



The First Eye Cancer Working Day

**CURIE
INSTITUTE**
Amphithéâtre
Constant Burg
12, rue Lhomond
75005 Paris
France

MONDAY, JUNE 15TH 2015

WORKING TOGETHER

Outreach | Fellowship | Collaboration | Education



One day prior to the ISOO Meeting, The Eye Cancer Foundation, The Curie Institute and The American Joint Committee on Cancer are hosting The First Eye Cancer Working Day event.

The Working Day is divided into several sections, each dealing with a critical problem facing our specialty. Sections begin with an overview presentation from the moderators, followed by an interactive group session to brainstorm, complete work, and plan for the next meeting.

The Eye Cancer Working Day is located at the Curie Institute, Paris, France. There was no fee to participate; however, due to limited space, pre-registration was required.

INTRODUCTION



WORKING TOGETHER

Outreach | Fellowship | Collaboration | Education

THERE IS POWER IN NUMBERS



- 140 Eye Cancer Specialists
- From every continent
- All have come to participate
- To do for and with others
- Projects we cannot do alone



THE FIRST EYE CANCER WORKING DAY

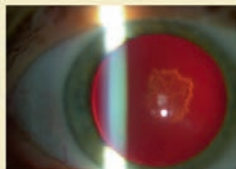
The Eye Cancer Foundation - The Curie Institute - American Joint Committee on Cancer

MULTICENTER INTERNATIONAL REGISTRIES



- Validate staging systems
- Evaluate methods of diagnosis
- Evaluate methods of treatment
- Encourage cooperation
- Create a specialty based EHR and prospective data collection

RADIATION SIDE EFFECTS



- Evaluate site-specific toxicity
- Create staging systems
- Use that system to compare radiation treatments
- Improve informed consent

DOCTOR REPORTED OUTCOMES



- Establish **community** benchmark results
- Compare your center to others
- Discover how to improve your results
- Results based government funding

RETINOBLASTOMA FELLOWSHIPS



- Unacceptable 70% WW mortality
- Training physician advocates
- Arming them with standardized protocols
- Addressing the psychosocial aspect
- Early detection and prompt treatment
- What will be our 10-year goal?

BASIC SURGICAL TECHNIQUES



- Basic standards and techniques
- Required equipment
- Need and role for pathology
- Open access

PATIENT REPORTED OUTCOMES



- Old: Random surveys / comments on healthgrades.com or vitals.com
- New: Quality of life measures
- A way to improve the patient experience.
- A whole new set of results!

Welcome to The First Eye Cancer Working Day

“**Today you are** the change
you want to see in the world.”

– *Ghandi*

PROGRAMME AT A GLANCE

08:00 AM Welcome Coffee, Tea and Pastry

> Morning: 08:20-12:00 AM

08:20-08:30 Introduction to The First Eye Cancer Working Day, *Finger*

08:30-09:30 Multi-Center, International Studies, AJCC Validation, Registries,
Moderators: Simpson, Gallie, Coupland, Saakyan, Heegaard, Damato, Esmaeli, Pavlick

09:10-09:30 Discussion

09:30-10:30 Radiation Side Effect Staging Project,
Moderators: Sauerwein, Westekemper, Kiilgaard, Mosci, Bornfeld, Tena, Dendale

10:10-10:30 Discussion

10:30-11:00 Coffee Break

11:00-12:00 Doctor Reported Outcomes (DROs) Project,
Moderators: Kivela, Seregard, Damato, Honavar, Shields

11:30-12:00 Discussion

12:00-01:00 PM Lunch Break

> Afternoon: 01:00-05:00 PM

01:00-02:00 Retinoblastoma Fellowships For Underserved Countries Project,
Moderators: Desjardins, Grossniklaus, Gabel, Dimaras, Honavar, Finger

01:36-02:00 Discussion

02:00-03:00 Basic Surgical Techniques Project
Moderators: Honavar, Shields, Esmaeli, Grossniklaus, Manjandavida, Finger

