



# Simons VIP Connect Newsletter

## UPDATES from the STUDY TEAM

### 2014 Regional Family Meetings Updates!

Simons VIP Connect is hosting Regional Family Meetings on each coast!



Redwood City, CA (July 18-19)

Philadelphia, PA (Aug 1-2)



**Registration is open!**

Visit <http://sfari.org/svip2014> to learn more and to register!

### Family Meeting Registration

as of 5/1/14

#### Redwood City, CA

- 7 families
  - All deletion families
- 23 individuals (10 children)
  - Ages 1-17
- All first time attendees!

#### Philadelphia, PA

- 21 families
  - 16 deletion, 5 duplication
- 74 individuals (38 children)
  - Ages 2-16
- 13 first time attendees!

### Opportunities to Connect

An important piece of the family meetings is time for families to get to know each other. At both Regional Meetings, extra time is planned for families to connect!

When making your travel plans, be sure to take these times into account!

#### **Friday evening: Dinner and activities**

Join other families and the Simons VIP team for dinner and entertainment!

#### **Saturday evening & Sunday: Family free-time**

Contact the Simons VIP Coordinators ([coordinator@simonsvipconnect.org](mailto:coordinator@simonsvipconnect.org)) to be connected with families local to Redwood City, CA / Philadelphia, PA for ideas of family-friendly activities and to plan time to connect!

SIMONS VIP CONNECT

VARIATION IN INDIVIDUALS PROJECT



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### DRAFT Meeting Agendas

#### Redwood City, CA (July 18th - 19th)

##### Saturday, July 19th

- 8:30am Welcome/Overview
- 8:45am What We've Learned: Medical Conditions—Dr. Wendy Chung
- 9:30am What We've Learned: Behavioral Findings
- 10:15am *Break/Family Networking*
- 11:00am Neurological Findings and Brain Imaging Studies
- 12:00am *Lunch*
- 1:30pm Advocating for Your Child
- 2:30pm Open Panel Conversation
- 4:00pm General Meeting Concludes
- 5:00pm Children's Program Concludes

#### Philadelphia, PA (August 1st - 2nd)

##### Saturday, August 2nd

- 8:30am: Welcome/Overview
- 8:45am: What We've Learned: Medical—Dr. Wendy Chung
- 9:30am: What We've Learned: Behavioral
- 10:15am: *Break/Family Networking*
- 11:00am : Neurological Findings & Brain Imaging Studies
- 12:00pm: *Lunch*
- 1:00pm: Advocating for Your Child
- 1:45pm: Special Needs and the Family: Getting the Big Picture—Dr. Robert Naseef
- 2:30pm: Open Panel Conversation
- 4:00pm: General Meeting Concludes
- 4:00pm: Guy Talk: For Fathers Raising Children with Special Needs—Dr. Robert Naseef
- 5:00pm: Children's Program Concludes

**Robert Naseef, Ph.D.** is a graduate of Temple University and has practiced as a psychologist for over 20 years. As the father of an adult child with autism, Dr. Naseef specializes in families of children with disabilities. He presents on topics related to coping strategies and support for the whole family, with a special interest in supporting fathers of children with disabilities. To learn more about Dr. Naseef, please visit his website:



<http://alternativechoices.com>



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### PHASE 2 PROGRESS

With the new Phase 2 of the Simons VIP study, we have introduced a redesigned version of Simons VIP Connect ([www.simonsvipconnect.org](http://www.simonsvipconnect.org)).

The website still has all the same great resources and community features, and now also includes a portal to online research participation!

While we were able to transfer the accounts and login information for our existing members, **we need your help**

**to rebuild and update the community information!** If you haven't done so yet, please be sure to login to the website to make sure all of your contact information is up-to-date and, if you are interested in participating in research, begin the **online consent process!**

The screenshot shows the Simons VIP Connect website interface. At the top, it says "SIMONS VIP CONNECT" and "SIMONS VARIATION IN INDIVIDUALS PROJECT". Below that is a navigation menu with links: Home, About Genetic Changes, Research Opportunity, Forums, Members, Ask an Expert, Community Information, My Profile, and Coordinators. A "Logout" button is visible. A message states: "In order to access even more information and to discuss interest in research, REGISTER today!". There is a "Register Now!" button. Below this is a photo of a woman and a child. To the right of the photo, text reads: "Linking individuals & families with genetic changes for support & research opportunities. The Simons VIP research is aimed at better understanding features of individuals with genetic changes associated with autism spectrum disorder (ASD) and developmental delay as well as needs of their families. As the initial phase of the study wraps up, we are now opening enrollment for Phase 2. This phase will allow us to hear from even more families since you can now participate entirely from home! Please scroll down and explore the website to learn more about genetic changes & the Simons VIP study." Below the photo is another "Register Now!" button. At the bottom of the screenshot, it says "2014 Regional Family Meeting Registration is OPEN!" and provides a link: "Visit http://sfari.org/svip2014 to learn more about the regional meetings and to register. Registration is free for Simons VIP Connect members. Follow the link for hotel information and a draft of the weekend schedule." Below that is a link: "Have questions about registration or research?"

#### Phase 2 by-the-numbers:

- 142 individuals have completed the online consent process
- 93 individuals (37 families) have started completing the online research surveys
- 78 individuals (30 families) have finished all currently available online research surveys
- 17% of Phase 1 families have re-enrolled and are participating in Phase 2!
- 6 NEW families are able to participate due to Phase 2's expanded eligibility criteria!

We are always open to suggestions to make the website function better for you and encourage you to reach out to the study coordinators (please see contact information below) with any feedback you think might help us provide a better experience for you!

#### **Contact the Simons VIP Study Coordinators:**

**Bethanny Smith-Packard**, Licensed Genetic Counselor, [bspackard@geisinger.edu](mailto:bspackard@geisinger.edu)

**Stephen Martin**, Research Coordinator, [samartin1@geisinger.edu](mailto:samartin1@geisinger.edu)

**Ashley Wilson**, Certified Genetic Counselor, [alw9024@nyp.org](mailto:alw9024@nyp.org)

**Toll-Free: 855.329.5638**