

# Platinum Study Newsletter

VOLUME 1, ISSUE 2

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## SPECIAL POINTS OF INTEREST:

- We update you very briefly on the study's progress
- We discuss why questionnaires are so important
- We discuss how you can further help the study by helping your coordinator

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## A Platinum Study Update

The Platinum Study now has over 800 participants throughout the U.S. and Canada. As we continue to enroll, we have already begun to synthesize the valuable data provided by you and your peers. This preliminary information has already undergone scientific review, with one abstract presented at the February 2015 Genitourinary Cancer Symposium of the American Society of Clinical Oncology (GU ASCO), two abstracts presented at the May 2015 American Society of Clinical Oncology (ASCO) Annual Meeting in Chicago, and a fourth abstract at the Multinational Association of Supportive Care in Cancer Survivors (MASCC) in Denmark this June. Thus, your generosity in participating in this study is providing new, scientifically important information that is being presented at national and international meetings.

The preliminary study results examine more closely the following topics after platinum-based chemotherapy:

- The types of hearing loss that may be due to cisplatin-based chemotherapy
- Various health conditions
- Cardiovascular disease risk factors
- The frequency of use of psychotropic medications (antidepressants and stimulants)

As always, all data are presented in aggregate with complete protection of your privacy. We thank you for your valuable contributions to this research as we continue to examine these topics and many more.

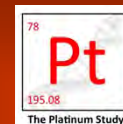


## The Platinum Study Website is Coming Soon!

Stay on the lookout. In the next newsletter, we will tell you more about a new website for The Platinum Study. It will keep you updated about research results, study activities, and health promotional information to help you stay fit. If you have any ideas about what you would like on this website, please let your research coordinator know.

Sports Illustrated features an article about testicular cancer survivors Lance Armstrong and Asher Price. Price writes the article which puts the spotlight on our study's own Dr. Larry Einhorn. You can find this article in the April 6, 2015 edition of Sports Illustrated or on the web at:

<http://www.si.com/more-sports/2015/04/06/lance-armstrong-asher-price-cancer-indiana>



**Featured in Sports Illustrated**



Dr. Beard  
from Dana-Farber  
Cancer Institute at  
Harvard Medical School

“Testicular cancer  
is the most  
common cancer  
among men age  
15 to 39 years old”

## Featured Clinician: Dr. Clair Beard

Our featured clinician scientist in this issue is Dr. Clair Beard. Dr. Beard is a genitourinary radiation oncologist with a special interest and expertise in the health outcomes of patients with both prostate and testicular cancer. She is the Director of the Testicular Cancer Center at Dana-Farber/Brigham and Women’s Cancer Center as well as an Associate Professor of Radiation Oncology at Harvard Medical School. Dr. Beard is working to develop a survivorship clinic where patients can be screened for late effects of testicular cancer and its therapies.

Dr. Beard lectures nationally and internationally on testicular-cancer topics and has co-authored the National Comprehensive Cancer Network follow-up guidelines for testicular cancer patients. These guidelines are used extensively by oncologists both within and outside the United States. She has also written three sections on testicular cancer for Up to Date, an on-line reference tool used by patients and physicians. Dr. Beard has a very large testicular cancer practice and is dedicated to keeping her patients healthy both before and after treatment.

## 40th Anniversary Celebration of Einhorn’s Effective Treatment

Dr. Lawrence Einhorn, the physician scientist who developed the curative treatment regimen for testicular cancer, was honored this past September. He tested the platinum-based drug Cisplatin with two additional drugs and found they were effective at killing testis cancer cells in September of 1974. This treatment dramatically improved the survival rate from approximately 5% to the 95% survival rate we see today. An estimated 300,000 survivors can celebrate this anniversary as well. Dr. Einhorn continues to work with testicular cancer patients and research. We are proud to have Dr. Einhorn as a valued and prestigious member of our research team for the Platinum Study and congratulate and recognize his accomplishments over the last 40 years.

Sources:

- <http://editor.des08.com/vol?FileID=a67cd5c5-f397-44f7-9ccd-8f6a9de81365&ListID=19824>
- <http://jco.ascopubs.org/content/32/28/3085>

## Quick Epidemiological Facts About Testicular Cancer

Who develops testicular cancer?

- Testicular cancer is the most common cancer among men age 15-39 years old. The incidence of testicular cancer has been increasing in many parts of the world over the past few decades, and research is ongoing to understand the underlying reasons for this observation.

How many diagnoses are there on average?

- 6 in every 100,000 White males
- 1 in every 100,000 African American males
- 2 in every 100,000 Pacific Islander males
- 4 in every 100,000 Hispanic males

Are there occupations that have higher rates of testicular cancer?

- Yes: Miners, Food processing workers, utility workers, and leather workers are at a higher risk.

What other risk factors influence the risk of testicular cancer?

- The strongest risk factor for testicular cancer is a family history of the disease.

