

# The *Visionary*

THE EYE CANCER FOUNDATION NEWSLETTER | FALL 2017

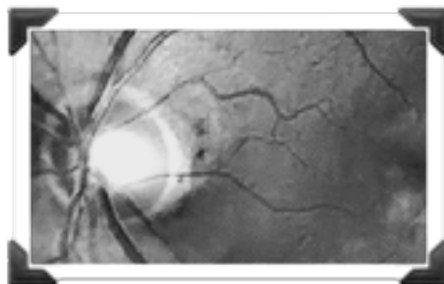
## *Saving Sight, Saving Lives*®

EDUCATION AND SUPPORT FOR EYE CANCER PATIENTS  
AND THEIR FAMILIES

**WORKING DAY**



**A NEW STUDY**



**AND MORE!**



**Read on to learn the latest in eye cancer research and care!**





# 2017 EYE CANCER WORKING DAY A PHENOMENAL SUCCESS

## THE GLOBAL EFFORT

*Our* latest Winter edition of *The Visionary* left off announcing and anticipating a meeting in which ocular oncologists from around the world gathered in the unified cause of advancing the field of eye cancer. This global event, [The Second Eye Cancer Working Day](#), was supported by The Eye Cancer Foundation, International Society of Ocular Oncology, and American Joint Committee on Cancer. The meeting took place on March 24<sup>th</sup>, 2017 at the International Convention Center in Sydney, Australia and was attended by world-renown leaders in ocular oncological care — such as, Drs. Bitá Esmali, Tero Kivelä, Paul T. Finger, Wolfgang Sauerwein, Santosh G. Honavar, and many more.

The Working Day provided a unique opportunity for eye cancer specialists from around the world to work together, face-to-face. The goal, continuing from the groundwork laid during the First Working Day in Paris,

France, was to help the subspecialty move forward into the mainstream of oncological care. The day was divided into five sections, each lead by a convener, and each dealing with critical problems faced in the ocular oncology specialty.

They were as follows:

### SESSION 1: Comprehensive Open Access Surgical Textbook (COAST)

Authors who coordinated various sections of this oncology surgical guide presented their work at various levels of completion. Participants offered welcomed suggestions to make each chapter both more comprehensive and better focused toward outreach to help doctors in underserved areas of the world.

### SESSION 2: Ophthalmic Radiation Side Effect Registry (RASER)

Presenters discussed information relating to a grading system for ophthalmic radiation side effects. Committed participating centers

were announced, and there was an outreach to include new partners. Questions were raised that helped to modify the staging systems and create data fields for this 20-center registry.

### SESSION 3:

#### Fellowship Outreach Retinoblastoma (FOR-RB)

The proposed curriculum for fellowship training in retinoblastoma management was opened for discussion. Input from participating experts from various training institutes was documented. Excellent feedback offered by participants will be used to help finalize the first curriculum for ophthalmic oncology fellowship education.

### SESSION 4:

#### Doctor Reported Outcomes (DRO)

Dr. Kivelä utilized an hour-long question and answer period to help guide ophthalmic oncology toward outcome reporting. Participants discussed available methods for data collection related to DRO aimed to improve quality assurance of centers worldwide. Subjects ranging





from online reporting of published outcomes to prospective collection of outcome data were also discussed. Additionally, participants considered the results of an ongoing multicenter project of Patient Reported Outcomes (PRO).

### **SESSION 5: Multicenter International Registries (MIR)**

New, completed, and ongoing international multicenter projects were summarized. The panel highlighted accomplishments, including retrospective registry-derived answers to important clinical questions related to choroidal melanoma staging, the failure of local control, retinoblastoma staging, and ocular adnexal lymphoma.

Ongoing registries were enumerated and attendees were invited to participate. These included vitreoretinal lymphoma, conjunctival melanoma, and eyelid tumors. The process and requirements for participation of new centers in the registries was also discussed. Dr. Zeynel

Karcioglu called for the establishment of a chemotherapy side effects registry (in consideration of the advent of intra-arterial chemotherapy for retinoblastoma (IAC) and the many biotherapies with ophthalmic side effects).

The day was concluded with discussion by Drs. Paul Finger, Martine Jager, Ashwin Mallipatna, Brenda Gallie, Tero Kivelä, Wolfgang Saurwein, and Bitá Esmali relating to future courses of action. Dr. Finger strongly suggested that the WD initiatives should be part of the International Society of Ophthalmic Oncology (ISOO), noting that most cancer subspecialties have them, and that ISOO committees need be formed to move forward.