02:40-03:00 Discussion

03:00-03:30 Coffee Break

03:30-04:30 Patient Reported Outcomes (PROs) Project
Moderators: Damato, T. McCannel, C. McCannel, Hope-Stone, Villaroman

04:10-04:30 Discussion

04:30-05:00 Summary and General Session for Future Planning
Moderators: Finger, Kivela, Coupland, Simpson, Desjardens, Gallie, Sauerwein, Grossniklaus, Gabel, Honavar, Damato, T. McCannel

SCIENTIFIC PROGRAMME

08:00 AM Welcome Coffee, Tea and Pastry

> **08:20-08:30 AM Introduction to The First Eye Cancer Working Day,**
Finger

> **08:30-09:30 AM Multi-Center, International Studies, AJCC Validation, Registries**
Moderators: Simpson, Gallie, Coupland, Saakyan, Heegaard, Damato, Esmaeli, Pavlick

- | | |
|--------------------|--|
| 08:30-08:35 | The Power of Registries,
<i>E. Rand Simpson</i> |
| 08:35-08:40 | The Uveal Melanoma Registry First Results,
<i>Svetlana Saakyan</i> |
| 08:40-08:45 | Retinoblastoma Registry Update,
<i>Brenda Gallie</i> |
| 08:45-08:50 | Ocular Adnexal Lymphoma Registries,
<i>Steffen Heegaard</i> |
| 08:50-08:55 | Conjunctival Melanoma Registry Update,
<i>Bertil Damato</i> |
| 08:55-09:00 | Vitreoretinal Lymphoma Registry Update,
<i>Sarah Coupland</i> |
| 09:00-09:05 | Eyelid Carcinoma - Lacrimal Gland Carcinoma Registries,
<i>Bita Esmaeli</i> |
| 09:05-09:10 | A Metastatic Uveal Melanoma Registry,
<i>Anna Pavlick</i> |

> **09:10-09:30 Multi-Center, International Studies, AJCC Validation, Registries**

DISCUSSION

Moderators: Simpson, Gallie, Coupland, Saakyan, Heegaard, Damato, Esmaeli, Pavlick

- Other possible registries?
- Standards for data collection, privacy?
- Qualifications for who enters the data, centers?
- Writing, internal peer-review and authorship?
- Cost, funding, can all the eye cancer foundations help?
- Retrospective to prospective, are we ready yet?

> **09:30-10:30 AM Radiation Side Effect Staging Project**

Moderators: Sauerwein, Westekemper, Kiilgaard, Mosci, Bornfeld, Tena, Dendale

- 09:30-09:40** Why Stage Radiation Side Effects,
Wolfgang Sauerwein
- 09:40-09:45** Lids, Conjunctiva, Limbus and Cornea,
Henrike Westekemper
- 09:45-09:50** Staging Radiation Cataract,
Jens Kiilgaard
- 09:50-09:55** Radiation induced Neovascular Glaucoma,
Carlo Mosci
- 09:55-10:00** Posterior Segment Radiation Complications,
Norbert Bornfeld
- 10:00-10:05** Maximal Tolerated Doses to Ocular Structures,
Lawrence Tena
- 10:05-10:10** Specific Side Effects After Radiotherapy in Children,
Remi Dendale

> 10:10-10:30 Radiation Side Effect Staging Project

DISCUSSION

Moderators: Sauerwein, Westekemper, Kiilgaard, Mosci, Bornfeld, Tena, Dendale

- Should staging be purely based on anatomic changes or eye function?
- Separating brachytherapy from teletherapy for staging?
- Betas, gammas, protons, electrons – should they be treated differently?
- How to stage radiation cataract, location, visual acuity, contrast sensitivity?
- Staging iris neovascularization or just neovascular glaucoma?
- Staging radiation retinopathy, papillopathy and optic neuropathy?
- Formation of committees and a road map