Sources:

<http://healthresearchfunding.org/famous-people-testicular-cancer/>  
<http://www.mass.gov/eohhs/docs/dph/environmental/investigations/cancer/cancer-risk-testicular.pdf>

Important

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**Epidemiology:** the study of the occurrence of disease in populations  
(from Merriam-Webster dictionary)

**Risk Factor:** any attribute, characteristic or exposure of an individual that increases the likelihood of developing a disease or condition.  
(from the World Health Organization website)

# Why ask so many questions?



One of the study procedures you may recall completing is a questionnaire. It may have been tedious at the time but it offers researchers a wealth of information. This questionnaire offers us a unique opportunity to learn about your health directly from you. Beyond questions about your age and ethnicity we ask about your activity level, lifestyle habits, medical history, current medications, family history, and your general health from your point-of-view. We can discover associations between these things when we examine this information in conjunction with other data we receive directly from testing or

your medical record. Every moment you spend filling in this valuable information could help us to identify new information that is critical to not only testicular cancer survivors, but survivors of many other cancers who have received platinum-based chemotherapy.

***“The American Cancer Society suggests that every cancer survivor could benefit from some additional support.”***

## Emotional Health after Cancer

There tends to be a negative stigma related to having emotional health concerns in both historical and modern times. Receiving a diagnosis of cancer, participating in treatment, and ultimately surviving can certainly be taxing on any individual. Even small adjustments such as not seeing your medical team as much after treatment, may make undesirable thoughts and feelings arise. The American Cancer Society suggests that every cancer survivor could benefit from some additional support. Support comes in many forms: family, friends, cancer support groups, online support communities, church or spiritual groups or even one-on-one counselors. Finding the best fit for your personality is important.

In many cases, your Cancer Journey can create feelings of loneliness, but you are not alone. If you are unsure of how to access support, please contact your physician or the American Cancer Society (1-800-227-2345) for assistance



- image from [www.copyblogger.com/emotional-copywriting](http://www.copyblogger.com/emotional-copywriting).

- from “How might testicular cancer affect your emotional health” <http://www.cancer.org/cancer/testicularcancer/detailedguide/testicular-cancer-after-emotional-health>



## A Platinum Study Researcher’s Story:

AnnaLynn Williams is a researcher working on the Platinum Study. She shared her cancer story with Rochester’s [Democrat and Chronicle](#) newspaper this past month. Her experience with having acute myeloid leukemia (cancer of the blood and bone

marrow) for which she underwent a bone marrow transplantation has added to her passion for research. Williams is cancer-free and working on the Platinum study as a part of her education at the University of

Rochester to earn a Ph.D. in epidemiology.

You can learn more about her story at: <http://www.democratandchronicle.com/story/lifestyle/2015/04/20/woman-watch-annalynn-williams/26075099/>

## Achieving A Healthy Lifestyle After Cancer

A healthy lifestyle is important for any person. However, after surviving cancer, making an effort to become as healthy as possible takes on new importance. Most doctors agree that a healthy lifestyle is composed of physical activity, a well-balanced diet with portion control, and the elimination of practices, such as tobacco use. Cancer survivors have a terrific opportunity to navigate various sources of information about healthy habits and then tailor them to fit life after cancer treatment. Below are some sources that cater directly to cancer survivors' needs:

- <http://www.cancer.org/treatment/survivorshipduringandaftertreatment/behealthyaftertreatment/index>
- <http://www.cancer.gov/cancertopics/causes-prevention/risk/weight-activity/physical-activity-fact-sheet>
- <http://www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-topics/survivorship/survivorship-nutrition-guide.pdf>
- <http://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20044015>

## Coordinator's Corner

Your Health Project Coordinators have been busy! They are diligently working to enroll you and your peers so that we can gain as much quality information about testicular cancer survivors as possible. If you are wondering what you can do to improve the quality of data you have provided us with, you can do the following:

- **Be sure to completely fill-out the study questionnaire; especially sections highlighted by your coordinator.**

*This is your opportunity to give your point-of-view to the researchers.*

- **Give a blood sample as soon as possible.**

*This sample will help us study genetic variants associated with cisplatin-based toxicities.*

- **Complete your audiometry visit.**

*We use state-of-the-art audiometry to learn more than ever before about hearing after cisplatin-based chemotherapy in TC survivors .*



### Somer LeAnn Case-Eads, MA (IU-SCC)

Ms. Case-Eads is a home-grown Hoosier who has worked at the Indiana University School of Medicine for 7 years. She earned a master's degree in Sociology from Indiana University and then found a passion for clinical research. Prior to the Platinum Study, she was a study coordinator in Adolescent Medicine, then Psychiatry for adolescents with Schizophrenia. Her career in cancer research began in breast cancer and germ cell tumors. She now coordinates many research studies: sexual health, diabetes, and cancer survivorship. Somer hopes to one day become the director of a research program that promotes healthy behaviors and improves quality of life for cancer survivors.

Somer also recently became a first-time mom to a baby boy, and loves being a mom more than anything else. Outside of work, she enjoys camping with family, hiking, fishing, flipping (e.g. remodeling) homes, and watching all sports.