

The First Eye Cancer Working Day Event Epilog

Dear Colleagues:

First, I would like to take the time to thank you for your hard work and dedication!

As you know The First Eye Cancer Working Day (WD) was not only a smashing success, but offered a first glimpse into a new future for ophthalmic oncology. With 158 attending the WD, we have witnessed our colleague's thirst for community-based projects that will elevate our specialty.

Clearly, all of our colleagues considered the working day subjects were worth pursuing. Nowhere was this more evident than in the sign-up sheets filled with names of eager eye cancer specialists. Each and every section was embraced.

In terms of the sign up sheets (DROs = 23, Registries = 37, Surgical Guidelines = 28, Radiation Staging = 43, RB Fellowships = 34 and PROs = 17).

As you know, during the subsequent ISOO Meeting, our colleague's enthusiasm was palpable. I received comments like, "it is about time," "thank you for organizing the WD," or "I am really sorry I missed it, can I get involved?" Clearly, Monday's work carried through to the few ISOO attendees who did not join us.

Our Work Product

During The First Eye Cancer Working Day:

1) We showed the current status of a number of registries. Some had been completed, most were still recruiting, but all showed that multi center, international data sharing is a reality. Dr. Rand Simpson organized this section where Dr. Svetlana Saakyan of Russia presented the first results of the multi-center uveal melanoma registry. Dr. Steffen Heegaard of Denmark presented another outstanding multi center international data-sharing effort to better understand ocular adnexal lymphomas.

Nascent and ongoing studies were presented to solicit even more centers,

doctors and their patients. For example, new registries were discussed. Dr. Sarah Coupland presented the need for a vitreoretinal lymphoma registry and Dr. Anna Pavlick explained why we should prospectively collect data on patients with metastatic uveal melanoma.

The excitement was palpable and carried into the subsequent ISOO Meeting. For example, R. Max Conway asked to champion a new conjunctival squamous carcinoma registry. I am sure we will all lend a hand helping them refine his data fields and recruit centers.

2) The development of a staging system for ophthalmic radiation side effects is a unique opportunity for cooperation between our specialties. Dr. Wolfgang Sauerwein brings great radiation oncology expertise to this project and has volunteered to champion this effort.

However, he is far from alone. Including the co-moderators, no less than 43 eye cancer specialists signed their names to be on this committee. One day, the ophthalmic radiation side effects staging project will create a staging system that will be tested in a prospective registry. Clearly, it will be used to differentiate radiation treatments and empower both the doctor and patient specific outcome projects.

I cannot think of a better person to lead this effort than Dr. Wolfgang Sauerwein. He has tremendous experience with both brachytherapy and external beam modalities including proton beam irradiation.

3) Clearly the world needs a basic, community-written ophthalmic oncology surgery guide. Our specialty needs to define consensus surgical guidelines and the generalists of the underserved world need an open-access, internet-based knowledge to guide their way. This effort can elevate surgical ophthalmic oncology care around the world. Dr. Santosh Honavar has gotten us off to a running start on this project and will organize the 28 volunteers and draft others to get the writing started.

4) Mortality from retinoblastoma has been proven avoidable in developed nations. What is needed is early detection and prompt treatment. We all learned from the WD presentations that the problem is more complex in the developing world. It will take more than sending fellowship trained eye cancer specialists back to their underserved country. For example, there are problems with access (roads), social mores and poverty. However, it remains just as clear that if there is no trained advocate in each country, there is no chance to save the lives of these children.

Our specialty should embrace a goal of halving worldwide mortality from retinoblastoma within 10-years. Let's start by finding appropriate fellowship candidates, ensuring they will be supported upon their return to their underserved country, equip them with standardized "approved" protocols endorsed by the ISOO and major worldwide oncology institutions (e.g. UICC) and help our newly minted fellows advocate against retinoblastoma related mortality in their countries.

5) DROs and PROs are sophisticated efforts that are frankly inevitable. That is, patients are asking for it, governments are demanding it and we will be required to furnish them. So, are we going to develop these programs or are we going to stand by and have our outcomes (however they be collected) reported to us? Or will our community define the terms of how this data is collected and analyzed. This is a major challenge of our time. I expect Drs. Kivela, McCannel, Gallie and Damato will continue to lead these efforts and form ophthalmic oncology based committees ensure the quality of data collection and the privacy of both doctor and patients are protected.

The Biggest News:

The biggest news is that The Second Eye Cancer Working Meeting will be held in Toronto, Canada next year. It will be a multi-day event with more work and much less didactic. Other opportunities to meet include during the AAO, AAOOP, EVERS and ARVO meetings. The leaders of each section should take it upon themselves to move forward forming committees to address each project.

Please let me know so that I may announce and support your efforts. As always, the bulk of the work will be performed **between** face-to-face meetings, using the latter to refine the prior completed work.

Once again, I thank you for all your hard work and dedication. There would be no working day without you.

Warm regards,

Paul

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