10:30-11:00 AM Coffee Break

> 11:00-12:00 AM Doctor Reported Outcomes (DROs) Project

Moderators: Kivela, Seregard, Damato, Honavar, Shields

- 11:00-11:10** Why Should We Periodically Report Our Outcomes?
Tero Kivela
- 11:10-11:15** Is Peer Review Publication Reporting Good Enough?
Stefan Seregard
- 11:15-11:20** The Risks and Benefits of Open Access Reporting,
Bertil Damato
- 11:20-11:25** The Risks and Benefits of Closed Access Reporting,
Santosh Honavar
- 11:25-11:30** Data collection and patient privacy,
Carol Shields

> 11:30-12:00 Doctor Reported Outcomes (DROs) Project

DISCUSSION

Moderators: Kivela, Seregard, Damato, Honavar, Shields

- How do we ensure the best quality data is collected?
- Who is collecting the data, EMR data vs. retrospective analysis?
- How can we provide a mechanism to report our outcomes?
- Can we perform an internal, society generated quality review?
- Should our goal be an anonymized central registry?
- Organizing a DRO exploratory committee to make recommendations to the group.

12:00-1:00 PM Lunch Break

We advise you to have lunch in Le Jardin du Luxembourg

> 01:00-02:00 PM Retinoblastoma Fellowships For Underserved Countries Project

Moderators: Desjardins, Grossniklaus, Gabel, Dimaras, Honavar, Finger

- 01:00-01:07** Retinoblastoma: 1 Name, 2 Diseases and 70% World Mortality,
Laurence Desjardins
- 01:07-01:12** The Kenyan Experience,
Helen Dimaras
- 01:12-01:17** The Curie Experience, *Laurence Desjardins*
- 01:17-01:22** Cost and Efficacy of Training in Developing Countries,
Santosh Honavar
- 01:22-01:27** Providing Pathology to Underserved Countries,
Hans Grossniklaus
- 01:27-01:34** How the ICO Coordinates Fellowship Programs,
Peter Gabel
- 01:34-01:36** The Eye Cancer Foundation and Princess Margaret Hospital Cooperation,
Paul Finger

> 01:36-02:00 Retinoblastoma Fellowships For Underserved Countries Project

DISCUSSION

Moderators: Desjardins, Grossniklaus, Gabel, Dimaras, Honavar, Finger

How best to provide fellowship trained ophthalmic oncologists for every unserved country within 10 years?

- Identifying the countries
- Identifying the candidates
- Cost effective training
- Preserving existing programs, while coordinating efforts
- The need for internationally accepted RB treatment protocols
- Early detection programs
- Psychosocial intervention for families
- Cost effective administration of Fellowship Programs

> 2:00-03:00 PM Basic Surgical Techniques Project

Moderators: Honavar, Shields, Esmaeli, Grossniklaus, Manjandavida, Finger

- 02:00-02:10** The Need for an Open-access Eye Cancer Surgical Technique Guide,
Santosh Honavar
- 02:10-02:15** Eyelid Tumors Excision,
Fairooz P Manjandavida
- 02:15-02:20** Conjunctival Tumor Excision,
Carol Shields
- 02:20-02:25** Plaque Brachytherapy,
Paul T Finger
- 02:25-02:30** Enucleation and Exenteration,
Santosh Honavar
- 02:30-02:35** Orbital Tumor Biopsy/Excision,
Bita Esmaeli
- 02:35-02:40** Effect of Histopathology on Surgical Technique,
Hans Grossniklaus

> 02:40-03:00 Basic Surgical Techniques Project DISCUSSION

Moderators: Honavar, Shields, Esmaeli, Grossniklaus, Manjandavida, Finger

- Set up writing committees
- Equipment standards
- Internal peer review
- External peer review
- Publication

03:00-03:30 Coffee Break

> **03:30-04:30 PM Patient Reported Outcomes (PROs) Project**

Moderators: Damato, McCannel, McCannel, Hope-Stone, Villaroman

- 03:30-03:39** What are PROs?
Bertil Damato
- 03:39-03:46** The Liverpool Experience,
Laura Hope Stone
- 03:46-03:53** The Los Angeles Experience,
Tara and Colin McCannel
- 03:53-04:00** The San Francisco Experience,
Andrea Villaroman
- 04:00-04:10** PRO future directions: How working groups can be used to standardize data collection for sharing and comparing reported outcomes.
Tara McCannel

