

What goes on at the annual RSRF symposium?

By Vicky Brandt, Skirball Institute of Biomolecular Medicine, NYU School of Medicine

Scientists are social creatures. Lab meetings, seminars, conferences, symposia... the scientific life is propelled by dialogue with other scientists. So it is not surprising that a research foundation like the RSRF would have an annual symposium to provide a forum for scientists with different areas of expertise to interact, share ideas, and challenge one another (in a respectful way, of course). What is a bit different about the RSRF meeting, however, is its emphasis on not-yet-published research and the Knowledge Gap meeting that takes place with the Scientific Advisors and a select group of senior researchers in the field. The RSRF Board of Trustees also takes advantage of the time to meet, evaluate where the organization is headed, consider the successes of the past year and set new goals.

This year's 7th Annual RSRF Symposium began on Sunday, June 25, 2006 with a presentation by Dr. Huda Zoghbi for parents, families and friends. (Dr. Zoghbi's slide presentation is posted on our [web site](#); there is also an accompanying [Research Update](#) that describes the current state of knowledge in the Rett field.) The



Omar Khwaja, the director of the new Rett Syndrome Clinic at Children's Hospital Boston, participates during a discussion session.



Poster Session

next

morning, Monica Coenraads, Scientific Director and a co-founder of RSRF, began the Monday all-day Board of Directors meeting with an overview of funding activities. In 2006, 92 letters of intent were submitted to the RSRF. Forty-three percent of these projects were suitable enough to RSRF interests that the investigators were invited to submit a full research proposal outlining their rationale for studying the particular problem they've chosen and justifying their chosen approach and their proposed budget for the work. These proposals then undergo a process known as peer review, the scientific equivalent of trial by jury: four scientists, specialists in the Rett field, scrutinize each proposal for potential problems, relevance to Rett, and likelihood of success. This year RSRF will award funds totaling \$2.3 million to 22 investigators. As interest in MeCP2, Rett, and related disorders takes off, RSRF expects to be receiving a great many more worthwhile grant proposals. The challenge is to meet the rising demand with expanding resources.

The Symposium itself began officially on Monday evening with an overview of the clinical symptoms presented by Sarojini Budden and Larry Swanson. The evening also provided free time for scientists to network as well as mingle with a handful of local Chicago families who came with their daughters. The remaining two days featured 20 talks, multiple discussions and two poster sessions.

At the Knowledge Gap meeting on Tuesday afternoon, there was lively discussion about the most promising avenues to pursue next in MeCP2 research. There was palpable excitement about the progress that has been made and eager anticipation of being able to translate the scientific discoveries into practical benefit for our families. Although the consensus was that we are not yet ready to invest in translational research, there was a sense that the field has made astonishingly rapid progress in the past seven years since the gene discovery. A lot more work needs to be undertaken in the lab to understand the neurobiology of MeCP2 dysfunction and to find potential targets for therapies— and it is taking place in labs all over the globe, thanks, in part, to RSRF. We came away from the Knowledge Gap meeting with several solid recommendations for directions to take in the coming year, and we will keep the Rett



Huda Zoghbi and Gail Mandel, symposium co-chairs, with Ely Nedivi of MIT.

community informed as we lay the groundwork for the future.



Carol Toft and her daughter mingle with researchers

After the symposium, Monica Coenraads conducted an online survey to gauge the success of the symposium from the researchers themselves. Eighty-seven percent of the participants responded that the symposium allowed them to meet someone with whom they will either collaborate or share information, data or techniques. Furthermore, 81% believed they learned something at the symposium that will save them time, money or accelerate their ability to reach a research goal. Finally, 79% of the participants learned something at the symposium that could alter the direction of their research in a positive way. These figures indicate the value of the symposium to the scientific community, and we will strive to make the meetings ever more useful to the scientists who are working so hard to help us.

To learn more about researchers' current understanding of the genetics and neurobiology of MeCP2 as it pertains to Rett syndrome, please see the accompanying "Research Update July 2006: Where do we Stand Now?" article or glance through the webcast of the

"State of the Research" presentation by Huda Zoghbi, M.D.

- [Article](#)
- [Webcast](#)