



**Newsletter of the International Thymic Malignancy Interest Group**

**December 2015**

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**Final Recap: Shanghai 2015 Annual Meeting by Dr. Vincent Fang**

On Oct 23-25 the 5<sup>th</sup> Annual ITMIG Meeting was held at the Regal International East Asia Hotel in Shanghai. The meeting was extremely successful with a record setting 241 participants from all major specialties. The two-day scientific program consisted of a



**Vincent Fang, Meeting Program Chair, Frank Detterbeck, Co-chair, front row center with local MCI staff.**

diverse group of invited speakers, 16 oral abstracts, 36 posters and two special “innovative lectures” in keeping with the outside-the-box thinking requisite to finding novel treatments for a rare disease. The full program and abstracts can be viewed on

[www.ITMIG.org](http://www.ITMIG.org) and will be published in an issue of the

*Journal of Thoracic Diseases*. The 2015 Annual Meeting featured many new ITMIG

accomplishments. First, the impressive engagement and contributions from the *ChART* (*Chinese Alliance for Research in Thymoma*) which was supplemented by other studies from Japan and South Korea in the great “Asian Session”. Then there were a series of reviews on the completed and ongoing studies made possible

by the ITMIG databases which emphasized the collaborative efforts of the ITMIG community. The “Mediastinal Session” announced that ITMIG is stepping into a broader arena by branching into the management of mediastinal tumors. And finally, the launch

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of the ITMIG Virtual Tumor Board certainly stood out as an exciting session which marked a new resource provided by the ITMIG infrastructure to help the global community improve patient outcomes.

ITMIG's impressive accomplishments in its first five years as well as all of its current active initiatives will certainly provide momentum and resonance all the way to our next annual meeting in San Francisco.

### **New ITMIG Steering Committee Officers by Dr. Frank Detterbeck**

The ITMIG constitution called for the election of new steering committee officers to assume the positions of President, Vice President, Secretary and Treasurer at the ITMIG 2016 meeting in September after having worked alongside the current officers until then. The Nominating Committee (Frank Detterbeck, Tomasz Grodzki, Ritsuko Komaki, Hisao Asamura) selected candidates for election from the names submitted by the ITMIG membership with the mandate to maintain a balance on the steering committee of specialties, geographic regions and age ranges. Voting by the ITMIG membership then took place just prior to the Shanghai meeting with the new officers (and existing officers and councilors) listed below. In the fall of 2016 it will be time to elect councilors for 2016-18.

President-Elect: Robert Korst (elected to a 2<sup>nd</sup> term)  
Vice-President-Elect: Anja Roden (elected to a 2<sup>nd</sup> term)  
Secretary-Elect: Vincent Fang, Thoracic Surgery, Shanghai, China  
Treasurer-Elect: Paul van Schil, Thoracic Surgery, Antwerp, Belgium

#### **Existing Steering committee (till September 2016):**

President: Robert Korst, Thoracic Surgery, New Jersey, USA  
Vice-President: Anja Roden, Pathology, Mayo Clinic, Rochester, USA  
Secretary: Pier Luigi Filosso, Thoracic Surgery, Torino, Italy  
Treasurer: Faiz Bhora, Thoracic Surgery, New York, NY, USA  
Councilor: Heather Wakelee, Medical Oncology, Stanford, California, USA  
Councilor: Vincent Fang, Thoracic Surgery, Shanghai, China  
Councilor: Nori Ikeda, Thoracic Surgery, Tokyo, Japan  
Councilor: Mirella Marino, Pathology, Rome, Italy

### **ITMIG Patient Engagement Drive Announces 2015 Winner by Dr. Robert Korst**

The 2015 Patient Engagement Drive was a success with Jim Huang taking home the prize. The Patient Engagement Drive was an attempt to rally ITMIG members to speak to their patients and families about ITMIG with the hope of increasing patient involvement in various areas of the organization. It is through such efforts that we spread the word about ITMIG; making us stronger and better able to accomplish our goals. Given the success in 2015, we are making the Patient Engagement Drive an annual event. Good luck to all!

