cisplatin: a platinum-compound chemotherapy drug; it stops cancer cells from growing, causing them to die.

(from www.cancer.org)

Core Study Team

Each cancer center in the study is represented by a doctor who is willing to oversee this research at their institution. We call these dedicated individuals principal investigators (PIs). PIs meet at least once a year to discuss study-related issues and results with other well-known and knowledgeable researchers with expertise in a number of fields. Our next meeting is scheduled in October 2014. Can you spot your PI?

Pictured from the left bottom to right: Lance Pagliaro (MD Anderson), Lois Travis (URMC), Lawrence Einhorn (Indiana), Sophie Fossa (Norway), Nancy Cox (Chicago), Robert Frisina (USF), Robert Miller (Mayo Clinic), Derick Peterson (URMC), Les Robison (St. Jude), Malcolm Moore (Princess Margaret), Howard Sesso (BWH), Clair Beard (DFCI) , Darren Feldman (MSKCC), Chunkit Fung (URMC).

Featured Clinician: Dr. Lawrence Einhorn

Dr. Einhorn from Indiana University Cancer Center

Our featured clinician scientist in this issue is Dr. Lawrence Einhorn. Dr. Einhorn is a Distinguished Professor of Oncology at Indiana University Cancer Center. He is well-known for pioneering the life-saving treatment for testicular cancer almost 40 years ago. These treatments have been recognized for improving the survival rates of patients with advanced testicular cancer from 5% in the 1970s to about 80% in the 2000s. Dr. Einhorn is not only a researcher and professor, but also a charismatic physician who continues to see patients at his cancer center in Indiana, and oversees a vibrant training program for young doctors. We are proud to have Dr. Einhorn's expertise when looking to study complex issues that arise after survival of testicular cancer as he has an understanding of the disease, the treatment, and all patient concerns. The FAQ's shown below represent questions that Dr. Einhorn's patients often ask him. Given your participation in the Platinum Study, Dr. Einhorn has also volunteered to personally address any questions that you might have, and can be reached directly at LEinhorn@iupui.edu

Any questions that you might have may also appear below in a future issue, just so that others can benefit.

Frequently Asked Questions with Dr. Einhorn

"...there are potential late consequences of chemotherapy that a standard history and physical examination and routine blood tests can help to uncover."

I completed chemotherapy 5 years ago and my doctor suggests that I need continuous follow-up on an annual basis. Is this really necessary ?

Dr. Einhorn: I strongly urge you to continue with the annual follow-up. First of all, for unknown reasons, about 2% of patients seemingly cured will experience a late relapse beyond 5 years. This usually happens when a patient has no symptoms and is picked up by a routine blood test such as a serum alphafetoprotein (AFP). These late relapses are still highly curable, with surgery alone and not needing chemotherapy, as long as it is detected when it is localized and relatively small. Secondly, there are potential late consequences of chemotherapy that a standard history and physical examination and routine blood tests can help to uncover. Thirdly, 1% of patients who are cured of testis cancer will develop a second cancer in the other testis. Self-examination is important, but also a physician evaluation and inspection of the remaining testis is still needed.

I have heard a lot about low serum testosterone, including in television and magazine advertisements. Do you think I need supplemental testosterone? I also read about side effects from testosterone. Should I be concerned if I need testosterone?

Dr. Einhorn: Some patients who have had removal of a testis, with or without platinum-based chemotherapy, will experience an abnormally low testosterone level. Symptoms include erectile dysfunction (difficulty having and maintaining an erection), weakness and fatigue, depression, irritability, and insomnia. When women go through menopause, they experience hot flashes. When a man has a low serum testosterone level, he will sometimes develop increased sweating at night or just generalized increased sweating. In addition to the above mentioned symptoms, a blood test for serum testosterone can be done and this is best performed in the early morning. If it is low, especially in the presence of symptoms, replacement testosterone can be given as an injection every 2-3 weeks, a gel that is applied to the skin, or an underarm preparation. Testosterone, when used illegally to try to build muscle mass and gain an athletic advantage, is associated with side effects. Replacing what your body needs and doesn't have, because of either the missing testis or the chemotherapy, should not be associated with any side effects.

Is there anything that I can do to prevent any of the late consequences associated with platinum-based chemotherapy?

Dr. Einhorn: You should pursue a healthy lifestyle. Most important is to be a non-smoker. If you currently smoke, stop smoking. Regular exercise and weight control and healthy diet are also important. Routine medical evaluation to periodically check for lipids such as cholesterol and to monitor blood pressure are likewise of value. Although the incidence of late consequences from platinum chemotherapy is very low, it still exists and these are some of the things that can be easily done to reduce the probability.

Why do we collect blood?

We collect a few tablespoons of your blood during the study because we want to learn more about how the treatment you received for testicular cancer could have been helped or hindered by your genetics.

