

Date: Wed, 08 Jun 2005 09:02:30 -0700
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Subject: [CGL] California Carcinoid Awareness
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SEA celebrated Carcinoid Awareness Month in May. We celebrated with about 120 carcinoid patients and friends, doctors and nurses at our 1 day conference on May 21. The day was intended as a celebration and so a wonderful friend decorated the room with zebra striped balloons. The day provided patients an opportunity to share and meet with other carcinoid patients, learn of their disease, learn how they can be advocates for carcinoid awareness. A full lunch was provided.

I am sharing with cgl a brief overview of what our conference/celebration consisted of for those who might want to do a similar event.

The conference included an overview of the basics of carcinoid tumors and the syndrome delivered by Edward Wolin, MD and then Anthony P. Heaney, MD, PhD, moderated the panel of 6 doctors as they discussed 3 different patient cases. This panel discussed the patient cases from all angles, showing pathology slides and fully animated surgical pictures. One of the highlights was the panel discussion and question/answer session. It was a real privilege to hear patient's questions answered by 6 well educated and experienced physicians. I would highly recommend the use of a "panel" of physicians at patient meetings..

The California Governor, Arnold Schwarzenegger, sent a signed letter of congratulations on our celebration of May as Carcinoid Awareness Month and James Hahn, Los Angeles City Mayor sent a proclamation of May as Carcinoid Awareness Month.

We felt that any effort that SEA might make to increase awareness of carcinoid could be increased a 100 fold by enlisting the efforts of all of the patients in attendance. To that end, each patient was given an "Awareness Packet" in a zebra striped bag which contained the following items:

- 1.. 3 fold brochure titled "Shine the Light On Carcinoid" which outlines how individuals can help in the endeavor to increase awareness
- 2.. Letter from California Governor (rolled and tied with gold ribbon)
- 3.. Carcinoid Awareness pins
- 4.. Carcinoid car magnet
- 5.. Carcinoid bracelet
- 6.. Information on how to order Awareness Items
- 7.. Stationary Packet (with black silk ribbon) - Cards & envelopes using slogan "Don't Rule It out" to be mailed by patients to physicians

8.. Information about the new book published by SEA titled "Carcinoid Tumor: A Guide to Diagnosis and Treatment", authored by Richard R.P. Warner, MD and Chip Reuben, MS -- and how to order it.

9.. Information on How to donate to the Awareness campaign via SEA
A very important segment of the day was the presentation of a plaque to Richard Warner, M.D. for his outstanding contribution to carcinoid awareness by his donation of his time and expertise in co-authoring the book published by SEA entitled "Carcinoid Tumor: A Guide to Diagnosis and Treatment". The plaque was presented to Dr. Warner in absentia. A second plaque was presented to Chip Rueben, M.S. for his donation of time and expertise to co-author the book and to manage the grant proposal to fund a portion of the production and to manage the production process.

SEA had planned to have the new booklet mailed as the major portion of our Awareness campaign in May. This didn't work out but we are continuing our Awareness efforts and these books will be mailed in June to physicians throughout southern California to help increase awareness and education of the methods of dx, treatment and monitoring available.

We will send information regarding this book to CGL in a separate e-mail.

There was a lot of work involved in the preparation for this meeting, all made possible by wonderful volunteers. Thanks go to Nik and Terresa Nevile, Carol Young and Ed Meaney, Terri & Larry Wright, Sheryl Martin, Patti Cline, Emily Nelson and Corri Way. Starbucks donated the coffee, Novartis Oncology was the major sponsor with donations from Ortho BioTech and Amgen Pharmaceutical.

The day was a lot of fun and thanks to our dedicated physicians, very educational.

Nickolette Way
SEA for Carcinoid Patients
Southern California