## COMMITTEE UPDATES

### Communication Committee by Dr. Nuria Novoa

During the last months the committee has been working to develop a new communication tool: a corporate Facebook profile. We are proud to announce that the ITMIG page is completed and ready for you to visit. The webmaster has already posted a link for easy access from the [www.ITMIG.org](http://www.ITMIG.org) to our Facebook profile. Please visit us at [www.facebook.com/ITMIG.org](https://www.facebook.com/ITMIG.org) or use the Facebook link on our webpage. Click the *like* button to become a friend.



Nuria Novoa

We want this page to become an easy link for all ITMIG members. News, initiatives, comments and events from ITMIG will be posted as soon as they appear. But most importantly it will become a place for local encounter so that members from different working groups and committees can communicate and exchange ideas while members from the same region can make contact and possibly work collaboratively.

We are open to and will consider implementation of all positive ideas proposed by members! Just contact us.

### Regional Champions Program by Dr. Anja Roden

It was very exciting to meet many of our regional champions at the annual meeting in Shanghai. We brainstormed on ways to promote the collaboration between more ITMIG geographic regions. Several opportunities were identified, including:

- Presentations about ITMIG and updates from the annual meeting at regional meetings of societies/associations that are interested in the diagnosis and treatment of patients with thymic epithelial tumors or mediastinal tumors in general. We will focus on a few regions initially.
- There may be opportunities for ITMIG to help promote local/regional databases. Alternatively, a regional database can easily be created using the HUBzero platform which would remain under the complete control of that region for their own purposes. Thanks to the *Chinese Alliance of Research for Thymomas (ChART)* that recently shared their database with the ITMIG database.
- Collaboration on guidelines and educational material including material for patients and patient advocates that could be translated into different languages. We are planning to translate certain aspects of our ITMIG webpage to enable patients from different countries to find and read our webpage and to connect with ITMIG members that speak the same language. Patients in different countries would like to communicate with other patients who have the same disease and possibly get locally organized. We are also considering translating certain pages on our Facebook site given that many people worldwide are very familiar with social media.

We would like to hear from you about what ITMIG can do to support your region. If you are interested in joining our group, please email Anja Roden ([roden.anja@mayo.edu](mailto:roden.anja@mayo.edu)).

## Membership Committee by Dr. Marlies Keizjers



Marlies Keizjers

One of the goals for the membership committee in 2015 was to encourage members to pay their dues for the year and past year if applicable. Along with emails, three rounds of paper mailings were sent to all members that needed to bring their membership up to date. In early January we will move those members who have not paid to a non-active list. The committee will continue to try to recruit new members and also help promote the annual meeting at conferences we attend.

## Education Committee by Dr. Edith M. Marom

The proposed TNM staging system for thymic epithelial malignancies and the new ITMIG CT based classification of mediastinal compartments continue to attract the interest of colleagues from multiple domains. Members of the Education Committee have been presenting them at their institutions and at national and international conferences where they continue to excite much interest. For example, in the diagnostic imaging field, it was presented last summer to the European Society of Thoracic Imaging annual conference in Barcelona, Spain.



**E. Marom, Sheba Medical Center, Tel Aviv; Brett Carter and Mylene Truong, MD Anderson Cancer Center, Houston; Santiago Rossi, Centro de Diagnostico Dr. Enrique Ross, Buenos Aires; Gerry Abbott, Massachusetts General Hospital, Boston**

More recently at the Radiological Society of North America in Chicago, Brett Carter, a Committee member, won a Certificate of Merit for his educational exhibition- “New ITMIG Classification of Mediastinal Compartments: Update and Approach to Mediastinal Masses”. Both of his exhibits, the mediastinal compartment exhibit as well as the proposed TNM staging system for thymic epithelial malignancies have been solicited for publication in the leading educational journal of diagnostic imaging, *Radiographics*. Thus advances brought by ITMIG through its research, database and educational material will now be disseminated to a large new audience. As we strive for a better understanding of these diseases and unite in a common language to describe them, we urge our members to bring ITMIG’s work to their colleagues in all related fields of medicine.

### **Mediastinal Working Group by Dr. Anja Roden**

We would like to thank everyone who completed the survey on pre-treatment management of patients with mediastinal tumors. We had a phenomenal response of eighty two completed questionnaires. An initial analysis revealed that a multidisciplinary approach to mediastinal lesions is common. Most patients are seen by thoracic surgeons pre-treatment; mediastinal tumors are most commonly evaluated by a dedicated chest radiologist and thoracic pathologist. Subset analysis, focusing on continents, regions and size of the institution will be performed.