The genetic testing to be done with your blood is strictly confidential and a new federal law, the Genetic Information Nondiscrimination Act (GINA), makes it illegal for entities (health insurance companies, group health plans, or employers) to discriminate against you based on genetic information.

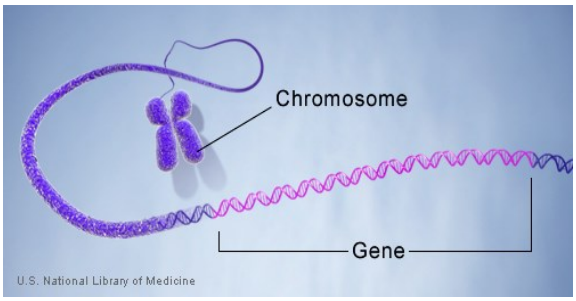
Our goal is to protect you and to learn ways to improve the lives of survivors like yourself!

"Most genes are the same in all people, but a small number of genes (less than 1% of the total) are slightly different between people"

What is a gene?

A gene is the basic physical and functional unit of heredity. Genes, which are made up of DNA, act as instructions to make molecules called proteins. In humans, genes vary in size from a few hundred DNA bases to more than 2 million bases. The Human Genome Project has estimated that humans have between 20,000 and 25,000 genes.

Every person has two copies of each gene, one inherited from each parent. Most genes are the same in all people, but a small number of genes (less than 1 percent of the total) are slightly different between people. Alleles are forms of the same gene with small differences in their sequence of DNA bases. These small differences contribute to each person's unique physical features.



- from The Genetics Home Reference: ghr.nlm.gov/handbook/basics/gene

Chemotherapy-Induced Neuropathy (CIPN): What is it?

CIPN is an enduring and sometimes irreversible condition consisting of pain, numbness, tingling and sensitivity to cold in the hands and feet (sometimes progressing to the arms and legs). It is experienced by up to 30-40% of patients receiving chemotherapy, especially platinum-based types like cisplatin, oxaliplatin, and carboplatin.

Signs of CIPN include: pain (may be there all the time or come and go, like shooting or stabbing pain); burning; tingling ("pins and needles" feeling) or electric/shock-like pain; loss of feeling (can be numbness or lessened ability to sense pressure, touch, heat, or cold); trouble using your fingers to pick up or hold things, or dropping things; balance problems; trouble with tripping or stumbling while walking; pressure hurting more than usual; temperature hurting more than usual (mostly cold, aka cold sensitivity); and shrinking muscles.

If you are experiencing any of the above, please contact your physician right away so that your symptoms can be managed as effectively as possible.

(from www.cancer.org)

Coordinator's Corner

Health Project Coordinators are essential to the operations of any study, as they interface directly with you, and serve as the eyes and ears for the study's Principal Investigators. In this regard, their attention to detail as they care for you and also their commitment to the study is important. Everything they ask you has been carefully considered by the entire Study Team. The Coordinators recently met in Rochester, New York where they carefully reviewed all the study details and how they could better serve you, especially as we go forward. If there is a specific coordinator that you would like to recognize, please email the study PI at your site, and we will feature them in a future issue. Also, please add what you appreciated about them so that we can provide them with the recognition that they so richly deserve.

Profile

Eileen Johnson, MS, RN (URMC)

Eileen has worked at the University of Rochester since 1984, starting out in patient care on a medical unit at the hospital. She earned a master's degree in nursing from the U of R in 1993, and has many years of research coordinator experience working with federally funded Alzheimer's research programs. Eileen was a study coordinator and project nurse for the Rochester Aging Study within the Center for Neural Development and Disease prior to joining the Platinum Study.

Coordinator's Meeting 2014

Can you spot your Coordinator ?

Pictured from the left bottom to right: Seher Gul (URMC), Eileen Johnson (URMC), Lois Travis (URMC), Lynn Anson-Cartwright (Princess Margaret), SarahLena Panzer (UPenn), Jackie Brames (IU), William Osai (MD Anderson), Deborah Silber (MSKCC), Somer Case-Eads (IU), Geri Pumper (Mayo), Marissa Velez (URMC), Melissa Worman (URMC).

Survivorship on the Web

United States:
American Cancer Society
www.cancer.org

Centers for Disease Control
www.cdc.gov

LiveStrong Foundation
www.livestrong.org

National Cancer Institute
www.cancer.gov

National Cancer Survivors Day
www.ncsd.org

National Coalition for Cancer Survivorship
www.canceradvocacy.org

Canada:
Canadian Cancer Society
www.cancer.ca

Canadian Cancer Survivor Network
www.survivornet.ca

Did You Know?

It's almost time for fall/winter sports...and there are some testicular cancer survivors out there who play professional football or hockey!

Josh Bidwell
Green Bay Packers/Tampa Bay Buccaneers/Washington Redskins

Phil Kessel
Boston Bruins/Toronto Maple Leafs

Andrew McDonald
Carolina Panthers