

ITMIG Newsletter - December 2012

ITMIG continues on a steep trajectory. Looking back, we have accomplished a lot since ITMIG was born on May 5, 2010. Looking forward, we have ambitious plans – but given all the things we have achieved despite the challenges, trying to rise to a higher level of accomplishments each year is justified.

ITMIG now has over 400 members, including all relevant specialties and spanning the globe. It is clear that ITMIG has engaged the vast majority of individuals who are active in this field.



Organizational Issues

The term of service expired for Meinoshin Okumura, Bob Korst, Ritsuko Komaki, Greg Riely, Kazuya Kondo and Alex Marx on the steering committee. We thank them for all of their work, and look forward to their continued involvement in ITMIG in many ways. The ITMIG membership elected 4 new councilors to the steering committee: Jun Nakjima, Mirella Marino, Daniel Gomez, Heather Wakelee. Furthermore, Enrico Ruffini and Jim Huang have formally taken over as secretary and Treasurer of ITMIG.

We have split the Education/Communication committee into 2 separate committees, the education committee, chaired by Edith Marom, and the communication committee, chaired by Pierluigi Filosso. We have also established the membership committee as a permanent standing committee, chaired by Ritsuko Komaki. Anyone interested in contributing to these committees (or any others) is welcome and should contact Pam Bruce. Finally, the membership process has been streamlined. The new ITMIG bylaws and committee structure is available on the ITMIG website.

Annual Meeting

The annual meeting was held in Fukuoka, Japan on November 25, 26, together with the Asia Pacific Lung Cancer Conference. This meeting was well attended, and featured many stimulating talks and discussions. The combined ITMIG/APLCC meeting attracted over 1,000 attendees. A more detailed description of the meeting the prizes can be found in a separate write-up, and the complete program and abstracts are available on the website.

A poster for the 5th Asia Pacific Lung Cancer Conference (5th APLCC) and 3rd International Thymic Malignancy Interest Group Conference (3rd ITMIG). The poster includes the following information:

- Website: <http://www.aplcc2012.org/>
- Logos for APLCC, ITMIG, and other sponsors.
- Event Dates: November 25 (Sun.) to 28 (Wed.), 2012
- Location: Hilton Fukuoka Sea Hawk, Fukuoka, Japan
- Theme: Globalization of Standard and Targeted Therapy
- President of the APLCC: Yusaku Nakamichi, Kyushu University
- President of the ITMIG: Meinoshin Okumura, Osaka University
- Important Dates:
 - Abstract Submission Period: April 1 to July 31, 2012
 - Online Registration & Accommodation opens: April 1, 2012
 - Abstract Notification: August 31, 2012
 - Early Registration Deadline: September 30, 2012
 - Regular Registration Deadline: October 31, 2012
- Contact Information: Conference Secretariat Office, 1-17-1 Yamato, Chuo-ku, Fukuoka 819-0001, Japan. Tel: 81-92-918-7100, Fax: 81-92-918-7101, E-mail: aplcc2012@aplcc2012.org

A screenshot of the ITMIG website showing the International Prospective Patient Database and International Retrospective Database. The website has a blue header and footer. The main content area is white with blue accents. The International Prospective Patient Database section includes three buttons: "Enter New Patient" (Add a new patient to the database.), "Update Existing Patient" (Update patient episode data for your hospital.), and "View Patients" (Browse and search patient data for your hospital.). The International Retrospective Database section includes a button: "Upload Spreadsheets or Explore the Data for the ITMIG Retrospective Patient Database". Below this button, there is text explaining that spreadsheets with retrospective patient data are submitted by hospitals and by organizations such as ESTS and JART. Spreadsheets are stored in the H&B repository for download and the data is available in the database for browsing and searching. De-identified data is available for the CRAB Staging Study. There are also instructions on how to use the ITMIG standardized spreadsheet to upload patient data and an example spreadsheet for organizations like JART or ESTS. The footer contains terms of use, accessibility issues, copyright compliance, and copyright information for 2010-2012.

ITMIG Database

The retrospective database has been launched and is a resounding success. The engagement of people spread around the globe and in approximately 50 institutions has been simply astounding. There will be close to 8000 cases in the retrospective database once all of the cases have been cleaned and entered. This is an unprecedented resource for all of us, and an astounding example of global collaboration. The prospective database is being launched, and will be even richer. If we can support this to the same degree, it will provide yet another quantum leap forward.

