



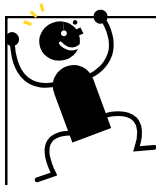
# Simons VIP Connect Newsletter

## UPDATES from the STUDY TEAM

**SIMONS VIP CONNECT**

VARIATION IN INDIVIDUALS PROJECT

### PHASE 2 UPDATES



Thanks to everyone for the great response to our request to help rebuild and update the community information on Simons VIP Connect!

[www.simonsvipconnect.org](http://www.simonsvipconnect.org)

In just 3 days last weekend, we had 12 families visit the community and update their information!

- ⇒ Six families had participated in Phase 1 and re-enrolled in Phase 2
- ⇒ Three families were not eligible for Phase 1 and can now participate in Phase 2
- ⇒ Three families were brand NEW to the online community

To continue to rebuild our community, if you haven't done so already, we would encourage you to login to the website to make sure all of your contact information is up-to-date. As a reminder, we were able to transfer the accounts and login information for our existing members. If you are interested in participating in research, you can begin the **online consent process** at the time that you update your information!

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

- 162 individuals have completed the online consent process
- 102 individuals (40 families) have started completing the online research surveys
- 85 individuals (32 families) have finished all currently available online research surveys
- 18% of Phase 1 families have re-enrolled and are participating in Phase 2!
- 4 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!



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### 2014 Regional Family Meetings Reminders!

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!

### 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!

To view last week's "Updates from the Study Team,"  
please visit the website!  
(Home > Community Newsletters)

#### **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)

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