The Registry Continues to Grow!

The Twin Research Registry at SRI International is an active registry of fraternal and identical twins of all ages. There are now more than 3,400 active members: 75% from California and the rest from all over the USA. 87% are adults, and 13% are under the age of 18, registered by their parents. Young twins have a higher rate of fraternals (53%) than adult twins (30%).

Registered members can participate in research studies to help advance science, and to learn more about twins.
2013 Health Survey: The Results are In

Thanks to those members who participated in our 2013 Health Survey! More than 1,400 completed the survey this spring. The results were presented to the investigators of Stanford University’s Immunology team, with whom SRI will work to study in more detail the genetic and environmental influences on some of the surveyed health conditions. Stay tuned: we may be calling you to participate.

The adult survey showed these results:
- 74% are female
- 78% are identical twins
- 47% are married
- Average age: 49
- Average number of years of education: 16
- In “excellent” or “good” health: 87%

The survey asked about a variety of diseases and health conditions, although many were rare. The highest rate was for those who had ever had chicken pox (84%). Other health conditions reported include sinus problems or shortness of breath (25%); asthma, either now or in past (17%); gastroesophageal reflux disease, or GERD (13%); intestinal or stomach problems (12%); food allergies (11%), and thyroid disease (10%).

The young twin survey showed these results:
- 55% are female
- 50% are identical twins
- Average age: 9.5 years old

More than 95% of the young twins are in good or excellent health. The highest percentage of health conditions reported include sinus problems (17%), asthma (12%), stomach problems (10%), dermatitis (9%), and chronic ear infections (6%).

Congratulations to the winners of Kindle e-readers who were randomly selected from all survey respondents.

Current and Upcoming Studies

Seasonal Flu Vaccine: Identical and fraternal twins 1-8 years of age are needed to help investigators better understand the genetic components of the body’s immune response to the flu vaccine. Participants will receive this year’s vaccine at Stanford Medical Center. Recruiting starts in August for appointments in September through December 2013. Participating twins will be compensated for their time and travel, and zygosity will be determined. A skilled pediatric phlebotomist is on staff for blood draws. Parents: if you would like your twins to participate, please call our Recruiter, Jill Rubin, at 925-687-2468.

Smoking and the Immune System: This study is about the environmental contributions of tobacco smoke to the immune system. Non-smoking and smoking identical twins between the ages of 5 and 55 are needed for the study at Stanford University. Participants will receive the influenza vaccine and a lab-based report of their zygosity.

Do identical twins have identical hair? A study analyzing hair protein profiles will soon address this question. Results will help determine if twins can be distinguished by their hair proteins. If so, then hair protein expression might have a nutritional/environmental component. For further information about participating in the study, contact Melody Wu (pwwu@ucdavis.edu) or Robert Rice (rhrice@ucdavis.edu) at the University of California, Davis.

Cornell Lung Study: Weill Cornell Medical College’s Department of Genetic Medicine seeks adult twins for a research study looking for genetic links to lung disease. Call 646-962-2672 to see if you are eligible to participate.

Recent Publications

Our paper about the history and future of SRI’s Twin Research Registry was published in October 2012 by the scientific journal Twin Research and Human Genetics. It gives an overview of twin research at SRI and the creation and growth of the Registry since its 1995 founding. The paper provides a synopsis of our many projects and studies, including nicotine and other drug metabolism, genetic influence on mutagen sensitivity, opioid efficacy, environmental and genetic influence on asthma, and influenza immunity.
Recent Publications, continued
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We are grateful for our twins’ continuing participation and dedication to research. Photos of two pairs of Registry twins made the journal’s cover! (Krasnow RE, Jack LM, Lessov-Schlaggar CN, Bergen AW, Swan GE. The twin research registry at SRI International. Twin Res Hum Genet. 2012 Oct 19: 1-8.)

A new paper, “Mass cytometry reveals the different influences of genetics and environment on human natural killer cell diversity” by Catherine Blish, M.D., Ph.D., and colleagues has been reviewed favorably by the journal Science Translational Medicine. Thank you to the twins who participated in the flu study for their contributions!

PHOTOS AND STORIES FROM OUR TWINS

Two (Unique) Peas in a Pod
Gay B.
age 74 (Read and OK’d by twin sis Gwyn S.)

Twins. Who doesn’t love to hear twin tales? It really is a relationship worth envy. Never alone, always having a close buddy, flesh of my flesh, bone of my bone. I have been blessed to experience it from the inside out. We were cute kids: blond curly hair, always in our little white gloves and dressed to kill. We were so well ‘programmed’ that we were almost 20 years old before we realized we didn’t have to dress alike.

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A great gift to us was the Children’s Experimental Theater, where we learned to act on stage and asked to actually feel the feelings that were not accepted in our home. That also helped us to learn to relate to others instead of getting stuck in what has been called ‘twinspeak’. We went through the entire school system, including two years of college and hospital medical tech training together, and both became medical technologists in 1958. We even worked for the same doctor’s laboratory for three years and married men who were best friends. We were married in the same hotel with the same invitations, music, and caterer.

