

Newsletter of the International Thymic Malignancy Interest Group

Winter 2017.

Volume 6, Issue 1

Dear Colleagues,

It is with considerable pleasure that we extend to you the invitation to attend the 8th International Thymic Malignancy Interest Group Annual Meeting (ITMIG 2017), to be held on September 21 – 23, 2017 in Torino, Italy.

Established scientists and clinicians from all over the globe will join together to contribute to and energize research in thymic tumors and the thymus gland. This conference features the latest scientific and clinical developments related to the management of thymic malignancies.

Registration begins in March. Please visit <u>www.itmig2017.org</u> for more information. We look forward to seeing you in Torino this September and hope you take a little bit of extra time to travel through a territory of art, culture and nature.

Best Regards,

Prof. Pier Luigi Filosso ITMIG 2017 Conference Chair

Scientific Program Members:

- Robert Korst, USA
- Frank Detterbeck, USA
- Heather Wakelee, USA
- Vincent Fang, China
- Andreas Rimner, USA
- Nuria Novoa, Spain
- Giorgio Scagliotti, Italy
- Frederico Rea, Italy
- Paul Van Schil, Belgium

Contents:

1
2
2
3
-7
8

ITMIG Fundraising Gala by Dr. Robert Korst

On November 3, 2016, ITMIG held its first formal fundraising event in New York City.

With the theme of highlighting ITMIG accomplishments, the 2016 gala was successful in raising over \$12,000 for research patients with thymic for malignancies. Gala co-chairs, Marisa Korst and Pam Bruce, put together a wonderful event with cocktails and a sit-down dinner, along with a silent auction and raffle items. The Manhattan Penthouse was the venue with sweeping panoramic views of the city at holiday time. Entertainment was generously



provided by students from The Julliard School. Attendees came from as far away as the west coast of the U.S. and from Europe to participate and show their support for patients with these rare malignancies.



Given the success of this event, we are planning another fundraising gala next fall. Put it on your calendars: Thursday, November 9, 2017, same venue. So, let's get together to get the word out! If you are interested in participating in putting on the next gala, please reach out to Marisa Korst, mskorst@yahoo.com.

New Councilors Elected by Dr. Robert Korst

Thanks need to be extended to the ITMIG Councilors whose terms are expiring. These include Nori Ikeda, Vincent Fang, Mirella Marino and Heather Wakelee. An online election was recently held in order to elect new councilors for the new two-year term. We are happy to announce that the new Councilors are Dr. Sukhmani Padda, Dr. Conrad Falkson, Dr. Alan Kirk and Dr. Ichiro Yoshino. We extend a warm welcome to the successful candidates and look forward to their increased involvement in ITMIG.

Progress Made with the ITMIG Clinical Trial:

Thymoma Patients with Metastatic Pleural Disease

ITMIG hopes to initiate its own clinical trial for patients with thymic malignancies. This effort, spearheaded by Joe Friedberg at the University of Maryland, involves a single-arm pilot trial of surgical resection combined with intraoperative instillation of heated povidone-iodine solution into the pleural cavity. This is a feasibility trial that also will evaluate some efficacy endpoints. The trial will be a multi-institution, international effort and any ITMIG member that treats patients with stage 4A thymoma is encouraged to contact Joe if they want to participate, jfriedberg@smail.umaryland.edu. Currently, the protocol is completed and ready for submission to the University of Maryland Institutional Review Board.

COMMITTEE UPDATES

Communication Committee by Dr. Nuria Novoa

2017 Committee Goals

- Change the core line of the Facebook page and Twitter profile to create a more scientific profile by posting more entries of papers published by ITMIG members, other authors and other related scientific links. These posts are to be updated regularly.
- Increase ITMIG social media presence by making a minimum of two posts a month on Facebook or Twitter.



Nuria Novoa

• Start communications with interested patients on social media platforms.

Our social media presence had its biggest increase in the second half of 2016 due to the September Annual Meeting and the November New York Gala.

ITMIG's Twitter profile began with the Annual Meeting in San Francisco. Different posts were published with the most interesting data presented at the sessions. For example, Dr. Sonnet's results on the randomized study on the efficacy of thymectomy to improve clinical symptoms and Quality of Life of Myasthenia Gravis patients reached 130 people. Or the specific data presented by Dr. Burt about TETs molecular subtypes that reached 120 people including 97 non-directly related to ITMIG. Another interesting aspect of the congress occurred during the patients advocate session. We had the opportunity of contacting two leaders of different thymic patient advocacy social communities; these contacts will hopefully be the beginning of a positive relationship between ITMIG and these communities.

