

Newsletter of the International Thymic Malignancy Interest Group

Summer 2016

Volume 6, Issue 1

2016 Annual Meeting: San Francisco by Dr. Frank Detterbeck

The 2016 ITMIG meeting is coming up soon, September 15-17, in San Francisco and it is shaping up to be another exciting meeting thanks to the intense work by the Program Cochairs, Heather Wakelee and Joe Shrager as well as the entire Planning Committee. A record number of abstracts have been submitted and are currently under review. The meeting begins with ITMIG committee meetings on Thursday afternoon which are open to anyone who wishes to attend followed by a welcome reception at 6:30 PM. The scientific program includes several talks discussing such exciting themes as-Biologic Underpinnings including results of the Thymic Cancer Genome Atlas Project, Immunity and Autoimmunity, Management of Pleural Implants and Clinical Trials. There will also be updates on multiple ITMIG projects and initiatives and a Multidisciplinary Tumor Board for which we encourage you to bring a case for discussion.

We look forward to seeing old friends and meeting new ones from the ITMIG community in San Francisco! Registration and further details are available at www.itmig2016.org, the ITMIG Annual Meeting website. Early registration deadline is July 29th!

2015 Fundraising by Dr. Robert Korst

ITMIG held its second fundraising drive at the end of 2015. Once again, this drive was very successful raising a total of \$17,673 from both ITMIG physician members, as well as patients and patient advocates. Thanks to both ITMIG participating physicians and patient advocates who support the purpose and objectives of ITMIG by their generous donations of both time and money. Our plan is to hold another fundraising drive in 2017. Special thanks to everyone who supported us for this drive; hopefully we will continue to increase donor participation in the future.

2016 ITMIG Celebratory Gala by Dr. Robert Korst

On Thursday, November 3, 2016, ITMIG (in conjunction with the Foundation for Thymic Cancer Research) will be holding its first Celebratory Gala in New York City. This is a formal fundraising event

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that will begin with a cocktail hour from 6-7 PM followed by a gourmet dinner. Entertainment will be provided (TBA) and attendees will be able to participate in raffles and auctions with the goal of raising money for thymic cancer research. An online auction will also accompany this event.

The 2016 Gala will be held at the Manhattan Penthouse with tickets at \$250 per person. Please spread the word among colleagues, friends and acquaintances so that we can fill the venue in order to raise as much research money as possible. Anyone interested in more information or in helping to plan this event, please reach out to either Pam Bruce (pbruce@thymic.org) or Marisa Korst (mskorst@yahoo.com).

COMMITTEE UPDATES

Thymoma Cancer Genome Atlas by Dr. Nicolas Girard

The Thymoma Cancer Genome Atlas (TCGA) project is almost completed! The final analyses are ongoing and the results will be published soon. Please note: The high number of cases in this project – 124 thymic tumors collected worldwide with the support of ITMIG - should allow an assessment of coexistent alterations in thymic malignancies. Meanwhile, raw data are already available to researchers on the Cancer Genome Atlas portal (https://tcga-data.nci.nih.gov/tcga/) and the National Cancer Institute Genomic Data Commons (https://gdc-portal.nci.nih.gov). The next steps will be for ITMIG to contribute to validation studies; possibly focusing on clinically-defined

Communication Committee by Dr. Nuria Novoa

subgroups of patients in connection with the outliers project.

The ITMIG webpage and Facebook domain, the two platforms of general information, are active and functioning well. Our long time webmaster, who has generously and anonymously volunteered his time and effort, has decided not to continue for personal reasons. We are in the process of obtaining another webmaster. We want to thank both contributors, new and old for all their help and cooperation. As you probably know, the webpage provides access to a lot of information about both ITMIG's structure as well as scientific content. It also allows direct access to the current databases and to the content of the annual meeting. For those who do not know it, I suggest you visit us at www.itmig.org.



Nuria Novoa

On the other hand, our Facebook domain is growing slowly. I want to thank all who have visited and posted a comment or information on the page. Special thanks to Marlies Keijzers for her collaboration. Most of our visitors are females from India, USA and Romania. It is interesting that most of our visitors are between 25 to 34 years of age reflecting the demographics of social media and users generally users of portable devices rather than personal computers. Only 10% of our visitors are 45 years of age or older. Some visitors have requested a contact telephone number to be added. The announcement of the 2016 annual meeting and the announcement of the future Gala Dinner are the most

"liked" posts on the page. Some European professional societies have localized us and post our contents on their Facebook wall as we do reciprocally. Our Facebook page is open for the members to post any comment in any language. It has no restrictions except that no commercial posts are allowed. As I commented when we started this new platform we want this to be the venue for an informal meeting place for our members. We will continue to offer relevant information and enhancing our communications. We encourage you to visit us at www.facebook.com/itmig.org.