The efforts of the Eye Cancer Working Day's do not end when the bags are packed and the participants return to their countries. Indeed, The Working Day Eye Cancer initiative lives on with another successful dinner meeting at the AAO 2017. The 'Working Day Dinner' at

AAO-2017 was hosted on November 9th at the famous *Arnaud's Restaurant* in New Orleans, Louisiana. Dr. Brenda Gallie discussed "Big Data Registries" that collect both prospective and retrospective information for retinoblastoma, conjunctival melanoma, intraocular lymphoma and radiation side effects. Dr. Sonal Chaugule discussed the upcoming open access, eye cancer surgical textbook. Dr. Bertil Damato discussed doctors outcomes reporting through the Iris Registry. Dr. Paul Finger remarked on The Eye Cancer Foundations work with the ICO helping train eye cancer specialists to work in unserved countries, as well as underscored that all these initiatives are part of an ongoing effort to streamline the field; with every day comes new ideas, new plans, and new steps forward.

*The Working Day efforts will continue with another dinner to be announced in Barcelona, Spain during the upcoming World Ophthalmic Congress organized by the International Council of Ophthalmology.*

# A NEW SUPPORT GROUP FOR EYE CANCER PATIENTS!



*S*tress and anxiety following treatment for choroidal melanoma have been well recognized among patients and studied among doctors. Fighting against cancer is an emotional journey. And although research confirms that it is common to feel stress following a cancer diagnosis, many patients agree

that having a solid support system is crucial to finding one's bearings and coming to terms with “a new normal” — both of which are important in overall quality of life.

Friends and family can be excellent support systems, but there can also be a benefit to sharing and working through feelings with other patients who have had very similar experiences. This is why The Eye Cancer Foundation sponsors The New York Eye Cancer Center Support Group, an emotional outlet for eye cancer patients, survivors, and family.

Facilitated by Licensed Clinical Social Worker, Karen Campbell, there have been three successful meetings thus far. These close-knit sessions provide mutual compassion and understanding for what patients are going through on a personal and psychological level, as well as relaxation exercises offered by Mrs. Campbell.

A support system cannot be limited simply due to travel inconveniences — hence, members unable to attend in person are able to phone in. Whether first-time attendees or newcomers, members expressed that the sessions have eased their anxieties by reassuring them of the fact that they are not alone. If you are a patient, a survivor, or a family member of an eye cancer patient and you need to obtain support and have your voice heard, consider attending these sessions by [contacting](#) The Eye Cancer Foundation.

*We hope to see you soon!*





AJCC  
American Joint Committee on Cancer

# AJCC Cancer Staging Manual

*Eighth Edition*

—  
**DEVELOPING A  
COMMON  
LANGUAGE  
FOR EYE CANCER  
SPECIALISTS**  
—

*The Ophthalmic Oncology Task Force (OOTF) led by Chair Dr. Paul T. Finger is building a foundation of multicenter, international consensus guidelines to allow for better communication and patient care*





**“SHARING A COMMON SCIENTIFIC LANGUAGE (STAGING SYSTEMS) ALLOW US TO COMMUNICATE OUR IDEAS AND ENABLE PROGRESS” – DR. PAUL T. FINGER**

Communication is vital in nearly all areas of life, and the medical field makes no exception. In order for doctors to compare their results, they must describe the stage (size and distribution) of the cancer they are treating. This is the only way oncologists can effectively discuss and coordinate the care for patients around the world. And towards this goal, Dr. Finger as Chair of the Ophthalmic Oncology Task Force for The American Joint Committee on Cancer has worked over 12 years to create, write, and publish three editions of The AJCC Cancer Staging Manual and most recently its sister equivalent for the UICC.

As Dr. Finger explains in *Foundational Elements for*

*Collaboration in Ophthalmic Oncology* (a recent editorial published for the American Academy of Ophthalmology) the AJCC staging system was made from the collective effort of 10 subcommittees, composed of more than 50 eye cancer specialists from 18 countries. These doctors came together to develop a clinically useful textbook describing, with rigorous detail, the methodology of classifying eye cancers. In fact, working together, these systems represent the greatest consensus work ever created by the eye cancer specialty.

