HELLO SYDNEY!
The Working Day meeting has increased momentum following the immediate success of it’s first meeting in Paris, 2015. The Second Working Day will take place March 24, 2017 in Sydney, Australia. Read more on the developing details inside this issue.

IN S I D E

PAGE 3
Outlining projects of the second Eye Cancer Working Day

PAGE 4
The 2020 Campaign: Saving the lives of 1,000 children by the year 2020

PAGE 6
LOSTYEYE: A networking community for enucleated patients

RESEARCH

ADVANCEMENTS

CHANGE
Dear Reader

Across all its stages, enduring eye cancer can feel like a painfully lonely journey. The Visionary intends to lift a portion of the emotional burden by providing the always-valuable and always-authentic resources of information and community.

A healthy exchange of ideas is crucial to any treatment. There is strength in numbers, and as the holidays approach and families amass we hope to bring to you, our reader, an extended sense of togetherness. We hope to assure you that you are never alone.

In this newsletter, please find the latest and most promising information on ocular oncology, collected by the people who strive every day towards improved treatment options.

warm regards,
and happy holidays!
The Eye Cancer Foundation
http://eyecancercure.com
The Second Working Day

In 2015 at the Curie Institute in Paris, doctors from around the world met for The First Working Day, dedicated to improving the practice of eye cancer treatment through international collaboration. The meeting successfully discussed several projects to streamline eye cancer treatment, particularly in countries where few to no doctors are available to cancer patients. With the groundwork thus lain, The Eye Cancer Foundation is pleased to announce The Second Working Day, taking place March 24, 2017 in Sydney, Australia.

What are the initiatives to be discussed?

• **Registries:** Retrospective eye cancer registries continue to offer statistically significant medical evidence (e.g. for AJCC-UICC eye cancer staging) and thus a common description for all eye cancer specialists. Ongoing registries and open questions will be our work!

• **RB fellow initiative** addresses the worldwide problem of retinoblastoma, mortality in underserved countries. Read further on in the newsletter to learn more on this critical issue.

• **Quality assurance** through Doctor Reported Outcomes (DRO)

• **COAST:** This Comprehensive, Open-Access Surgery Text, provides consensus-based, streamlined methods of eye cancer treatment for all eye doctors around the world.

• **RASE:** Ophthalmic RAdition Side Effects must be prospectively registered and stages in order to determine the differences between our methods of radiation treatment.

With over 100 eye cancer specialists from 4 continents, The Second Working Day promises to push us forward into the mainstream of oncologic care. To do this, each initiative works towards the goal of creating evidence-based medicine, educational programs, outreach to the underserved, as well as multi-center quality assurance. We have found that what is made by the community will be used by the community; to do this we must help each other and those who do not have access to subspecialty care.
“I’m on pediatrics rotation right now, and every morning when I examine newborns, I have to check their eyes by shining a light to screen for signs of retinoblastoma,” says a friend, who is enrolled currently in medical school, to me. The process seems simple enough, doesn’t it? In the United States and likewise developed countries, both newborns and toddlers are routinely screened for eye diseases. This includes RB, the most common eye cancer found in children. Though public awareness of the disease and it’s frequency remains significantly low, retinoblastoma affects nearly 10,000 children a year.

An added fact: this is a story of two worlds. RB treatment boasts a 98% cure rate with early diagnosis and treatment. However, these diagnosed children live in medically developed countries.

“There are many countries where practice in eye cancer medicine is not yet modernized. These are countries where not even one doctor specializes in eye cancer treatment. There children with undiagnosed and untreated retinoblastoma usually die from metastatic disease.”

We cannot stand by while these children are left without vision or life. This is why we created the 20/20 Campaign.
In partnership with the International Council of Ophthalmology (ICO), The Eye Cancer Foundation has established the goal of saving the lives of 1,000 children by the year 2020. The Campaign seeks to partner with the people and doctors from more developed countries with those countries not fortunate enough to have eye cancer specialists. By providing doctors with training in retinoblastoma treatment and then placing them strategically in unserved regions, parents around the world won’t have to watch their children lose their life.