International Staging Committee

The thymic domain of the international staging committee has begun its work to define an official stage classification system. More will be forthcoming during the course of the year. The retrospective database will have a major impact on this effort. It was hoped that we could have had enough cases in the prospective database to perform some initial validation using this, but the current timelines imposed by the AJCC/UICC will not permit that. The additional richness of the prospective database would provide an ability to explore aspects of thymic tumors that are not possible with the retrospective data. Thus the stage classification effort will be a work in progress that undergoes further refinement as time goes by. An initial stage classification proposal will be discussed at the next annual ITMIG meeting.



Histologic Classification

An international multidisciplinary panel, including most of those actively engaged in the microscopic evaluation of thymic malignancies has been working for quite some time at refining histologic classification. The focal points of this effort have been two weekend meetings, involving experts from around the world. The first of these was held at Sloan Kettering Cancer Center in NY in 2010, and the second at the University of Heidelberg in December 2011. These involved a lot of preparation, an intense “get down to work” weekend with a lot of discussion, debate, consideration of things ranging from past standards to novel approaches, and were followed by an active ongoing email

collaboration. The outcome of this is a proposal for refinement of the WHO classification, which till now has met some needs but left some things to be desired. A paper outlining this ITMIG proposal is undergoing final revisions at this time.

There is still much work to be done, however, starting perhaps with validation of the ability to consistently apply the stage and histologic criteria and, building on the database resource, prognostic validation of the system. The classification so far has focused on histologic appearance, but the next phase must take into account the biologic behavior. This work is yet to be done, but would have implications for practical clinical utility as well as potentially to simplify the histologic classification into groups. ITMIG is determined to continue to support these efforts.

A thymic carcinoma and thymic carcinoid workgroup is gaining traction. Planning is underway to consider holding an intense workshop meeting to develop a structure for how to approach nomenclature and results reporting in this area. The effort is led by Greg Riely; as always anyone interested in contributing to this effort should contact Greg or Pam Bruce.

ITMIG as a Model

ITMIG was invited to present before an audience of nearly 1000 at the American Society of clinical Oncology (ASCO) a talk with the title “ITMIG as a Model for Rare Diseases”. This also involved a paper, published in the 2012 ASCO education book (and available on the ITMIG website). This was a major tribute to the accomplishments ITMIG has achieved in a short time frame, the determination with which we have pushed forward, and the focus on innovation.

The Creation of the International Thymic Malignancies Interest Group as a Model for Rare Diseases

By Frank C. Detterbeck, MD

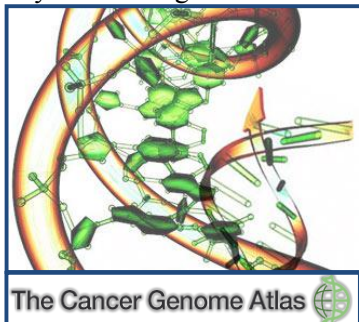
Overview: Similar to other orphan diseases, little progress has been made in the past decades in thymic malignancies. A determination to make a difference, despite the challenges facing a rare disease, led to the formation of the International Thymic Malignancies Interest Group (ITMIG) in 2010. This organization has brought together the majority of those focused on the management of thymic malignancies and has built a foundation for scientific collaboration, including con-

sistent use of terms, an international database, and multidisciplinary engagement of clinicians and researchers from around the world. ITMIG has embarked on the development of novel approaches to research particularly suited to a rare condition. ITMIG has gained substantial recognition for the rapid progress that has been made and serves as a model for the advancement of knowledge in a rare disease.

Research

Ongoing efforts to institute prospective research have been underway for some time. The background work is beginning to pay off. A major initiative is to conduct an international phase III randomized trial investigating the role of adjuvant radiotherapy in completely resected stage III tumors. Working with the International Rare Cancer Initiative (IRCI) we have secured a commitment from the cooperative oncology groups in the US (ECOG) and Europe (EORTC) and the UK to support this. Discussions are underway with groups in Japan and China. If ITMIG can actually implement and accrue to such a study, it would be a huge accomplishment. The fact that we are at the point of actually getting started is an amazing feat in itself.