Both ITMIG profiles (Twitter and Facebook) allowed us to increase the number of people reached around the world. In November the New York Gala was another opportunity to increase the society's social media presence. A total of 210 likes followed the posting of the different comments and pictures of the event. Of particular interest is the fact that the posts had 267 responses; reaching 230 people not directly related to ITMIG.

In summary, 2016 has increased our global presence on social media with a total of 130 likes. Per the latest data since the San Francisco meeting there have been connections from different parts of the world with the greatest number of visitors from the U.S.A, Philippines and Spain. In addition, we have had one visitor each from Iraq, Hong Kong and Honduras that interact on the page. Welcome everybody!

News as to the announcement of the New York Gala, the San Francisco Congress and scientific data presented at the congress have had a large impact with over 100 reactions. The goal is to become considered influencers in the thymic world. Please, if you want to participate in this exciting project, do not hesitate to contact Nuria Novoa, nuria.novoa@usal.es.

Regional Champions Program by Dr. Anja Roden

It was very exciting to meet many of our Regional Champions at the annual meeting in San Francisco. We discussed communication opportunities including translating some sites of the ITMIG webpage into multiple languages to make it easier for patients and patient advocates to find our webpage in their native language. As ITMIG is now on Facebook we might want to explore similar options as this is so popular worldwide. This project will be in collaboration with the Communication Committee.

We would like to continue to promote collaboration between ITMIG and different regions throughout the world. One opportunity would be to use the Hubzero platform as a national database and at the same time share these cases with the ITMIG database. This endeavor is in collaboration with the Database Committee. We are currently working on this project with Dr. Juan Carlos Trujillo-Reyes and his team from Spain.

We discussed updating the "regional champion kit". This kit currently contains standardized approaches to thymic epithelial tumors as proposed by ITMIG together with a template for specimen orientation. These resources need to be updated.

Together with the Research and Infrastructure Committee we are continuously working to update our list of ongoing clinical trials worldwide pertaining to thymic epithelial tumors. Please let us know if you become aware of any new trials that should be added.

We would like to hear from you about what ITMIG can do to specifically support your region. Also if you are interested in joining our group, please email Anja Roden, roden.anja@mayo.edu.

Membership Committee by Dr. Marlies Keizjers



Marlies Keizjers

The Membership Committee was busy in 2016 with "the paying dues campaign" which resulted in new active and non-active ITMIG members. Since last year members can pay their dues and register for recurring payments online by visiting <u>www.itmig.org</u> and logging into their personal membership profile. The 2017 goal of the Membership Committee is to keep the active members committed to ITMIG. We are also going to recruit new people interested in ITMIG to become members and to get more involved. We can achieve this by promoting ITMIG membership at various larger related meetings and by reaching out to every new member. We will also advertise our next annual meeting in Torino at these larger conferences.

Education Committee by Dr. Edith M. Marom

During the second half of 2016 the Education Committee and its subcommittees continued to make progress. The thoracic video project led by Vincent Fang continued its preliminary work on creating an online publication with educational videos of minimally invasive thymic surgery. These videos will be published in the Journal of Visualized Surgery (JOVS, owned by the AME publishing company). If you are helping this please contact interested in with project Vincent Fang. vwtfang12@shchest.org. The Tumor Board, led by Benny Weksler, continued to discuss interesting and difficult cases via WebEx and Image32 which enable the sharing of clinical information, imaging studies and pathology slides. These tumor boards have representation of experts in the field from all relevant domains; thoracic surgery, medical oncology, diagnostic radiology, radiation oncology and pathology. If you are interested in submitting cases please contact Pam Bruce, <u>pbruce@itmig.org</u>, or Benny Weksler, bweksler@uthsc.edu, for further details on submission. The educational online modules have been completed and with the new online support will be loaded during the first half of 2017. The Mediastinal Working Group led by Anja Roden completed the data collection of the prevalence of different mediastinal masses as presented by cross sectional imaging via a radiology multi-institutional international study. The Education Committee goals for 2017 are to continue with all of these projects. Please see more details of the Mediastinal Working Group below.

