Summer 2012 Newsletter

SIMONS VIP CONNECT

VARIATION IN INDIVIDUALS PROJECT

Simons VIP Connect Family Meeting a Success!

One hundred and five participants from twenty-eight families attended the second family gathering focused on 16p11.2 deletions and duplications.

The weekend began on Friday, July 13, 2012 with registration and a family hospitality room for families to stop by and meet each other.

Saturday morning began with breakfast before presentations started. Childcare was provided and the kids enjoyed playing games and doing craft projects and other activities!

Presentations given at the meeting included updates on 16p11.2 deletions and duplication and next steps for the Simons VIP study, as well as talks about managing difficult behaviors, advocating for children and caring for the caregiver. An open panel of study team members and presenters also answered questions from the families.

Log-in to the Simons VIP Connect website (www.simonsvipconnect.org) to download the speakers' slides and watch the presentations!
You can also view the family slideshow created by Belinda Chatman!

Throughout Saturday and on Sunday morning, many of the families volunteered their time participating in research activities. These activities included a study of brain activity by EEG, a motor skills evaluation, and a blood draw to perform metabolic testing and to study cell signaling and gene expression. **For more information about research activities performed at the family meeting, please see the webinar on the Simons VIP Connect website!**

Fun at the Family Meeting

Families and Simons VIP staff spent the evening of July 14th at the Field Museum in Chicago! After dinner, families got to explore the museum, dress up and take pictures in a photo booth, learn about insects, hold a tarantula, and much more!







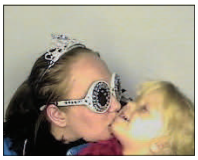




To see more pictures from the weekend, log-in to the Simons VIP Connect website: Members —> Family Meet 2012








Family Resources

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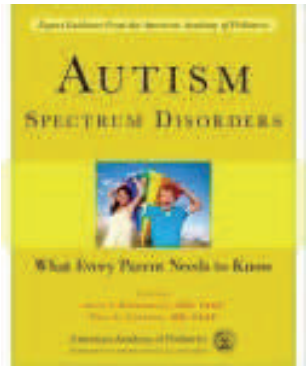
New Book by American Academy of Pediatrics



Title: Autism Spectrum Disorders: What Every Parent Needs to Know
Author: American Academy of Pediatrics
Editors: Alan I. Rosenblatt, MD, FAAP and Paul S. Carbone, MD, FAAP

Available in October at bookstores.
Available now at www.healthychildren.org/AutismBook

Autism Spectrum Disorders: What Every Parent Needs to Know is the perfect go-to guide for parents and caregivers of children on the autism spectrum, from babyhood through adolescence and beyond. From the nation's leading authority on pediatric health care with the guidance of distinguished pediatricians and autism experts Alan I. Rosenblatt, MD, FAAP, and Paul S. Carbone, MD, FAAP, father of a child with autism, Autism Spectrum Disorders delivers a refreshingly comprehensive and accessible index of the most up-to-date expert medical and behavioral advice.

Offering valuable information on the different types of ASDs, from autism to Asperger syndrome to pervasive developmental delay-not otherwise specified (PDD-NOS), Autism Spectrum Disorders provides a number of screening tools and advice so parents can effectively partner with their child's pediatrician to provide the best possible care for their children with autism.

United Healthcare Children's Foundation Provides Grants to Families

The United Healthcare Children's Foundation (UHCCF) is seeking grant applications from families in need of financial assistance to help pay for their child's health care treatments, services or equipment not covered, or not fully covered, by their commercial health insurance plan.

Qualifying families can receive up to $5,000 to help pay for services and equipment such as physical, occupational and speech therapy, counseling services, surgeries, prescriptions, wheelchairs, orthotics, eyeglasses, and hearing aids.

To be eligible for a grant, children must be 16 years of age or younger. Families must meet economic guidelines, reside in the United States, and have a commercial health insurance plan. Grants are available for medical expenses families have incurred 60 days prior to the date of application as well as for ongoing and future medical needs. Parents or legal guardians may apply for grants, and there is no application deadline.

"The United Healthcare Children's Foundation is dedicated to improving a child's health and quality of life by making it easier to access needed medical-related services. The grants enable families to focus on their children's care instead of worrying about how they'll pay their medical bills," said Matt Peterson, president, United Healthcare Children's Foundation. "Eligible families in need are encouraged to apply online for a medical grant today and take advantage of this valuable resource."

