

# Visionary

The Eye Cancer Foundation, Inc.



## The First Eye Cancer Working Day

The Eye Cancer Foundation continues to promote multicenter, international cooperation

Supported by The Eye Cancer Foundation, The AJCC-UICC Ophthalmic Oncology Task Force developed the first universally accepted staging system "language" for ophthalmic oncology. We also sponsored the first international, multicenter, "consensus" guidelines for ophthalmic plaque brachytherapy of choroidal melanoma and retinoblastoma.

On June 15<sup>th</sup>, 2015 at the Curie Institute – Paris The Eye Cancer Foundation is supporting the first international eye cancer "Working Day." We have invited over 500 eye cancer specialists and have an ambitious agenda to "Save Sight and Save Lives" all over the world.

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### Fellowship Education

We support international clinical training in order to make sure each country has at least one eye cancer specialist.

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### Ophthalmic Pathology

The ECF supports international ophthalmic pathology education and research in Liverpool, England.

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### A Message from US!

ECF sponsored research is presented at major ophthalmic meetings and published in the most important journals.

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## Fellowship

A photograph showing Dr. Santosh Honavar with his Eye Cancer Foundation sponsored fellow, Dr. Doan Le Trang from Vietnam. At his Centre for Sight, Dr. Trang's training focused on the care of children with retinoblastoma.

The Eye Cancer Foundation has a mission to educate ophthalmologists returning to their underserved or unserved countries.

Therefore, The Eye Cancer Foundation tries to make sure our fellows have the most useful experience possible.

## International Eye Cancer Fellowships for Countries Without a Specialist

The Eye Cancer Foundation coordinated fellowship eye cancer education for Dr. Doan Le Trang. She is now the first internationally fellowship trained eye cancer specialist in Vietnam. She is practicing at The Vietnam National Institute of Ophthalmology.

Studying with Dr. Santosh Honavar in Hyderabad's Centre For Sight, Dr. Trang was involved in the care of over 250 children with retinoblastoma. Now trained in the management protocols used for advanced retinoblastoma, she will establish the first retinoblastoma Service in Vietnam. Clearly, The Eye Cancer Foundation has been instrumental in bringing specialty eye cancer care to Vietnam.

Then The Eye Cancer Foundation continued to support Dr. Honavar's teaching program. He has also trained Dr. Jyoti B. Shrestha from Nepal. Her Indian fellowship with Dr. Honavar will allow her to return with an educational experience that will most closely prepare her to treat pediatric eye cancers in Nepal.



The Eye Cancer Foundation is grateful to Dr. James Muecke ([sightforall.org](http://sightforall.org)) of Adelaide, Australia for helping us locate the right candidates for ECF support.

## RETINOBLASTOMA WORLD

Like many eye cancers, retinoblastoma seems like two diseases. In western countries almost all children survive (even if they develop metastatic disease). This is because most western retinoblastomas are discovered early, thus when local treatment or eye removal is curative.

In contrast, retinoblastoma in under-developed countries is more often discovered late, even too late for local treatment. In these sad cases,

babies and their families only choice is palliative therapy to keep them "comfortable."

At The Eye Cancer Foundation, we believe that more research is needed to focus on treatment of advanced retinoblastoma. We want to see a cure for advanced retinoblastoma within 10-years.

*Right now, early detection and ECF-sponsored clinical training offers our best chance to save vision and children's lives around the world.*



## Ophthalmic Pathology Training in Liverpool, England

Dr. Sarah Coupland Teaches Ophthalmic Pathologists from the USA and Brazil

Liverpool offers a unique opportunity for trainees and specialists in pathology as well as scientists seeking clinical training in ocular oncology. This is because Liverpool Ocular Oncology Centre (one of the leading ocular oncology referral centers in England) is led by Prof. Heinrich Heimann, maintains a close collaboration with the Liverpool Ocular Oncology Research Group (LOORG) ([www.loorg.eu.com](http://www.loorg.eu.com)) and is led by the internationally respected eye pathologist Prof. Sarah Coupland.

Recently sponsored by the The Eye Cancer Foundation, Dr Chandrani (Rani) Chattopadhyay from MD Anderson Cancer Center (left photograph) successfully completed a fellowship at LOORG. Similar to Prof. Coupland's team, Rani has a particular interest in uveal melanoma, the most common cancer arising in the eye in adults. Unfortunately, close to half of uveal melanoma patients, develop

secondary (and often fatal) tumors in the liver, despite adequate treatment of the eye. Rani and LOORG worked together on cell lines, and cell culture models to understand and determine uveal melanoma drug sensitivities.

This year, LOORG is hosting another ECF Fellow. Dr. Iguaracyra (Cyra) Araujo, a consultant pathologist from Bahia, Brazil (right photograph). Cyra has great expertise in lymphomas, tumors that arise from cancerous white blood cells. These tumors can occur inside the eye as well as in the surrounding tissues (eyelids, orbits and conjunctiva). Together, Prof. Coupland and Dr Araujo are comparing and analyzing ocular lymphomas from Brazil and England for certain genetic changes, aiming to better understand how they arise. Around the world, The Eye Cancer Foundation's support continues to enable collaborative research to better understand and cure eye cancer.



# Working Together

Outreach | Fellowship | Collaboration | Education

## Endorsements

The First Eye Cancer Working Day is endorsed by the International Society of Ophthalmic Oncology (ISOO), the American Joint Committee on Cancer (AJCC), the Commission on Cancer (COC), the American Brachytherapy Society (ABS), The European Ophthalmic Oncology Group (EOOG), the American College of Surgeons, and the International Council of Ophthalmology (ICO).

