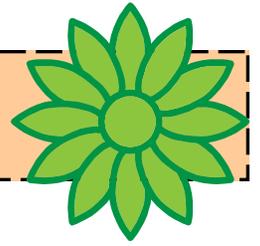


Spring 2011 Newsletter



SIMONS VIP CONNECT

VARIATION IN INDIVIDUALS PROJECT

16p11.2 Family Weekend in Gatlinburg, TN!

This summer, families of children with 16p11.2 deletions and duplications will have the chance to meet one another! A family weekend is planned for July 22-24, 2011 in Gatlinburg, Tennessee. This weekend will be a casual and informal gathering to allow the Simons VIP Connect families to get to know each other. A few members of the Simons VIP research team will also attend and speak during the weekend. Be on the lookout for a special newsletter in May for information about accommodations in Gatlinburg and a schedule of events.



To register for this family weekend, or for more information, please contact Dawn Miller at gathering@simonsvipconnect.org. Dawn is the parent of a child with a 16p11.2 deletion and is organizing this event.

Press Kit Now Available

Is your local newspaper or other news media interested in writing a story about your family? Simons VIP Connect has a "Press Kit" for families to use when approaching their local newspaper and/or other media outlets to enhance awareness of 16p11.2 Deletions and Duplications. To request our press kit materials, please contact Andrea. If you do have a story published about your family in your local paper, we would love to see it! Articles will be posted on our website with the permission of each family.

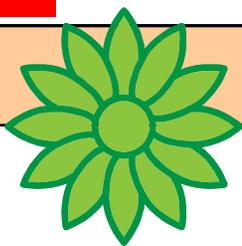


Simons VIP Connect Welcomes Bethanny!

Bethanny received a dual major in Bio-Molecular Science and Psychology from Clarkson University in 2007 and a Master's of Science from the University of Pittsburgh in 2009. She was board certified in genetic counseling in September, 2010. Bethanny works at Geisinger Medical Center in Pennsylvania and is excited to be part of the Simons VIP project. In her free time, she likes to read, watch movies, and play roller derby.



Bethanny Smith-Packard, M.S., C.G.C.



Update From Your Genetic Counselors

Andrea and Audrey are Genetic Counselors in the Department of Human Genetics at Emory University in Atlanta, Georgia

Audrey Bibb, M.S., C.G.C.

Andrea Paal, M.S.



Over the past several months, Andrea and Audrey have enrolled 52 families in the Simons VIP study. After completing consent paperwork and a medical history interview, these families will travel to either Houston, Boston, or Seattle for their clinical evaluation. Seven families have already completed their site visit and the remaining families will travel before the end of the summer. We plan to enroll 148 more families to reach our goal of 200.



All About Simons VIP Connect Families:

- 148 Families – 112 in the USA (found in 39 states) and 36 Internationally
- # Families with 16p11.2 Deletion – 81
- # Families with 16p11.2 Duplication – 44
- # Families with other genetic changes – 17

Simons VIP Connect Family Map



SIMONS VIP CONNECT
 VARIATION IN INDIVIDUALS PROJECT

Don't Miss Our Webinar Series!

Simons VIP hosts monthly webinars on topics of interest to 16p11.2 families.

Webinars are recorded and posted on our website for future listening. To access these, select the "About 16p" tab and click on "Webinars".

Many Simons VIP families have distributed these presentations to family, friends, and even their child's physicians to help educate them about the various medical aspects of 16p11.2.



Upcoming Webinar:

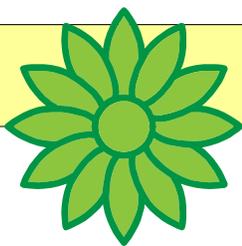
May 5th at 1pm EST

Speaker: Robin Kochel, Ph.D. Robin is a Developmental Psychologist and the Simons VIP Principle Investigator at Baylor College of Medicine in Houston.

Topic: Developmental and Behavioral Features of Children with Autism and Autism Spectrum Disorders.

Contact the Simons VIP Genetic Counselors:

 <p>Audrey Bibb 404-778-8597 A.L.Bibb@emory.edu</p>	<p>Andrea Paal 404-778-3213 Andrea.Paal@emory.edu</p> 
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New Discussion Boards Launched!

SIMONS VIP CONNECT

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Do you want to talk openly with other parents of children with 16p11.2 about your child's successes and challenges?

Do you have questions that you would prefer to ask other 16p parents in a private forum?

You now have the opportunity to do just that! The Simons VIP Connect Forum provides a safe and private area where members can share and learn from each other's experiences. All forums are moderated by Simons VIP Connect genetic counselors. Get started

communicating with other parents by logging in to our website and clicking the "Forums" tab.



New Contact Feature

You may now make instant online connections with other Simons VIP parents! Click the "Members" tab after logging in to our website, select the username of the parent you wish to

contact and write a brief message on the contact request form. The other parent will receive an email to alert them that you wish to communicate and will have the option to respond.

Our family matching service is also still available. If you'd like for Andrea or Audrey to match you with another Simons VIP family based on specific criteria, they are happy to do so.

Our site in Houston is now open and will see their first family mid-May!

Simons VIP Clinical Site Visits



L to R: Julia Wenegrat (Site Coordinator), Dr. Sean Ackermann (Research Assistant); Raylin, Jen Corpuz (Research Assistant)

"All and all it was a great trip! The team in Seattle went above and beyond to make sure that our visit was smooth. They made us all feel very at ease. Although there is still so much to learn about 16p, I feel I left Seattle with a better understanding of my Ashley. I want to thank you for allowing us to be a part of this study. I truly feel blessed."
- Melissa, mom to Ashley (16p11.2 dup)

"Our experience in Seattle was absolutely wonderful. We are so thankful for this opportunity. The team was super!!!" - Christie, mom to Raylin (16p11.2 dup)

Simons VIP has picked the crème de la crème to conduct their study. We could not have had a better experience. We were treated with such sincerity and compassion by the Boston Team. We absolutely loved Dr. Hanson and Alyss!! - Karen, mom to Daniel (16p11.2 del)

My kids loved everyone there and all of us were so comfortable. Cinco still asks if we can go back and visit "our new friends in Seattle". I am grateful that the doctors spent so much time with my children and were able to direct us to helpful resources. It was a great learning experience for all of us. - Deborah, mom to Cinco and Theo (16p11.2 dup)



L to R: Audrey, Stephanie Baker (Administrative Assistant), Sarah, Alyss Lian (Site Coordinator), Celia Tam (Research Assistant), and Daniel.