To apply, visit the UHCCF website - bit.ly/LnCAcJ

Family Facebook Group Changes Name
"Gathering Group – 16p VIPS"

Web Resources!

The Global Genes Project: Advocacy group that supports the needs of the rare and genetic disease community and brings rare conditions together to promote research and therapy programs
http://globalgenes.org

16p Chromosome Abnormalities Blog: A family run blog on 16p that features posts about 16p families, as well as tips and information about therapies, IEPs, and other common issues
http://16pchromosomeabnormalities.com

Wrightslaw: Provides parents, educators, and advocates information about special education law, education lab, and advocacy for children with disabilities. Check out the "Special Ed Advocate" newsletter—the recent issue focuses on back to school tips!
http://www.wrightslaw.com/

Simons VIP Connect Updates

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Family Meeting Follow-up

In the post-meeting survey over 95% of the families were satisfied with the meeting.
"I had no idea what to expect coming into this meeting. I left the meeting very happy that I went… It was wonderful to meet a group of families that understood, could relate, and had ideas to bounce off of each other. The information that I learned from the Simons team was beyond rewarding!"

"We had opportunities to gather with other family members every day. I do wish we had more time to spend with others. I would feel that way whether we had 3 days with them or a whole week. There just isn't enough time to really get to know everyone."

"The open forum was the most helpful where we could encourage one another to find support. Many of the parents expressed how much it meant to them to hear that other parents were experiencing similar issues. It created great solidarity, which is necessary for us to cope with this."

Families responded about the provided childcare
"We would not have been able to attend if it wasn't for the child care. Appreciated it very much!"

Everyone responded that Saturday evening at the Field Museum was a special evening.
"Great food! Awesome venue! Getting the chance to explore the great exhibits after hours was a neat experience for our family."
"It was fun, not just for the kids, but also for the parents."

All About Simons VIP Connect Families:

413 Families
— 338 in the USA including **47** states —
and from **11** countries

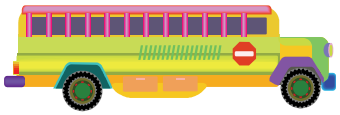
Families with 16p11.2 Deletion—**220**

Families with 16p11.2 Duplication— **101**

Families with 1q21.1 Deletion—**23**

Families with 1q21.1 Duplication— **17**

Families with other genetic changes— **52**



Survey on Infections, Temperature and Fever

During the panel discussion at the 2012 Family Meeting many families voiced concerns about the frequency of infections and fevers. Some parents reported that their child's "normal" temperature was higher than usual and that their child seemed to sweat more than other children. In response, the Simons VIP study team is asking all families with a 16p11.2 deletion or duplication to complete a short survey and to provide information about each child in their family.

We want to know about all of your children – those with a 16p11.2 deletion or duplication and those who do not have a chromosomal change. The survey is designed to provide information on up to 5 children per family. If you have more than 5 children, please contact us at coordinator@simonsvipconnect.org or 1-888-493-6682.

Depending on the results of the survey, additional information may be added to the Medical History Intake or evaluation as part of the study. We will share the results of the survey with you.

Complete the survey at
https://www.surveymonkey.com/s/TKW69CC

Neurology Interview Letter

Early results of Simons VIP indicate that epilepsy and seizures may play a larger role in 16p11.2 deletions and duplications than originally thought. The study is expanding to include gathering additional information from families about epilepsy by a phone interview.

All participants in the study should receive a letter soon about this additional project. If your child has been diagnosed with epilepsy at any time, please consider participating in this part of the study. Telephone interviews will be scheduled for each family with Dr. Sudha Kessler from the Children's Hospital of Philadelphia or Dr. Annapurna Poduri from Boston Children's Hospital.

Questions about this new part of the study can be sent to coordinator@simonsvipconnect.org.

Contact the Simons VIP Genetic Counselors:

Audrey Bibb, 404-778-8597, A.L.Bibb@emory.edu
Andrea Paal, 404-778-3213, Andrea.Paal@emory.edu

Contact the Simons VIP Newsletter Editor:

Bethanny Smith-Packard, 570-214-9136, bspackard@geisinger.edu