Membership Committee by Dr. Marlies Keizjers

Objectives

New members

We will reach out to all new members with information about ITMIG. If new members are interested they can participate in ITMIG projects or committees.

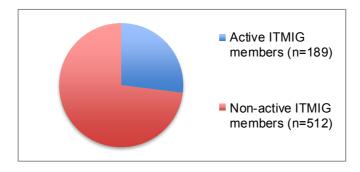
Membership dues paying campaign

We reached out to the ITMIG community in 2015 by mail and hardcopy invoices. There were no penalties for missed dues in past years and ITMIG memberships were only renewed with payment. The campaign ended in the beginning of 2016 and resulted in 189 active paying ITMIG members. Members who do not pay their dues will be "non-active ITMIG" members. Non-active ITMIG members cannot take advantage of membership benefits.



Marlies Keizjers

It is important to continue the dues paying campaign in 2016 and send invoices and reminders out. We should discuss if members who will not pay in 2016 but have paid in 2015 should become a non-active ITMIG member.



Getting ITMIG Members involved

We want to get the "paying ITMIG members" more involved. The "getting involved" list of projects will be updated and distributed at the annual meeting in San Francisco.

On the ITMIG website, www.ITMIG.org, members can subscribe and pay their dues online including the option to make monthly dues payments with auto-pay. At this moment we are looking for a new website designer. Know anyone to take over this volunteer position? Contact Pam Bruce option2 portion? Contact Pam Bruce option2 proceduring.org.

Education Committee by Dr. Edith M. Marom

During the first half of 2016, the Education Committee has made progress in several domains. Educational online material was finalized and will be uploaded to our website once a new website master is recruited. Some of our Education Committee members as well as other ITMIG members have been busy disseminating our ITMIG educational material at different non-ITMIG conferences. For example, Brett Carter in the last Radiological Society of North America won a certificate of merit for his educational poster on ITMIG's classification of the mediastinal compartments slated to be published in the leading educational journal, Radiographics. Two subcommittees, the Mediastinal Working Group spearhead by Anja Roden and the Mediastinal Tumor Board spearheaded by Benny Weksler have made great strides



Edith M. Maron

Tumor Board by Dr. Benny Weksler

ITMIG Tumor Board convened five times this year. We discussed interesting and difficult cases from three different continents. The platform used Webex meetings which allows for easy communication and sharing of images, including radiology and pathology slides and is realistic enough to mimic a live tumor board. Tumor Board panelists represent each of the following specialties: surgery, medical oncology, radiation oncology, diagnostic radiology, and pathology. We are always looking for cases and we welcome submission from any of our members.



Benny Weksler

If you are interested in submitting, please contact Pam Bruce, (pbruce@ITMIG.org), myself (bweksler@uthsc.edu), Edith

Marom (edith.marom@gmail.com), or Frank Detterbeck (frank.detterbeck@yale.edu).

Mediastinal Working Group by Dr. Anja Roden

The Mediastinal Working Group is currently concentrating on two main projects:

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- (i) Study of prevalence of mediastinal abnormalities
- (ii) Modification of our existing prospective database to allow for collection of mediastinal lesions/tumors other than thymic epithelial tumors

Data on prevalence of mediastinal lesions and masses are sparse and outdated. To study the prevalence of these mediastinal abnormalities, enthusiastic radiologists from ten institutions in Canada, China, France, Israel, Italy and the United States are currently searching their radiology databases using agreed-upon standardized terms. This data will be centrally collected and the prevalence of mediastinal lesions will be evaluated. Edith Marom and Anja Roden are leading this project.

The infrastructure of our prospective thymic epithelial tumor database is solid and has the capability to be expanded to also collect other mediastinal lesions/tumors. The current data entry form was reviewed and the working group discussed possible additional data fields that would allow for accurate entry of additional tumor types. In collaboration with the Database Committee these data fields will be added in the near future. Stay tuned.

Research & Infrastructure Committee by Dr. Anja Roden

We are holding monthly conference calls devoted to two or three working groups per conference (including thymic carcinoma, research & clinical trials, biology/tumor bank, database, outlier analysis and global asset). During our calls the working groups' chairs are providing updates on their current activities. You can read their updates below under their respective working group/committee article. These discussions often spark new ideas and foster communication and collaboration amongst committees and working groups. Everyone is welcome to join our telephone conferences; they take place every 3rd Thursday monthly at 10AM EST. Contact Anja or Pam Bruce at pbruce@itmig.org.