Mediastinal Working Group by Dr. Anja Roden

Our new project, which will challenge us throughout 2017, is the study of mediastinal hemangiomas. These rare tumors are difficult to diagnose on imaging studies. The few that have been described were from selected collections; it seems that most do not have typical imaging features. This, at least in part, is due to the lack of larger studies of these neoplasms in that location, reflecting the rarity of mediastinal hemangiomas. We aim to identify typical radiologic findings, review pathologic features, record surgical approaches to identify the most successful and practical approach and to study clinical presentation, demographics and outcome of patients with these neoplasms. Members of the Mediastinal Working Group have identified consecutive mediastinal hemangiomas from their pathology databases. We are currently working on our IRBs. We would very

much welcome anyone who would like to share a case(s) and join the effort. Please contact Anja Roden, <u>roden.anja@mayo.edu</u>, if you are interested.

We continue to work on our study of the prevalence of mediastinal lesions. We collected over 3,000 cases from 3 continents and 6 countries. Currently, the data are for statistical analysis. We shared our preliminary data at the last Annual ITMIG Meeting.

Our goals for 2017 are:

- (i) Finalize the prevalence of mediastinal lesions study.
- (ii) Finalize the survey study.
- (iii)Further the Hemangioma study project.

Research & Infrastructure Committee Dr. Anja Roden

Our last few conference calls have been devoted to discussing goals of the committees and working groups (including Thymic Carcinoma, Research & Clinical Trials, Biology/Tumor Bank, Database, Outlier Analysis) for 2017. Many exciting projects are either under way or planned for the new year. You can read about these below under the respective working group/committee reports. One of our goals is to keep our clinical trials list up to date. We are still looking for Regional Champions who could help us with this work; specifically, from Asia (Japan, South Korea), Europe, South America and North America. Please let us know if you are interested in joining the effort, (roden.anja@mayo.edu).

Everyone is welcome to join our telephone conferences; they take place every month on the 3rd Thursday at 10AM EST.

Outliers Analysis Working Group by Dr. Robert Korst

The Outliers Working Group will focus its initial efforts on collecting data and histologic specimens from patients that have had type A or AB thymoma that has metastasized. The goal is to try to identify common characteristics of these patients in order to shed some light on what makes these patients different than the vast majority of type A or AB patients that are cured with surgical resection alone. Ultimately, these studies will tie into the results of The Cancer Genome Atlas which demonstrated the molecular profile of these tumors.

Thymic Carcinoma Working Group by Dr. Andreas Rimner

We had a very well attended Working Group meeting at last year's annual ITMIG meeting in San Francisco. We continue regular attendance by about 10 "active" members from multiple disciplines during our monthly conference calls.

A survey of the ITMIG membership on a series of 12 complicated clinical vignettes was published in the Journal of Thoracic Oncology (Shepherd et al).

Four major projects are ongoing:

- 1) Dr. Arun Rajan and Dr. Anja Roden have initiated a joint clinical/pathologic project correlating histologic changes/transformation with clinical disease progression.
- 2) Dr. Andreas Rimner started a project examining the outcomes of definitive RT in patients with unresectable thymic malignancies.
- 3) Dr. Alexander Marx has started characterizing histologic subtypes of thymic carcinomas.
- 4) Dr. Charles Simone and Dr. Abigail Berman have started a project analyzing the failure patterns in thymic carcinomas in relation to the radiation treatment fields.

We (Dr. Charles Simone, Dr. Andreas Rimner, Dr. Usman Ahmad, Dr. Xiaopan Yao) are looking forward to starting our ITMIG Retrospective Database Study on the role of postoperative radiation therapy in thymic carcinoma patients soon and hope to present preliminary data at this year's ITMIG meeting in Torino.

I would like to especially thank all the members of the team for their enthusiasm, motivation, scientific input, collaborative and positive attitude and for truly becoming a group of friends with a special interest in this orphan disease! We look forward to another exciting year of moving this field forward.

Finance and Development Committee

Patient Advocates Group by Dr. Robert Korst

The Patient Advocates Committee focused its efforts on the 2016 ITMIG Celebratory Gala. The Committee will continue in this direction by planning the 2017 event. In order to make this happen, help is needed by anyone who wants to contribute even the smallest amount of their time. Interested parties should contact Pam Bruce, <u>pbruce@thymic.org</u>.