"It is our mutual goal to decrease the high rates of worldwide mortality associated with the most common primary childhood eye cancer, retinoblastoma. Towards this goal, we agree that supplying subspecialty-trained retinoblastoma specialists to unserved and underserved countries is our first priority." — Dr. Paul T. Finger, Chairman of the Eye Cancer Foundation

The Eye Cancer Foundation is funding 25 retinoblastoma fellowships in ophthalmic oncology. Partnership with the ICO promises an expansion of the 2020 Campaign. With our combined efforts, the future will be clear and bright.

Our goal to end mortality from retinoblastoma can be fully realized by the generosity of our donors.

Toward this goal, we are partnering with the International Council of Ophthalmology (ICO) and encouraging all the world’s Retinoblastoma Charities to join us. By giving, you will partake in a partnership opportunity. You will provide much needed education and support for international fellows and this investment will last for generations.

It can be a one-time or recurring donation to The Eye Cancer Foundation. Please visit eyecancercure.com/2020 to help fight for our children’s lives today.
Easing the Way into Life After Eye Loss

Discussion & Support platform for those who have lost an eye!

It is a common (though certainly understandable) misconception that losing an eye leads to a reduced quality of life. But, did you know that renowned greats like entertainer Sammy Davis Jr., author James Joyce, and even President Theodore Roosevelt have all lost an eye? These people present examples of the human spirit’s perseverance, which seems unlimited. But, consider the transition to monocular vision is not easy for everyone. There lies the value of the website losteye.com, as well as many online resources available to those seeking help.

In this era, most patients do not have to lose their eye (enucleation) in treatment of their tumor. However, there exists specific reasons for enucleation that are particular to each patient. According to his website, Jay Adkisson opted for eye removal surgery after being diagnosed with choroidal melanoma at the age of 35. After that traumatic event, that he did not want others to endure the stress alone, so he created a website for patients who lose an eye. losteye.com is a “completely free, noncommercial website for the information and support of those who have recently lost an eye, or who may lose an eye due to surgery, disease, etc.”

The website offers itself as a guide to those facing enucleation from pre to post surgery. Many pages address the wide-ranging emotions a person may feel. Take, if you like, a look at the page discussing frustrations with eye loss: he wrote, Depth Perception… is grossly overrated! Other pages detail the necessary adjustments for daily life such as driving, playing sports, protecting the good eye, prosthetics, as well as dealing with the fear of permanent vision loss. However, the Losteye community
reassures that eye loss need not feel like a handicap. “Believe it or not,” Jay says, “five days later I was back at work at my law practice!” In fact, enucleated patients will continue to lead normal, healthy lives.

Members write:

“Jay, I was so pleased to get your website from my ocularist. I lost my left eye to a melanoma June 2003. I am an RN and went back to work as soon as I got my great prosthetic. I go to your website all the time. It makes me realize I am not alone. I have not met anyone who has had this surgery. Thanks — Joan”

“My name is Saeed and I am going to have my right eye removed next week. I have never thought that this could happen to me, and I am having big difficulty dealing with it. I found your website and it was such a tremendous help just before my surgery. Thank you for having done a great job by sharing your experience and letting people doing the same thing. Your upbeat personality and the way of looking at this trauma has already helped me a lot. Thank you again for a great website.”

Perhaps most spectacularly, Losteye features a buzzing community forum. On this platform of expression, people across the world connect; questions are asked and answered, stories are shared, and advise is enthusiastically given.

The opportunity to connect with others is of immeasurable value, and Losteye provides that connection.

The Eye Cancer Foundation supports fellowship education, patient communication and research around the world. “We are the foundation that is getting the work done. But, we need your help!”
The Eye Cancer Foundation Annual Giving Fund

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

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The Eye Cancer Foundation depends on the generosity of individuals, businesses, churches, foundations and organizations. The Eye Cancer Foundation is a 501(c)3 organization and donations are tax deductible. Please fill out this form and mail a check or cash to:

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