## Funding

The Working Day event is supported by the Eye Cancer Foundation (ECF) and the Curie Institute. Ten ECF travel awards have been made available to young investigators treating eye cancer patients in underserved countries.

## Purpose

Participants will focus on projects that we cannot accomplish on our own and those better accomplished as a multi-center, international effort. Initiatives are directed at raising the quality of care for all eye cancer patients.



On June 15th, 2015, The Eye Care Foundation and Curie Institute will host the First Eye Cancer Working Day event. The Working Day will be divided into several sections, each dealing with a critical problem facing our specialty. Interactive group sessions will be used to brainstorm, complete work, and plan for the next meeting. The Working Day will be located at the Curie Institute in Paris, France.

## Our Agenda



### AJCC-UICC Staging Registry Project

Moderators: [E. Rand Simpson](#) and [Brenda Gallie](#), Canada

The ongoing, retrospective multi-center, international data-sharing registry project has been completed for uveal melanoma. Currently recruiting studies include conjunctival melanoma, intraocular lymphoma, and retinoblastoma. There is still much needed work on other eye cancers. This session will be used to coordinate, recruit, and expand these initiatives.



### Radiation Side Effect Staging Project

Moderator: [Wolfgang Sauerwein](#), Germany

The 2014 American Brachytherapy Society (ABS) consensus guidelines strongly suggested establishment of staging for ophthalmic radiation side effects. This committee is tasked to create a universal staging system for ophthalmic radiation side effects.



### Doctors Reported Outcomes "DRO's"

Moderator: [Tero Kivela](#), Finland

The ocular oncology community would benefit from periodic outcome reporting. There will be privacy issues; however, multi-center cooperation for the benefit of our patients can be built stage-by-stage. Established guidelines for outcome reporting would help us better compare and thus improve our results.

Continued...



### International Fellowship Programs

Moderator: [Laurence Desjardins](#), France

There are many countries with no identifiable eye cancer specialist. Our community needs to develop an ongoing program to eliminate this discrepancy within 10-years. There will be discussion of funding mechanisms and coordination with existing programs like the International Council of Ophthalmology.



### Basic Surgical Techniques

Moderator: [Santosh Honavar](#), India

The Commission on Cancer (COC) recommends the development and publication of basic standard surgical techniques for the world-wide eye cancer community. This group will define which operations need be included and assign writing groups.



### Collaborative Protocols

Moderator: [Sarah Coupland](#), UK

This group will coordinate current and prospective, multi-center, international research and clinical protocols. Many such studies exist and need expansion to aid in their significance. This will be an opportunity to share and expand our initiatives.



### Pathology Outreach

Moderator: [Hans Grossniklaus](#), USA

Eye cancer specialists should define basic standards for evaluation of eye cancer specimens to elevate the level of care in underserved countries. This group will consider developing an international telepathology initiative.



### Patient Reported Outcomes "PROs"

Moderator: [Bertil Damato](#), USA

Physicians typically measure the success of their treatments in terms of objective outcomes. However, there is a movement towards including the patient experience into the metrics driving health care decisions. This group will discuss the utility and implementation of "Patient Reported Outcomes."

## Message from The Eye Cancer Foundation



**2014** was a great year for the ECF and the world of ophthalmic oncology. We supported fellowship education around the world, presented important original research work at all the most important international ophthalmic scientific meetings and then published that work in major ophthalmic journals. Our social media presence includes separate **patient** and **doctors** forums on Facebook. In fact, our patient forum hosts nearly 500 people.

**2015** promises to be an even better year. The first official ECF sponsored "working day" will help fulfill our mission to promote multicenter, international cooperative studies. However, we never forget that we could not accomplish all this great work without your support. Thank you for all you have done and what you will continue to do to make this possible! Best regards, Paul T. Finger, MD

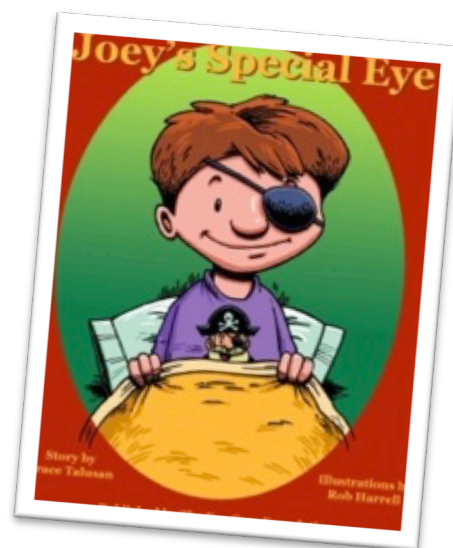
## Happiness can be found in giving to others!

*Don't wait for another day or for someone else to get this done!*

The Eye Cancer Foundation is interested in promoting multicenter, international cooperation to find the best methods for diagnosis and treatment of eye cancers. However, we cannot do this without your support. Please consider a yearly donation to continue and expand the research and educational activities as described in this Visionary.

There are opportunities to name programs specifically funded by individual donors, provide named funds for specific purposes and legacy funds in memory of loved ones.

The best time to support The Eye Cancer Foundation is now!



## SAVING SIGHT, SAVING LIFE!

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*We can do so much, but only with your help!*