Gwyn and I have lived apart since we married, but we still talk by phone, email, and text many times a week. We are two peas in a pod: we married best friends, both had one boy and two girls, both divorced, both medical technologists and caretakers. I think we would be a fascinating study for psychiatrists: the nature vs. nurture experiences of identical mirror twins are amazing.

It was difficult learning to live independently when the odds were so stacked against individuality! It has taken us many too many years to separate. We were ‘discovered’ at a twins festival at age 59 for a study of twins, and have had many exciting times with that. However, that did not help us to become individuals—it encouraged our alikeness, and the search for individuality continued. We are able to talk about areas we have never even thought about before. It is as though an invisible cord has been cut, and we are finally two unique individuals that can communicate with words and feelings.

So twinship has a new meaning to me. It is as though I have a brand new very best friend, my twin. We will support and love one another in new intense ways until the end of one of our lives, but I will not be left unwhole if she dies first! That removes a huge fear for me. Yet the closeness goes way beyond friendship and sisterhood. What a gift!
The “Good Luck” Twins

Nancy

When my sister Karen and I were born on August 14, 1948, we were six and a half weeks early. We were both whisked to intensive care and put in incubators.

I was the big one, at 4 lbs., 9 ozs. My sister was 3 lbs., 2 ozs.—so, so tiny! We were 7 lbs./11 oz. together, which my father considered “good luck.” I responded to feeding right away, but my sweet sister did not. My discontentment and screaming awakened my sister from her sleep, and she began to respond and take feedings. The nurses continued this process for a number of days until my sister responded to the doctors and her condition began to improve. I reached the magical number of 5 lbs. before Karen did. So, I got to go home. The hospital kept Karen for a month until she was closer to an acceptable weight to leave the hospital.

I cannot even imagine my life without my sister in it. She has been my strength, my steadfast friend, and my devoted soul mate for my whole life. There is nothing we wouldn’t do for each other.

There are many more stories to tell, as I’m sure, most twins can attest to. For now, I will just say how blessed I feel that Karen has been there for me my whole life.

Rachel and Rebecca

“I LOVE LOVE being a twin and every time I get email from SRI I’m SO happy to be a twin!”

— Rachel
From the SRI Blog:

**Twins Hold Special Role in Medical Science**

In December 2012, our director Dr. Gary Swan shared information about the importance of twin research in a blog post on SRI’s website. Go to ow.ly/gIjHn for the entire posting. Here is an excerpt:

Twins hold a special place in medical science by uniquely providing insight into how behavior and genetics affect disease, aging, and response to medical treatments. Through twin studies, scientists understand the interplay between genetics and the environment in ways that the study of unrelated people—or even other types of siblings—is unable to do.

Because identical twins share 100 percent of their genes and fraternal twins share 50 percent, comparison of a twin pair similarity (for measurable traits) can explain the relative role of genes, or the environment, in the causation of that trait.

For example, if identical twins are more similar than fraternal twins for a particular characteristic, then genetic factors may play a more important role in causing that trait. But if fraternal twins are similar to identical twins for a trait, then genetic and environmental factors may be equally important in the trait’s causation, called “etiology.”

This is critical information as we seek to discover, treat, and prevent diseases such as cancer, heart disease, and hypertension. Twin studies also provide important insights for studies about brain aging and addiction.

We’re enormously grateful for our twins, 1,375 of whom have participated in studies that have led to important scientific findings and published papers.

Web Links of Interest

- Twin girls in Germany play an amazing mirror prank in a ladies’ room (Wimp.com): [http://ow.ly/mV7Bz](http://ow.ly/mV7Bz)
- Why do identical twins end up having such different lives? (Guardian UK): [http://ow.ly/mV721](http://ow.ly/mV721)

Newsletter Feedback

Tell us your twin story! Email us with interesting, fun tales and you may be featured in our next newsletter. Please include permission for us to share your story.

Green is good! Join the more than 2,000 Registry members who receive information from us by email, saving paper and trees. Send us your email address by contacting twin@sri.com. You will receive the annual newsletter by email, and occasional emails about new study opportunities. All information is confidential and not shared.

Newsletters are archived on our website at [www.sri.com/twin](http://www.sri.com/twin).
Is your contact info correct?

If you have moved or changed your phone number or your email, please let us know. When recruiting for studies, we want to make sure we have current information. Thank you!

How to Contact Us

We need both of you: research opportunities are open to twin pairs only. If your twin has not registered, have her or him call us at 800-SRI-TWIN (800.774.8946) or email us at twin@sri.com.

Visit our website for more information at www.sri.com/twin and to register. Twins under 18 will need their parents to register: just call 800-SRI-TWIN or download the registration packet from www.sri.com/twin.

Email us at twin@sri.com to ask questions, update us with a new address or telephone number, or just to check in with us.

You can call 800.SRI.TWIN. We check for messages daily, and will return your call as soon as possible.

For information about study opportunities, call us at 800-SRI-TWIN (800.774.8946).

Check out the SRI Twin Research Registry page on Facebook at www.facebook.com/TwinSRI.

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www.sri.com/twin