In 2013 ITMIG will finally launch the Collaborative Observational Study. This uses a novel approach, suited for a rare disease and more indolent tumors, and to our starting point of various treatment approaches being used with little data to guide us. Bayesian statistics can be used to evaluate how reliable observed differences in outcomes associated with different treatment approaches are. A structure for adaptive evolution and changing the treatment approach can be used to validate initial observations. These are uncharted waters, but the foundation has been built and it is time to set sail. Anyone wanting to board the ship for this adventure should contact Frank Detterbeck or Pam Bruce.



ITMIG is collaborating with The Cancer Genome Atlas (TCGA) project of the US National Institute of Health (NIH). This involves complete sequencing of the genome of thymic malignancies, and promises to be an important step in developing a better understanding of the biologic underpinnings of these tumors. While a lot of work needs to be done, this is targeted to take place in 2013.

Other research initiatives are also in development, and new ideas are also always welcome. In particular, we need to develop a translational research program. Anyone interested in contributing to any of these initiatives or with new ideas should contact Heather Wakelee.

2013 ITMIG Annual Meeting

The 2013 annual meeting will take place in Bethesda, MD (near Washington DC, USA) on Sept 6-8, 2013 (Friday-Sunday). This will be a stand-alone meeting, although we are working on involvement of the NIH and MGFA in the meeting. Save the date – there should be a great deal of further progress to report and insights to discuss. Further information will be coming.

Education

Edith Marom has created a beautiful interactive educational module for imaging (see http://ccehub.org/photo_gallery/). Other modules to promote and understanding of the ITMIG standards need to be built.

Work is underway to develop ITMIG standards in areas we did not address initially.



New Projects in Development

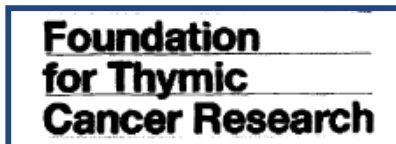
Many projects are under development. These include translation of the summaries of the “ITMIG Standards” into other languages, development of a mediastinal node map for mediastinal tumors, and proposal of a clinical stage classification system. Plans are underway to build the HUBzero database to accommodate radiographic and microscopic images. This would be quite a unique resource. Finally, the website needs to be updated and upgraded.

A new initiative involves development of a modern definition of mediastinal compartments, rather than applying definitions derived from a lateral Chest Radiograph to a CT. This is in keeping with ITMIG’s mission to serve the needs of mediastinal tumors in general.

A major new initiative is to use the insights gained in the field of education to benefit clinicians who encounter a patient with a rare disease. Teaching simple facts involves certain techniques, while teaching skills like clinical judgment and problem-solving are most effective and efficient using different techniques. Development of a sophisticated, interactive platform and curriculum that can be tailored to specific needs holds promise to be an innovative significant leap forward in improving the ability to deliver care for our patients.

Challenges

The key to ITMIG's success is the broad engagement of people around the world and the culture of open collaboration towards a common cause that has come to characterize our organization. We have accomplished a lot in a short time due to this, but looking back is not our focus, Looking forward it is clear that there is a great deal of work to do to capitalize on the great foundation we have built. We must expand our engagement further – there is plenty to do for anyone who wants to take a piece or project and move it along, and it is only through the collective efforts of many that we can succeed. If you are interested to help but don't know how, please contact Pam Bruce or Frank Detterbeck and we can find the right match.



As our vision grows and our momentum builds, our funding needs grow as well. The foundation for Thymic Cancer Research (a patient focused organization) has been our funding lifeline. We have to help the foundation to grow. ITMIG members need to spread the word about the foundation, and we need to engage as many lay people as we can in supporting our initiatives. We have managed to do a lot, but our financial situation is precarious, and without broadening this engagement we could easily come to a standstill rather than picking up speed.

We need ITMIG members to be assertive local champions for ITMIG within their institution. This is needed to build more interdisciplinary collaboration, and to share the work and satisfaction of being part of ITMIG initiatives. "Institutional kits" have been put together by Jess Schwartz – these contain summary sheets for various specialties as well as laminated plastic "mediastinal boards" that greatly aid the orientation and communication between a surgeon and pathologist. These are available from Pam and provide a good way to disseminate the standards that help us collaborate effectively.

We have made tremendous progress, and stand poised to make even greater leaps forward. It is only by having many individuals take on a task that we can do this, and we have to broaden the number of people who are actively contributing in order to maintain the momentum.