Please consider getting involved. We would love to have your ideas and input and work with you on implementing them. You can go to our ITMIG webpage, under collaboration and "getting involved" to search for projects that might interest you. There are projects for any career level and any specialty.

Retrospective/Prospective Research Committee by Dr. James Huang

Since the last newsletter, interesting data arising from the ITMIG Database have continued to gain attention. Congratulations go to Drs. Andreas Rimner (MSKCC) and Daniel Gomez (MDACC) for their recent publication in the Journal of Thoracic Oncology on the outcomes of postoperative radiation in patients with resected thymomas. Dr. Brian Louie (Swedish) stimulated a provocative discussion at the recent meeting of the American Association for Thoracic Surgery with his results on a comparison of subtotal versus total thymectomy. Dr. Vincent Fang (Shanghai Chest) presented a follow-up analysis looking at geographic differences in surgical approach to thymic resections at the recent European Society of Thoracic Surgeons meeting.

As always, each of these projects was being conducted in cooperation with our Statistical Core, spearheaded by Dr. Xiaopan Yao with data management provided by Dr. Alberto Antonicelli and to this team we are now fortunate to include biostatistician, Dr. Yue Shang- all at Yale. We received a number of excellent proposals in response to our 2nd RFA last fall, including studies examining patterns of recurrence, postoperative radiation in thymic carcinoma and outcomes of chemotherapy in patients with thymic malignancies; we expect to get these projects under way in the upcoming months.

Database Committee by Dr. Nicolas Girard

Thank you to all the contributors of the Prospective Database, available at www.ccehub/ITMIG. As more than 700 cases are now registered in the database, the challenge is to ensure the completion of data collection as well as an optimal follow-up of patients while making the process as easy as possible for ITMIG investigators. A reminder system that allows for the direct identification of missing data-elements is now available for new and already registered cases. Registration of specimens available for research is now possible with the integration of the virtual tumor bank in the system. Regional areas dedicated to the registration of patient cases from one country or a collaborative group may be developed. Discussion is ongoing to have images- radiological and pathological- uploaded to the system.



Nicolas Girard

The Biology and Tissue Bank Committee by Dr. Nicolas Girard

This committee aims to foster biological and translational research by offering a platform to share ongoing projects and discuss new results; working with other ITMIG committees and working groups to collect cases for specific projects and building the infrastructures to make this happen. Collaboration with the TCGA infrastructure is being developed. Interested members may contact Pam Bruce at pbruce@itmig.org to contribute to the group.

Outliers Analysis Working Group by Dr. Robert Korst

The Outliers Working Group continues to make progress focusing on patients who are deemed to be "outliers" based on their clinical behavior. The four outlier groups as defined by the working group are:

- Stage 1 thymoma patients that have recurred after resection
- WHO class A/AB thymoma patients that develop metastatic disease
- Thymic carcinoma patients with myasthenia gravis



Robert Korst

• Thymic carcinoma patients that have remained disease free more than 5 years after initial curative treatment

The working group decided that it would use the existing Hubzero database to house the data for this project and preparations are underway to upgrade the database to accept both new data fields as well as new forms of data (images, etc.). Anyone interested in joining this working group should contact Bob Korst (korst382@gmail.com).

Thymic Carcinoma Working Group by Dr. Andreas Rimner

We have about ten "active" members who call in regularly to our monthly conference call. A survey of the ITMIG membership on a series of twelve complicated clinical vignettes is currently under review by the co-authors and soon to be submitted for publication.

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.

During the 2015 RFA cycle we (Dr. Charles Simone, Dr. Andreas Rimner, Dr. Usman Ahmad) were approved to study the role of postoperative radiation therapy in thymic carcinomas in patients captured by the ITMIG retrospective database. Initiation of this project is pending availability of the biostatistics core.

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

This subcommittee has focused on preparing for the 2016 ITMIG Celebratory Gala. We have been able to engage many patients and their advocates for their input in creating this event and many patients/advocates are making donations for the raffles and auctions. Hopefully, we will be able to meet and mingle with as many patients and advocates as possible during this event in New York City.

In addition, for the first time, the 2016 ITMIG Annual Scientific Meeting in San Francisco will have a session dedicated to patient advocates. This will be an opportunity for them to voice their ideas for enhancing their engagement and participation in ITMIG in the future. We can then work together to implement some of those ideas which will serve to make our organization stronger!