You may have heard of a tumor classified as “stage 2” or “stage 4”, benign or malignant, and so on, but

“During the 6 years since the previous edition, each subcommittee undertook a new, detailed review of the literature. Then, multiple teleconferences and face-to-face discussions were led to achieve consensus regarding methods of ocular tumor diagnosis and treatment. With this foundation, tumor-specific committees (uveal melanoma, retinoblastoma, ocular adnexal lymphoma, orbital sarcoma, orbital carcinoma, eyelid carcinoma, conjunctival melanoma, conjunctival carcinoma) decided how eye cancer patients should be TNM staged.” — [Foundational](#)

[Elements for Collaboration in Ophthalmic Oncology](#)



## TOUGH DECISIONS WERE MADE CONCERNING THE MATURITY OF RAPIDLY ACCUMULATING NEW EVIDENCE

“Examples of new evidence include genetic prognostication of uveal melanoma (eg, gene expression profiling, BAP1, and others) as well as the subdividing stages of in situ conjunctival melanoma. These controversies stress the need for more data collection and a continuously evolving AJCC-UICC staging system.

The addition of a new biomarker, “H,” to form TNMH for retinoblastoma is most exciting. **For the first time, the AJCC has allowed heredity to be part of cancer staging.** This pioneering decision was based on clear medical evidence we presented to the AJCC Editorial Board. Just as Knudson’s hypothesis on RB gene discovery led to understanding the genetic link between genetics and retinoblastoma, ophthalmology is leading the way into a new world of genetically-based cancer staging.” — [Foundational Elements for Collaboration in Ophthalmic Oncology](#)

have you wondered how doctors come to this conclusion?

Staging a tumor relies on rules on how to measure and locate tumors in the eye and/or throughout the body. By gathering a large profile of data from 3,500 tumor patients, the AJCC team has also analyzed how tumor size or failure of initial treatment can be used to predict the risk for metastasis.

The AJCC-UICC tumor staging allows every eye cancer specialist from the United States to Indonesia to describe each patient's cancer in a standardized way, which proves to be tremendously useful for eye cancer specialists otherwise unable to access international resources. It provides descriptions of the size, shape,

and distribution of the primary eye tumor, as well as the involvement of lymph nodes, or its spread within the body. Using the AJCC-UICC eye cancer classification, each medical professional can now effectively communicate the exact extent of each patient's local and systemic cancer.

*As a result of an intensive world-wide effort, the eighth edition of the AJCC Cancer Staging Manual is the most clinically useful TNM-based staging system for ophthalmic oncology.*



### \* FACT !

The Eighth Edition of the AJCC Cancer Staging Manual includes 12 new staging systems, re-defined staging definitions, and a refreshed look on personalized care in the medical field



### \* FACT !

The Eighth Edition of the AJCC Cancer Staging Manual is available electronically as well as in print via the Springer Publishing website. Click below:

<http://cancerstaging.org>



# EYE CANCER FOUNDATION FELLOW PUBLISHES STUDY ON CHEMOTHERAPY SIDE EFFECTS

*A paper co-authored by Dr. Bikramjit P. Pal highlights a study conducted under the guidance of Dr. Tero Kivelä while supported by a fellowship grant provided by The Eye Cancer Foundation. Dr. Pal worked under Dr. Kivelä at the Helsinki University Eye Hospital during a six-month fellowship from October 2015 through March 2016. During the fellowship, they conducted a study to follow the course of blood-brain barrier disruption maculopathy in a patient undergoing treatment for relapsed central nervous system lymphoma.*

## ILLUMINATING THE FIELD OF EYE CANCER THROUGH SUSTAINED RESEARCH

A primary central nervous system (CNS) lymphoma is a cancer inside the skull. Thankfully rare, CNS lymphomas account for about 3% of central nervous system cancers. Chemotherapy treatment is difficult due to the blood-brain barrier, a highly selective semipermeable membrane that separates circulating blood from the brain. Because many substances can't pass through it, the blood-brain barrier protects the brain from most pathogens, but also limits the effectiveness of many chemotherapy agents.

A process called blood-brain barrier disruption (BBBD) can improve chemotherapy effectiveness in patients suffering from central nervous system lymphoma. The process involves the infusion of a warm hyperosmotic agent that allows the chemotherapy drugs to cross the barrier. BBBD results in a higher concentration of the drug by a

factor of 50 to 100 times as compared with the standard intravenous route.

But, there are risks involved in this BBBD-aided mode of treatment. Because the eye is part of the CNS and also shielded by the blood brain barrier, BBBD can cause a complication known as maculopathy. Maculopathy is damage to the macula (the functional center of the retina) resulting in a progressive loss of central vision. Mild to moderate loss of visual acuity (VA), and a non-progressive nature, are the hallmarks of this condition in patients undergoing BBBD.

The study followed a 57-year-old patient diagnosed with central nervous system large B-cell lymphoma. He had a normal ophthalmic evaluation on his first visit. He was treated with blood-brain barrier disruption therapy and intra-arterial methotrexate with minimal eventual loss of visual acuity to 20/32 in his right eye and 20/25 in his left.



