April 2011 ITMIG Update

Much progress has been made on several fronts. This update covers activities of ITMIG since January 2011. This is also posted on the website (<u>www.itmig.com</u>) along with the January 2011 update.

March Pathology Workshop

A highlight of this spring was the March pathology Workshop, a 2 ½ day event that took place in NY on March 25-27, organized and led by Alex Marx. Details of this are covered in a separate attachment. This involved 24 experts from around the world, including both pathologists and clinicians, who assembled to discuss the state-of-the-art of histologic classification of thymic malignancies, and issues that needed attention.

The meeting began with a series of "brainstorming" presentations by each participant, which highlighted the advantages and disadvantages of current classification schemes, and ideas about how one might address some of the problem areas. This was followed by much discussion, organized around a slide review of problematic cases. Much creative thinking ensued during this discussion, and several novel ways of thinking about thymic tumors and criteria that should be considered for classification began to emerge. All the while the tension was considered between subtyping and fostering exploration of new areas and the practical matter of having truly reliable knowledge on which to base patient management decisions. This was a stimulating and extremely productive session. Finally, a summary discussion centered around developing a concrete strategy for next steps. Among several initiatives a follow-up meeting is being planned in Heidelberg in the fall of 2011.

The meeting did not resolve all the issues, of course. This would have been impossible and was never among the goals. However, it clearly established a spirit of open minded examination of advantages and disadvantages and problems with the current status of histologic classification, and brought about collaborative collective thinking "outside the box" to find ways to transcend the existing shapes of pegs and holes. The spirit and atmosphere at this event was a tremendous accomplishment and definitely a highlight among ITMIG undertakings.

JTO Supplement Issue on ITMIG Policies and Definitions

The results of the November workshops have been written up as papers, summarizing the consensus on standard policies, procedures and definitions for ITMIG to use in order to achieve consistency and make collaboration possible. These papers have been through extensive debate and refinement, and were overwhelmingly accepted for adoption by the ITMIG membership. The final papers have been accepted for publication in a special issue of the Journal of Thoracic Oncology, which will be printed in late June, 2011. This represents a huge amount of work, and is nothing short of a quantum leap forward in building a foundation to advance the science.

We are currently working on developing an institutional "tool kit" with materials summarizing what different clinicians need to know or have available at the point of care. These will be available by the time of the Amsterdam meeting for anyone who would like them.

<u>Database</u>

A tremendous amount of work has gone into creation of an international database. This effort has been led by Jim Huang, chair of the database committee, and Ann-Christine Catlin, Senior Research Scientist at Purdue University. Data elements that have emerged from the November pathology workshops have been assembled in a user friendly web-accessible format on the HUBzero platform at Purdue University. The database is currently undergoing refinement by the workgroup leaders of the November workshops, and will be ready for use by the time of the Amsterdam meeting, which was our original goal. Those who have seen this have been very impressed at its sophistication, level of detail and crosslinking, and its friendly interface. Educational tools and other resources to facilitate implementation are currently being developed. At least as important as the work of developing the face of the database has been the work in solving the regulatory issues. Through extensive work by ITMIG and the legal and confidentiality office at Purdue University, a process has been worked out so that the data can be entered easily, yet stored in a completely de-identified manner. This means that individual patient consent is not needed, and each individual research project does not need to clear regulatory hurdles that would have been stifling without this process. This also allows the data to be shared with CRAB for use in the staging project, and with individual groups and organizations such as the ESTS thymic group if they choose to use the ITMIG website to house their data. This is also a quantum leap forward in realizing our goal of developing a resource for all to use, with no major restriction on accessibility.

<u>Website</u>

Finalization of an ITMIG website upgrade has been much more slow to be accomplished than was anticipated. The website is up and running, but some features are still being worked on. The new site has much more depth that the previous one, and is being continually updated with posting of the minutes of committee meetings, news updates and more. It is also the portal of entry to the thymic tissue bank or the HUBzero ITMIG database. It is fairly close to the interface for ITMIG activities that we had envisioned. Daniel Gomez has led this effort.

<u>Members</u>

ITMIG has continued to grow, and now has a little over 325 members, and the growth rate does not seem to be slowing. However, there are still individuals who are aware of ITMIG and, in fact, involved in ITMIG initiatives, but who have not registered as members. Unfortunately, it makes it difficult to maintain communication consistently, and leaves them out of the resources which are now coming to fruition.

ITMIG also needs to figure out how to match members' interests with the needs of the organization. There are countless projects ready to develop, missing only an individual who wants to take ownership and drive it forward. At the same time, there are members who want to get involved and don't know how to. We have to solve this gap. ITMIG is an open collaborative and welcoming group. You don't even have to raise your hand – you only have to lift your finger and click your mouse. Let Pam Bruce or any ITMIG workgroup or committee member know if you have an idea or an interest in a particular area. There are plenty of things to do, and the more we pull together the more we will accomplish.

ITMIG is asking members to pay membership dues of \$50 per year. We want to keep this rate very low in order to keep it affordable. However, it does represent an important source of income that allows us to build the infrastructure of ITMIG. We urge everyone who has not yet done so to please visit the website <u>www.itmig.com</u> and pay dues via the online system.

I also want to remind people that ITMIG is an open society, and that anyone wanting to participate in steering committee conference calls is welcome to do so (just let Pam Bruce know). We want people's ideas and thoughts to be heard.

Upcoming Elections

Yes, it is that time again. The structure of ITMIG calls for the election of new officers in 2011 (President, Vice President, Secretary and Treasurer), to assume the role in 2012. However, they would begin participating in the steering committee (SC) meetings at the 2011 annual meeting so that there is some transfer of organizational knowledge and consistency in ongoing projects, while also bringing in new blood and ideas.

ITMIG members are encouraged to nominate themselves or others. This is an open invitation – there is no requirement of recognition or experience, only a willingness to contribute. The ITMIG philosophy is <u>not</u> to view the steering committee positions as a sort of predetermined ladder or as a position of prestige, but as a position of responsibility. ITMIG is an open, flexible society in which change can occur easily and fluidly as best serves us in allowing this organization to flourish.

Please send your nomination to Pam Bruce at <u>pbruce@thymic.org</u> by June 15, 2011. Don't be shy. This is about accomplishing a goal and the satisfaction of making progress, not about politics or prestige.

Annual Meeting

The ITMIG annual meeting is schedule to take place in Amsterdam on July 7 and 8, immediastely following the IASLC meeting (World Conference on Lung Cancer). We encourage all ITMIG members to attend. This is especially important in this stage of our gestation. The program features a session on innovative treatments for stage IVa thymoma, imaging, the extent of surgery needed, and abstracts and posters with a 1,000 euro prize going to the best abstract and presentation. There is a session to get us started on our goal of developing an "outlier analysis" approach to research, like the airline industry does with crashes. The innovation session features speakers on the mechanism of metastasis and the relationship of cancer and the immune system by two of the world's leaders in these areas. There is also an update on ITMIG projects and the roll-out of the database.

Just before or just after the annual meeting we will conduct business meetings of many of the ITMIG committees and workgroups. A schedule for this will be posted on the website and emailed out separately. Anyone interested in a particular workgroup is welcome to attend these additional meetings.

If you have not yet registered for the meeting please do so, either through the ITMIG website or through <u>www.congresscare.com</u>.

New projects

Several new initiatives are under development. These include a thymic carcinoma workgroup, a mediastinal tumor workgroup (to address other non-thymic mediastinal tumors) and a pathology workgroup. If you are interested in any of these please let us know and get involved. These workgroups will be meeting face to face in Amsterdam in July.