

CONVENTION ORGANIZERS:

The convention is to be hosted as a joint effort between *The Robinow Syndrome Foundation*, based in Minnesota and a group of multidisciplinary investigators studying varying aspects of Robinow Syndrome at the University of Minnesota and the Mayo Clinic. The Convention co-chairpersons and organizing committee are listed below.

CONFERENCE CO-CHAIRPERSONS:

Karla M. Kruger, President & Founder, *The Robinow Syndrome Foundation*, Andover, Minnesota

Kim R. Ortiz-Kremeier, Research Manager, *The Robinow Syndrome Foundation*, Shell Knob, Missouri

Jamie L. Lohr, M.D. Assistant Professor of Pediatrics, Division of Pediatric Cardiology, University of Minnesota School of Medicine, Minneapolis, MN

Karla Kruger and Kim Ortiz-Kremeier

Together are co-chairpersons of the 2008 Robinow Syndrome Foundation convention. Karla & Kim are both parents of affected children. Both have successfully co-coordinated all of the prior RSF meetings, with assistance from some host families. Karla, along with Kim maintain the daily functions of the Foundation which includes a database, recording of medical research and literature and family contacts. Both assist families in advocating for medical care, answer questions and offer information of any known or recommended specialists. The RSF website: <http://www.robinow.org> which provides notification and registration for patients, families, medical and educational personnel is maintained by both. They also co-ordinate patient and family registrations, provide award opportunities for families in need of financial support to attend the conventions and they co-ordinate all social activities.

Dr. Jamie Lohr, co-chairperson. Dr. Lohr is a Pediatric Cardiologist at the University of Minnesota with an interest in early heart development, particularly that of the cardiac outflow tract. Dr. Lohr has studied the role of Wnt signaling in cardiac development, and is interested in the subset of genes that cause both craniofacial and cardiac defects. Dr. Lohr attended the 2006 Robinow Syndrome Convention in Dayton, Ohio with Dr. Soraya Beiraghi, to enroll patients with Robinow Syndrome in a study to determine if genes in the Wnt signaling pathway were implicated in this disorder. This work led to the discovery of functional mutations in Wnt5a in one of the initial families in which Robinow Syndrome was described and an additional sporadic case with a dominant phenotype (Person, et al, in preparation). Dr. Lohr will oversee all aspects of convention organization, finalize speakers and agenda for the scientific sessions and coordinate research opportunities for the participating investigators and families.

These are currently scheduled. Subject to change & additions.

LOCAL ORGANIZING COMMITTEE:

The organizing committee is a collaborative group of researchers at the University of Minnesota and the Mayo Clinic.

Soraya Beiraghi, DDS. Professor and Chief of Pediatric Dentistry, University of Minnesota School of Dentistry, Minneapolis, MN.

Dr. Beiraghi is a pediatric dentist who provides clinical care to patients with Robinow Syndrome and other craniofacial disorders through the University of Minnesota School of Dentistry and Craniofacial Clinic. Dr. Beiraghi is an experienced clinician and dysmorphologist who first hypothesized a role for Wnt5a in Robinow Syndrome.

Stephen Ekker, Ph.D. Professor, Department of Biochemistry and Molecular Biology and Consultant, Mayo Clinic, Rochester, MN. Adjunct Professor, Genetics, Cell Biology and Development, University of Minnesota, Minneapolis, MN.

He is a geneticist and developmental biologist with expertise in Wnt signaling and the modeling of human disorders in zebrafish. Dr. Ekker recently left the University of Minnesota for the Mayo Clinic but has continued his collaborations with this group. Dr. Ekker will serve as a liaison for the scientists and clinicians from Mayo Clinic.

Anna Petryk, M.D. Assistant Professor of Pediatrics, Division of Pediatric Endocrinology, and Genetics, Cell Biology and Development, University of Minnesota School of Medicine, Minneapolis, MN

She is a pediatric endocrinologist in the department of pediatrics at the University of Minnesota who studies the role of novel genes, including Wnt5a and twisted gastrulation in craniofacial development using a mouse model system.

Lisa Schimmenti, M.D. Associate Professor, Departments of Pediatrics and Ophthalmology, Division of Genetics and Metabolism, University of Minnesota, Minneapolis, MN

She is a pediatrician and medical geneticist with an emphasis in the modeling of human genetic disorders with an emphasis on disorders of eye formation and hearing. She has agreed to serve as our keynote speaker and will serve in an advisory role on the organizational committee.

ADMINISTRATIVE SUPPORT:

Ann Hagen, of the MinnCRest Craniofacial Research Training Program, School of Dentistry, University of Minnesota, She will continue to supply support for the Scientific sessions of the 2008 Robinow Syndrome Foundation Convention. Ms Hagen's time is donated by the MinnCRest Program and she has assisted with speaker invitations, sponsor invitations and advertising and promotions.

Christine Sieben, of the department of Pediatrics works for Dr. Lohr.

She has secured the convention venue and coordinated catering. She will be responsible for registration for scientific attendees, creation and distribution of the session syllabus, coordination of childcare and overseeing the general implementation of the scientific sessions.

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