The study helped track the progression of maculopathy and provides some insight into the processes involved. It will certainly pave the way for further study.

“Although the maculopathy seems to be non-progressive and non-vision threatening, and the BBBD therapy usually is life saving as it was for our patient and cannot be abandoned, patients need regular follow-up as the full spectrum of this condition is probably not yet completely understood. Future studies incorporating fundus autofluorescence and OCT angiography may help in this regard.”

Dr. Pal acknowledged the support of The Eye Cancer Foundation fellowship grant in the paper.

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## **THE ECF OFFERS FELLOWSHIPS TO DOCTORS FROM UNSERVED AND UNDERSERVED COUNTRIES**

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The [fellowship grants](#) offered to eye cancer doctors by The Eye Cancer Foundation provide specialized training in the treatment of retinoblastoma and other eye cancers. Once they complete their training, The Eye Cancer Foundation fellows commit to return home to create eye cancer treatment programs. Dr. Pal, for one, plans to begin oncology services at a tertiary eye care facility in Kolkata, India. This center serves a huge population, not only in eastern India, but also in the neighboring countries of Nepal and Bangladesh where access to quality care for eye cancer is severely limited.

The fellowship program offered by the The ECF has proven exceptionally successful so far, with 12 fellows already having been trained and more to come. Most recently, Dr. Milly Shakoor from Bangladesh has begun a fellowship with Dr. Santosh Honavar in Hyderabad, India, and Dr. Abhilasha Maheshwari from India is studying under the tutelage of Dr. Paul T. Finger in New York City, United States.

Through its [2020 Campaign](#), The Eye Cancer Foundation plans to multiply this success story across the world. With your help, we can train 20 eye cancer specialists to work in 20 countries by 2020. Our immediate 2020 Campaign goal is to save the lives of 1,000 children by 2020. But that's only the beginning.

Our ability to train doctors and supply them with the equipment they need to properly diagnose and treat retinoblastoma is only limited by the generosity of our donors. You can become part of the cure with your continual support of The Eye Cancer Foundation's ongoing campaigns.



**DR. KIVELÄ (LEFT) WITH DR. PAL IN SIENNA, ITALY. DR. PAL WAS INVITED TO SIENNA TO PRESENT RESEARCH WORK HE PERFORMED IN HELSINKI DURING HIS FELLOWSHIP**

# WE CAN DO SO MUCH, BUT ONLY WITH YOUR HELP!



## THE EYE CANCER FOUNDATION ANNUAL APPEAL

As the year draws to close, as we round out the end of 2017 with holidays celebrating unity, generosity and love, now comes the time for reflection. The year 2017 marked great, landscaping efforts in the field of eye cancer research and training from The Eye Cancer Foundation, culminating perhaps most fantastically with the profound success of *The Second Eye Cancer Working Day* held in Sydney, Australia,

among many other exciting projects. The achievements of this year have served as poignant reminders that hard work and focused philanthropy can support great progress. These accomplishments, shared throughout our buzzing [website](#), could not be completed without the generous help of donors. For this, the volunteers at The Eye Foundation are extremely grateful.

Your support enables The ECF team to provide much needed fellowship opportunities for new eye cancer specialists from previously unserved countries. As you may know, 7,000 babies with retinoblastoma die each year in the less developed

world. The ECF has made a priority of training eye cancer specialists for these countries and will need to support them upon their return. [The 2020 initiative](#), which aims to train 20 retinoblastoma doctors in 20 underserved countries, has already provided fellowship education for 12 deserving ophthalmologists. The ECF's partnership with The International Council of Ophthalmology (ICO) enables this, ensuring the quality of training these fellows receive. It is through your support that these fellowships were established with success, and because of this, children who were born to less fortunate circumstances have a chance at vision and life.

The ECF is especially excited to have sponsored The Second Eye Cancer Working Day, an event bringing together eye cancer specialists from around the world, which embodied much of what The Foundation is all about. In the Working Day, there were sections on developing big data registries used to answer questions that could not be addressed by single center studies. There were initiatives for standards in fellowship education, Dr. Tero Kivelä presented an initiative to promote doctors reporting their clinical outcomes. In addition, The ECF's open access surgical text and movie atlas was highlighted, and will become public within the next sixth months.

Your gift today demonstrates your dedication to supporting an exciting, functional, and deeply important effort to promote multi-center and international cooperation in ophthalmic oncology. Your gift today will save both vision and lives all over the world. With so much to look forward to, The ECF team hopes they can count on your support.

Please consider making your gift to The Eye Cancer Foundation today, and be a crucial part in this fight against eye cancer today by visiting <http://eyecancercure.com/donate>.