> **04:10-04:30 Patient Reported Outcomes (PROs) Project DISCUSSION**

Moderators: Damato, McCannel, McCannel, Hope-Stone, Villaroman

- How have these influenced your practice/improved your patient care?
- How to get started in your center?
- Data collection and patient privacy?
- What to do with the data?
- Giving your patients feedback
- Data sharing (local, governmental and publications)
- Multicenter PRO data comparisons

> **04:30-05:00 PM Summary and General Session for Future Planning**

Moderators: Finger, Kivela, Coupland, Simpson, Desjardins, Gallie, Sauerwein, Grossniklaus, Gabel, Honavar, Damato, McCannel

YOUR LUNCH IN “LE JARDIN DU LUXEMBOURG”

Situated on the border between Saint-Germain-des-Prés and the Latin Quarter, the Luxembourg Gardens, inspired by the Boboli Gardens in Florence, were created upon the initiative of Queen Marie de Medici in 1612. The gardens, which cover 25 hectares of land, are split into French gardens and English gardens.



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CME CREDITS

THE FIRST EYE CANCER WORKING DAY has been accredited by the European Accreditation Council for Continuing Medical Education (EACCME) to provide the following CME activity for medical specialists. Please fill in the form given with your badge at the welcome desk and bring it back to our hostesses from Monday afternoon onwards. You will then receive your Certificate for CME credit points.

OUR MODERATORS



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 (ACS)
- The International Council of Ophthalmology (ICO)

The First Eye Cancer Working Day was supported by:

- The Eye Cancer Foundation (ECF)
- The Curie Institute
- The American Joint Committee on Cancer (AJCC)



The First Eye Cancer Working Day

Welcome to Paris! It is a great pleasure to see so many like minded eye cancer specialists seize the opportunity to meet and work together. Care was taken to select 6 projects that either can only be done or are best accomplished by our eye cancer specialists as a community.

As Chair of the 7th and now the 8th edition, AJCC-UICC Ophthalmic Oncology Task Force I was in charge put together representative groups that have shared their knowledge. In the subsequent committee meetings, it becomes clear that no one person can claim ownership to all the knowledge in our specialty and that no external group knows how to care for eye cancer patients better than us!

There exists a vast reservoir of untapped knowledge and surgical expertise that we just don't share. It's not that we are selfish, but peer-review publications and academic presentations just aren't enough. It is going to take working together as a group, sharing experience and data to bring out the best each and every one of us has to offer.

The fact you are here means we have started this process!! As a beginning, our colleagues have created a number of independent eye cancer registries, each involving the cooperation of at least 100 eye cancer specialists from around the world. New registries are open and wish that you join them and others are just in the planning stage. However, this is only the beginning. Today we have come together to start a process that has the power to shape our profession.

We will start to work on addressing the world-wide problem of retinoblastoma mortality, the need for staging of radiation side effects, for periodically reporting both doctor and patient outcomes as well as the need to establish basic, open-access community generated guidelines for eye cancer surgery. There exist many places around the world where there are no eye cancer specialists, but the internet is in reach... let us teach those generalists willing to help until we can place a trained eye cancer specialist within reach.

Today's event could not have been possible without the support of Dr. Laurence Desjardins, the Curie Institute, the American Joint Committee on Cancer and The Eye Cancer Foundation. We are also indebted to the hard work and inspiration of our section moderators. Each section of the working day has been divided into presentations and discussions. The purpose of the presentations is to introduce or review these new concepts.

What I expect of each and every one of you is to figure out how to move these projects forward. It may be as simple as joining an existing initiative, or as complex and figuring out how we are to periodically report and compare our outcomes or stage radiation side-effects. What better place to do that than the Curie Institute to start that work Madam Curie!

The great thing about today is that we all came here to work, to improve our profession and thus make our piece of the world better place.

Thank you for this!

Paul T. Finger, MD