

ITMIG Newsletter – December 2013

Annual Meeting

The 2013 annual meeting was held in Bethesda, Maryland, close to the US National Institutes of Health, on September 6-7. We had approximately 125 attendees which were a combination of members, patients, and people from the NIH. The program included invited speakers and abstract sessions, and highlighted topics such as the overlap between thymic malignancies and the immune system, myasthenia gravis, genomics and new ways of thinking about databases and structuring innovation and progress. The overall feedback from the attendees was very positive.

Congratulations to those that received the following awards:

Best Oral Presentation: Dr. Jun Nakajima, The University of Tokyo Graduate School of Medicine, Japan. *"Myasthenia Gravis Associated with Thymic Epithelial Tumor - Retrospective Clinicopathological Analysis Of Japanese Database Cases."*

Best Poster Presentation: Dr. Nicolas Girard, Hospices Civils de Lyon, France. *"RYTHMIC: a nationwide network for thymic malignancies in France."*

Best Thymic Cancers Paper: Dr. Yesim Gökmen-Polar, Indiana University School of Medicine and Simon Cancer Center, USA. *"A Gene Signature to Distinguish Thymic Carcinoma from Thymoma."*

The 2014 Program Committee is currently planning for our meeting in Antwerp, Belgium. ITMIG disciplines and seeking engagement of all who want to contribute to advancing the state of the science. The preliminary proposals show this shaping up to be another strong scientific program. There should also be a lot of new information gathered from ITMIG activities (database, staging etc) that are underway. More information will be coming in early 2014.

ITMIG 2013 Election

The ITMIG members elected new officers; who will formally step into these positions in the fall of 2014, after a year of working alongside the existing officers.

The results from the election: 1). **President:** Robert Korst, a Thoracic surgeon and Director of the Leigh Valley Cancer Center in New Jersey. 2). **Vice President:** Anja Roden, a thoracic pathologist at the Mayo Clinic in Minnesota, USA 3). **Secretary:** Pier Luigi Filosso, a thoracic surgeon at the University of Torino, Italy, who has contributed many papers on thymic disease throughout his career.

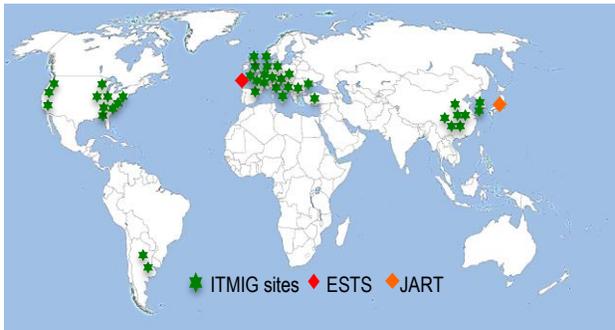
4). **Treasurer:** Faiz Bhora, a thoracic surgeon at St. Lukes/Roosevelt Hospital in New York.

ITMIG Database

The ITMIG retrospective database is an astounding success. Approximately 50 institutions around the globe have gone through their institutions clinical experience and contributed their data, thus creating an unprecedented global database of over 6000 cases. This resource permits progress in ways that have never before been possible. ESTS and JART have assembled their own databases, each involving about 2,500 cases, and may also be available for global projects at the discretion of those organizations.



Results of the first projects using the retrospective database we presented at the annual meeting.



Carrying out these projects (an analysis of thymic carcinoma and carcinoid tumors and of thymoma subtypes) has allowed us to refine the process of using the data and to build the statistical support. An invitation to the ITMIG membership for projects resulted in 17 submitted requests. Analyses of these are beginning. Invitations to submit further proposals will come in the future as we finish the ones already on the table.

Development of a Stage Classification System

The ITMIG/IASLC partnership to develop proposals for an official stage classification system is well underway. Preliminary analyses were presented at the annual ITMIG meeting in order to get input from the ITMIG membership. The amount of data available for analysis, and the extent of the analytic process that has been employed is an astounding advance over what has been possible in the past. So far approximately 300 graphs and analyses have been generated looking at the data in multiple different ways. The proposals for stage classification from the thymic domain of the staging committee should become available for public comment during 2014.

Histologic Classification

ITMIG conducted 2 workshops to address problematic areas of histologic classification. This involved a great deal of thoughtful, collaborative thinking involving most of the experts across the world. The paper that represents the product of all this work is currently under journal review.

The WHO has launched the revision of the Histologic classification manual for all cancers. The WHO process is an independent one, but because ITMIG laid the groundwork with the collaboration of the world's experts, the WHO revision will clearly build on the work that ITMIG has done. This was in part exactly the goal – to provide the basis for thoughtful revision by the WHO.

