# LETTER FROM THE EDITOR

Can you name the six US airports named after US presidents? Well, I just flew between two of them: Washington National (for the Democrats)/Reagan (for the Republicans) and George Bush (Houston). The others are JFK (New York), Abraham Lincoln (Springfield, Illinois), Gerald R. Ford (Grand Rapids, Michigan), and Theodore Roosevelt (Dickinson, North Dakota). There were a couple of reasons for the journey. One was to chair the Scientific Advisory Board (SAB) meeting of the Lymphoma Research Foundation (LRF), awarding about a million dollars to support high-quality fellowship and career development grants. The other was a bit more challenging. One of the LRF's Board members—the Board being composed mainly of wealthy lymphoma patients, unlike the SAB, which is composed of non-wealthy doctors—decided it was time overdue to cure his follicular lymphoma. A decade ago, he went through chemotherapy and an autologous stem cell transplant (no comment), and remains in remission to this date. Nevertheless, he wants a cure not for lymphoma in general, but specifically for his follicular lymphoma. So, he decided to encourage the LRF to convene a meeting at which attended 6 members of the Board, 11 members of the SAB, and a facilitator (see my letter from a few years ago about meeting facilitators—my impression remains the same).

Our team was composed of an exceptional, and feisty, bunch of clinical and translational researchers. We spent the first 5 and a half hours developing and then prioritizing a list of important Advocacy (A), Clinical (C), or Translational (T) (ACT!) topics that need to be addressed to either cure follicular lymphoma or convert it to a disease with a survival outcome commensurate with an age-matched population (two very different ways of thinking about things), and design ways in which, with appropriate funds, the LRF could facilitate their implementation. We discussed workshop-defining endpoints for clinical trials and patient selection, a new mechanism for grants, mandating inter-investigator collaboration; targeted requests for applications and seed grants, both focused on follicular lymphoma (not his, but FL in general); and a number of other high-, intermediate- and low-priority items. We would draft a white paper for circulation and a somewhat different marketing document for the patient-fundraisers. After such a meeting, it is appropriate to ask the stakeholders whether they got what they wanted out of our efforts. For perhaps the first time the response was "No"! The SAB members were startled, to say the least. The patients didn't want to hear about infrastructure, cell banks, grants, and the like. They wanted the follicular genome mapped, which they felt was the key to the problem. They also insisted that a pathway be identified so that it could be impeded, or some other target clearly defined so it could be attacked and destroyed. And they wanted a pathway or target identified that day so they could raise money directed toward those efforts.

The Board members were finally pleased after dinner when we came up with a catchy objective regarding personalized therapy as the means to curing the disease, and identified a few critical areas, including the genome, the microenvironment, and the heterogeneity of the disease.

What the meeting did was to, indeed, highlight the obstacles we face in the pursuit of progress. These range from a lack of sharing of tumor and cell banks (in part because of a lack of information as to who has what), a lack of understanding of drug (especially rituximab) resistance, and an inability to predict (and prevent) aggressive transformation, to the unavailability of exciting new drugs for collaborative studies (don't get me started on that one!).

It boils down to the fact that it would sure help if significant amounts of additional money could be raised from alternative sources to support both translational and clinical research. However, money is not enough: we need new ways to conduct science not-as-usual. Scientific collaboration is critical, and we decided that the requests for proposals for new grants funded with these monies would mandate a demonstration of collaboration amongst investigators. We clinicians will need to work with our translational colleagues and biotechnology collaborators to define new structures for conducting clinical research if we are to move forward to that goal of personalized medicine as the mechanism for cure.

Until next month…

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