To investigate the prevalence of mediastinal lesions we completed a pilot study searching four radiology databases from three different countries (MD Anderson, Houston, USA, The Chaim Sheba Medical Center, Tel Aviv, Israel, Shanghai Chest Hospital, Shanghai, China and Mayo Clinic, Rochester, USA) and a pathology database (Mayo Clinic, Rochester, USA). The aim of the pilot study was to identify appropriate terms that can be applied for searches at multiple institutions. The results of the survey and the pilot study of the radiology and pathology database searches were presented at our annual meeting in Shanghai.

Those interested in participating in this work contact Anja Roden ([roden.anja@mayo.edu](mailto:roden.anja@mayo.edu)).

### **Tumor Board by Dr. Benny Weksler**

The ITMIG tumor board is a forum for presenting difficult cases available to all ITMIG members from around the world. We convene once a month virtually using a web conference platform. The tumor board is composed of a moderator, surgeons, oncologists, radiation oncologists, radiologists and pathologists. It is a great opportunity for all to present their cases and get an expert opinion from multiple specialists, all with significant interest and experience in thymic malignancies.



**Benny Weksler**

The ITMIG tumor board has convened several times, including the face-to-face tumor board conducted during the 2015 ITMIG annual conference in Shanghai. The virtual tumor boards have been successful in having meaningful discussions about complex patients and reaching therapeutic recommendations. We have worked out most of the initial technical issues and we have also created a framework for future productive meetings. If you have a case that you would like to present, please contact Pam Bruce ([pbruce@thymic.org](mailto:pbruce@thymic.org)) or myself ([bweksler@uthsc.edu](mailto:bweksler@uthsc.edu)).

## Research & Infrastructure Committee Dr. Anja Roden

### Retrospective/Prospective Research Committee by Dr. James Huang

At the recent annual meeting in Shanghai, we were fortunate to hear progress updates on several of the current projects arising from the ITMIG database. The outcomes of patients with thymic carcinoma and thymic carcinoid were reviewed by Dr. Enrico Ruffini (U. Torino). Dr. Cleo-Aron Weiss (Mannheim) provided an analysis of the importance of the WHO histotype. Dr. Bryan Burt (Stanford) presented an overview of the outcomes between patients undergoing minimally invasive vs. open surgery. Dr. Robert Korst (Valley Health) presented the analysis of PORT in resected thymoma being lead by Dr. Andreas Rimner (MSKCC) and Dr. Daniel Gomez (MDACC). Dr. Suki Padda (Stanford) described the characteristics of patients reporting autoimmune syndromes from the ITMIG dataset and Dr. Brian Louie (Swedish Cancer Institute) provided an initial comparison of patients undergoing subtotal versus total thymectomy.

As always, each of these projects was being conducted in cooperation with our Statistical Core, spearheaded by Dr. Xiaopan Yao (Yale) with data management provided by Dr. Alberto Antonicelli (Yale). With these projects nearing conclusion, the 2nd Request for Applications was announced this summer and once again many excellent proposals were received examining questions ranging from geographical differences to patterns of recurrence. The proposals have been reviewed and scored and the results will be announced shortly with new projects getting underway in early 2016.

### Database Committee by Dr. Nicolas Girard

The update of the prospective database has now been completed and provides the user with an even easier and friendlier experience. New data elements have been collected, including the 2015 TNM stage items. The virtual tumor bank has been integrated to foster translational research projects with well annotated specimens.

Areas dedicated to each individual contributor or regional group may be easily opened. An automated reminder system is available and may be set up by users that helps to identify and complete missing data. Real-time analyses of personal data are available to all users.



**Nicolas Girard**

A gold club of contributors has been formed to provide feedback to database developers; gold club members have access to more detailed dashboards of data recorded in the database. The consistency between the ITMIG prospective database and existing regional databases is now being checked to make combined analyses possible.

### Biology/Tumor Bank by Dr. Nicolas Girard

The accrual of specimens available for research in the virtual tumor bank will be facilitated by the integration in the cceHUB prospective database website. This will be particularly relevant for outliers characterization and a joint project between the Biology

and the Outliers working groups will be initiated in 2016. Discussion about the establishment of regional tumor banks will start in 2016.