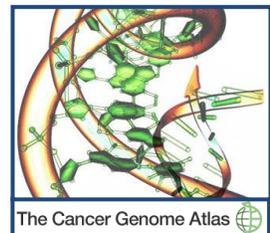
Research

Research Fund Established

ITMIG is very thankful for an extremely generous donation from Richard and Kathleen Ossey in Oregon, who have launched a research fund. This will have a significant impact in facilitating research using the infrastructure that ITMIG has developed. Nurturing the growth of this fund over time will continue to be important – we have built a tremendous amount through donated time from ITMIG members, but not everything is possible only through volunteer time. Richard and Kathleen Ossey have given us a major tool to help us move forward.

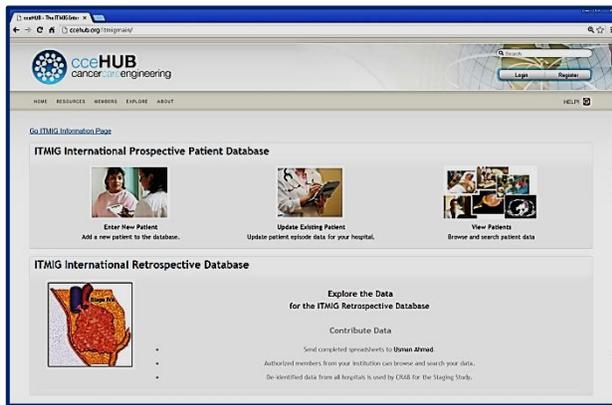
The Cancer Genome Atlas (TCGA) project

We have an opportunity to participate in the 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. The opportunity to have thymic disease included in this project builds a resource that is likely to have a great impact for future studies. Shipping of cases to the Core lab will be completed by January 2014, with analysis to follow.



Randomized Controlled Trial of RT

ITMIG continues to work on being able to conduct an international randomized trial assessing the role of adjuvant radiation in resected Thymoma and Thymic Carcinoma. Being able to conduct such a trial is something that was unimaginable a few years ago and is unprecedented for a rare disease. There are still barriers to overcome, but we have approval from the ECOG Executive Committee (US) the Medical Research Council (UK) and the EORTC (Europe), with discussions with Asian cooperative groups ongoing. This has been made possible by the strength of ITMIG and the help of the International Rare Cancers Initiative (IRCI), an international organization devoted to overcome the barriers to such international research. Heather Wakelee and Daniel Gomez have tirelessly built collaborations, overcome hurdles and remained undaunted by seemingly impossible challenges to bring this project to this point in a relatively short time.



Prospective Database

Now that the retrospective DB is essentially ready for use, we have to demonstrate the same engagement to populating the prospective DB. This will be a quantum leap forward again from the retrospective DB. It will require only a small amount of work at any one time, but requires a different commitment to entering data on cases as they occur. The sense of accomplishment is not as tangible, but ITMIG members have shown tremendous commitment and resourcefulness towards progress. The benefits from this will be

huge. We will have to work not only locally at each institution but also centrally to develop the processes that allow us to collect high quality data. We have astounded everyone in what we have pulled together to accomplish so far – if we each put in a small amount of time on an ongoing basis the result will be even more impressive.

Other Initiatives and New Ideas

Other research initiatives are also in development, ranging from intrapleural therapy to biomarkers. New ideas are also always welcome. Anyone interested in contributing to any of these initiatives or with new ideas should contact Heather Wakelee hwakelee@stanford.edu.

Office of Rare Disease Research Grant



ORDR
Office of Rare
Diseases Research

The grant submission was sent to the NIH in early November. This was a HUGE undertaking (>300 pages) and we want to thank all of those who supported this effort but most of all Bob Korst who was leading the effort. He put tremendous effort and time into the submission and we are thankful for his leadership on this initiative. As a reminder, the grant from the US National Institutes of Health (NIH) is made available every 5 years for groups focused on rare diseases. If ITMIG is successfully able to compete for this grant, it would take us to another level. The grant will be reviewed and scored in the spring, with funding to start in July of 2014. Bob Korst has put together a very strong proposal

There are many specific initiatives and requirements set by the NIH, and to meet these ITMIG has developed a number of very specific projects to be carried out in a limited number of centers able to fully commit to doing these. One subproject involves defining preoperative characteristics that identify tumors at high risk of local recurrence. Another involves developing an understanding of how to evaluate response to chemotherapy (i.e. how well does radiographic response correlate with histologic response,

given the varying lymphocyte content of thymic malignancies). A third project uses the prospective database for the purpose of the collaborative observational study. Finally the grant also includes a pilot project program, in which ITMIG will solicit applications and have the ability to fund a series of pilot research projects.

Although the structure of the grant is quite specific, the grant will have many benefits for ITMIG as a whole. The infrastructure that will be built for the projects in the grant can be adapted for use by ITMIG members in general. It allows us to refine processes of carrying out prospective research studies that will benefit us for non-ORDR grant studies. The insights gained from the ORDR projects are by design provide fundamental building blocks for additional clinical and basic research. The pilot project program is a mechanism to foster the development of new initiatives within ITMIG. Finally, the ORDR grant would put us in a better position to compete for other grants.

