

Jan update

It is always a different feeling looking back at what has been accomplished vs looking ahead at what still needs to be done, but it is time to do both and summarize what has been happening within ITMIG.

In 2011, a big focus for ITMIG was to work with Purdue University to build a sophisticated international database. In 2012, the goal is to actively contribute to the database. Implementation of the prospective and retrospective database is close to launch. A few small details of the legal and regulatory structure are still pending, but should allow us to contribute easily and maximize use of the resource. It is certainly time for ITMIG members to work out within their institution how they will manage their internal process, and to collection of retrospective cases should be well underway. Each institution should have one person who is willing to take ownership of thymic data for that institution, and organize the process among their group of collaborators. We expect to announce the launch within a few weeks. It will be critical for us to demonstrate that we can actually deliver the goods and enter data instead of just talking about how great it would be if we could. So get ready, roll up your shirtsleeves and expect details of the launch soon.

In December, the 2nd pathology conference for 2011 was held at the University of Heidelberg in Mannheim, Germany. A separate summary of this is attached. Further progress was made in identifying problem areas with the histologic classification and trying to develop solutions for us moving forward. Additional work is ongoing now by email. Well established, however, is the spirit of collaboration, focus on a goal, and willingness to challenge existing thinking.

Plans for the 2012 ITMIG meeting are well underway. This will take place in Fukuoka, Japan on November 25, 26, in conjunction with the APLCC (Asia-Pacific Lung Cancer conference) from Nov 26-28. The meetings are being planned as a very integrated joint event, and we hope that ITMIG members will make use of the opportunity to attend the APLCC and vice versa for APLCC members. There will be debates on controversial topics, innovative lectures, many updates on ITMIG activities and prizes for the best submitted papers. There will also be an opportunity to explore a wonderful part of Japan. We certainly hope to see you there. Further details regarding this event will be coming soon.

The research committee has been active in developing concrete trials for ITMIG to pursue. There are many hurdles with organizing such an effort across the globe, but we have help from the IRCI (International Rare Cancer Initiative), a multinational effort to help surmount many of the hurdles we face. We are proceeding with a variety of research projects, ranging from simple studies that involve only a few collaborators to a global randomized study, and involving traditional approaches and statistics to more novel designs. As soon as there is more clarity about the regulatory and funding issues we will provide further details. Anyone interested in participating in the process should contact Heather Wakelee.

Edith Marom has led an effort to develop an interactive educational resource that will be up on the website soon. We hope to follow this with further such resources soon thereafter regarding the areas we have developed standards for. Development of such modules is not rocket science, but we are having troubling sharing the work that needs to be done. There are so many tasks, both major and minor that can use someone's attention. I have the feeling there are individuals who say they are interested but then don't know how to get engaged, and others who are so engaged they can't keep up. This is a small, open organization. We have to pitch in where we can. It is up to us to take initiative, so please reach out to myself or committee/workgroup leaders to voice your ideas or willingness to take ownership of a project that is languishing.

We are developing plans for a meeting at the US NCI to discuss what ITMIG has done, and how best to position ourselves for NCI supportive funding. We have a fighting chance for this, but we need people to pay their dues, sign up and actually contribute their data, get involved - with moving some of the many projects along, developing a greater global network of interested patients and families that can network and fundraise for us. Finally we need to actually roll out a collaborative research project this year.

With the start of the new calendar year, it is time to pay annual dues for ITMIG. The cost is very low (\$50 US), certainly compared to other organizations. This gives us a very important small amount of

operating money and allows us to leverage for other support, so it is very important for the success of ITMIG. Unfortunately, in the past a large number of ITMIG members have not contributed their share of support that they pledged by signing up as members. We have to do better, so please do it now before it gets buried under the barrage of other things.

Finally, I want to let you know that ITMIG was asked to give a presentation at ASCO and to write a paper for the educational book on “ITMIG as a role model for progress in rare diseases”. I think this shows we have done a lot. Let’s keep gaining momentum – coasting eventually leads to standing still.

With warm regards,

Frank