Meanwhile, the Cancer Genome Atlas (TCGA) analyses are being completed to provide a first landmark paper in 2016. Data will be developed to further answer relevant questions in the clinic; especially on outlier patients.

### **Outliers Analysis Working Group by Dr. Robert Korst**

The Outlier Working Group has had a busy 2015 with a lot of traction gained. Outlier analysis involves the identification of events or outcomes that lie well outside the norm, collecting more detailed data on these “outliers” and attempting to learn the reasons why they are outliers.

The OWG has decided to pursue four clinical definitions of outliers, including:

- Stage I thymoma patients that have recurred
- Type A/AB thymomas that have metastasized
- Stage 3 thymic carcinoma patients that remain disease free for at least 5 years after treatment.
- Thymic carcinoma patients with myasthenia gravis

The OWG has queried the ITMIG retrospective database to identify patients that fit these four groups and is now in the process of collecting more detailed data. Analysis will be taking place in 2016. Anyone with an interest in joining this group should contact Robert Korst ([korsro@valleyhealth.com](mailto:korsro@valleyhealth.com))

### **Thymic Carcinoma Working Group by Dr. Andreas Rimner**

We have about 10 “active” members who call in regularly to our monthly conference call. In the last 6 months we have submitted a comparison of all primary neuroendocrine tumors and thymic carcinomas for publication (*P.L. Filosso et al.*). It is currently undergoing revisions and will hopefully be published soon. A survey of the ITMIG membership on a series of 12 complicated clinical vignettes is currently in preparation for publication.

Four major projects are still ongoing:

- 1) Dr. Alexander Marx has started characterizing histologic subtypes of thymic carcinomas.
- 2) Dr. Arun Rajan and Dr. Anja Roden have initiated a joint clinical/pathologic project correlating histologic changes/transformation with clinical disease progression.
- 3) 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.
- 4) Dr. Andreas Rimner is interested in reporting the outcomes of definitive RT in patients with unresectable thymic malignancies.

We have jointly submitted (Dr. Charles Simone, Dr. Andreas Rimner, Dr. Usman Ahmad) a project proposal for this year's ITMIG retrospective database RFA cycle to study the role of postoperative radiation therapy in thymic carcinomas in more detail. We are awaiting the decision of the database committee.

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 Group was organized in 2015 and “met” via conference call several times throughout the year. Led by Robert Korst, the focus of this effort is to try to engage as many patients and their advocates to become involved in a meaningful way with ITMIG. To this end, the group is comprised of more than 20 individuals and several have been instrumental in helping out with ITMIG directives and committees. Other group members have had novel ideas regarding fundraising that ITMIG hopes to implement soon. The primary goal of the advocates group in 2016 will be to help in any way possible with the 2016 fundraising gala that will take place in the fall. Any interested parties should contact Robert Korst with questions. ([korsro@valleyhealth.com](mailto:korsro@valleyhealth.com)).



**Robert Korst**

### ITMIG Fundraising Efforts by Pam Bruce

Although ITMIG has accomplished a great deal over the past five years, it has become clear that we will need to pursue additional fundraising avenues in order to continue to add momentum and maintain what we have developed. In addition to the member/advocate holiday fundraising drive concluding at the end of 2015, the decision has been made to organize a formal ITMIG fundraising gala in 2016. All organizations that carry out successful fundraising events had to start somewhere and for ITMIG it will be New York City. In this regard, we are looking for volunteers to help organize and carry out our first gala. No job is too small! Any and all efforts will be greatly appreciated, and no fundraising experience is required!

We also hope that ITMIG members will reach out to their patients, friends and family to help fill the gala, which will most likely take place in early November 2016. There will be online and live auctions, raffles as well as the opportunity to mix with your fellow ITMIG members and patients in a social environment where we all will be celebrating ITMIG accomplishments and patient success stories. Please contact Pam Bruce with any inquiries ([pbruce@thymic.org](mailto:pbruce@thymic.org) )

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[www.itmig.org](http://www.itmig.org)

**→ ITMIG 2016**  
7th International Thymic Malignancy Interest Group Annual Meeting

**Save the Date!**  
**SEPTEMBER 15–17, 2016**  
San Francisco, CA, USA