Development of a Network of Patient and Family Member Advocates

We have begun to develop a network of advocates. This is a direct outgrowth of the ORDR grant, which requires this. However, this should extend beyond the grant. The more people we have actively trying to find ways to make progress in a rare disease the better we will be able to accomplish it. While ITMIG has always had a close collaboration with the Foundation for Thymic Cancer Research (FTCR), we need to strengthen our mechanisms of interaction. We have to foster the growth with local patients and advocates. There are many things we need to do to increase awareness, stimulate new initiatives and collaboration. ITMIG will hold regular conference calls with the people who have volunteered to support ITMIG and its mission to fight thymic malignancies. If you are interested in participating, please contact Pam Bruce pbruce@thymic.org.

New Projects in Development

HUBzero expansion

In 2014 one of our major goals will be to expand the HUBzero platform. This would include developing the process for adding images (radiographic, microscopic) to accompany case entries in the prospective database. This would provide a rich resource for future research. This represents an innovative building of infrastructure that has not been done in any other cancer type. We need to centrally develop the process and technical aspects of this, but at the ITMIG member institutions we need to similarly develop habits and policies that allow this to be accomplished.

The HUBzero expansion plan also includes an automated system to ensure quality control and completeness of the data. While this will take an initial investment of time and money, it should save us all time and manpower in the long run. Both of these HUBzero projects are ready to start but are in need of funding to move forward.

Availability of ITMIG Standards

We want to remind people that ITMIG has a great resource ready to be used. The summaries of the ITMIG standards (published in the JTO supplement devoted to ITMIG July 2011) have been translated into multiple languages. So far we have translations into French, German, Spanish, Italian, Polish, Romanian, Hebrew, Japanese. We have to work on dissemination, both through the website as well as mailings in order to get them in the hands of the people who need them. If you need one of these, the laminated mediastinal boards, or want to volunteer to translate this into another language please contact Pam Bruce pbruce@thymic.org.

Education Committee

Part of the mission of the education committee is to address areas where data, definitions or guidance would help foster better collaboration and progress. The group is exploring publishing another supplement in the Journal of Thoracic Oncology or to publish a series of articles based on many of the projects the committee is working on. Some topics that we would cover are:



A modern Definition of Mediastinal Compartment; Histologic Classification of Thymoma - A Practical Guide for routine cases; ITMIG node map for Thymic Malignancies, An approach to patients with an anterior mediastinal mass for clinicians and radiologists. These papers are in various stages of completion.

Website

The ITMIG website is in the process of being upgraded. Our goal is to create a more user friendly site with more resources. As we have grown in the number of activities we have outgrown the ability of the platform to handle the technical needs. If you are interested in contributing to this effort please contact Pam Bruce.

Fundraising Drive

Starting with the ITMIG meeting, we conducted a fundraising campaign among ITMIG members to make a tax deductible donation. ITMIG members already donate hundreds of hours of time, but money is needed for some things. This campaign was successful in raising \$14,000. This provided a great boost. ITMIG is finishing the year having paid all of its debts, and is able to look forward to new initiatives and findings ways to get them accomplished. If you would like to make a charitable donation, we can always put any amount to good use (look at what we have done)> Please contact pam Bruce if you are interested. ITMIG is a not-for profit organization.

Building a Network of Regional Representatives

ITMIG is launching a campaign to develop a network of local champions in different countries and regions. These are people who can help spread the word about ITMIG in their region, and can help us adapt ITMIG tools to regional needs (language, technical interface etc.). If you are interested in being active to help make ITMIG more accessible in your region, please contact Pier Luigi Filosso pierluigi.filosso@unito.it or Pam Bruce pbruce@thymic.org.

Membership Dues

It's time to pay membership dues for 2014. The ITMIG website is set up to do with a few clicks. Although the membership voted to increase the dues to \$100 at the September meeting, this is still markedly less than most professional organizations. The dues we collect are vital to keep us moving forward and able to meet our basic costs. Please take the time and pay this now (www.itmig.org – members area, click on pay dues)!

Membership

ITMIG continues to grow every month! Currently our membership has nearly 575 members. Every month and at every conference we gain more recognition around the world. And there appears to be more and more interest in learning about thymic malignancies. In fact, at the World Lung conference in Sydney the room was overflowing with people who were interested in hearing about ITMIG and thymic malignancies.



Want to Get More Involved?

ITMIG continues to build its culture of being an open society devoted to creating resources that promote progress. If you have ideas or a project you want to pursue, we encourage you to get involved so we can use the strength of ITMIG to help it along.

All of the existing work groups and committees continue to hold regular conference calls to keep up the momentum with projects. Some of these groups are: Database Committee, Thymic Carcinoma Workgroup, Research Committee, Membership Committee, Steering Committee. If you are interested in joining any of our groups please contact Pam Bruce.