The Registry Keeps Expanding!

The Twin Research Registry at SRI International is an active registry of fraternal and identical twins and other multiples of all ages. As of July 2015, there are now more than 4,345 twins in the Registry. Most (65%, or 2,842) live in California. Every state plus Washington, D.C. is represented—New York is the next highest to California, with 100 twins! In addition, there are 118 twins who live outside the US—38% from the UK and 22% in Canada. Most twins in the Registry are adults aged 18 or older. Thirteen percent are under age 18 and were registered by their parents.

Registry members can participate in research studies to help advance science. Many studies offer a benefit such as a free vaccination or health-related information.
Seasonal Flu Vaccines: Identical and fraternal twins ages 12 to 49 are needed to help investigators better understand the genetic and environmental influences on the body’s immune response to the influenza (flu) vaccine. Participants will receive this year’s FDA-approved seasonal flu vaccine (the same one given by physicians and pharmacies) as part of the study conducted by the Stanford University-Lucile Packard Children’s Hospital Vaccine Program. Recruiting starts mid-summer for appointments in early September to December 2015—please expect a call from our recruiter Jill Rubin! Participating twins will be compensated for their time and travel, and zygosity will be determined. This is the seventh year that twins have been included in Stanford’s vaccine studies (see the Results section below for a summary of exciting findings from this study to date).

Longitudinal Flu Vaccine: Healthy identical twins aged 2-5 years are needed for a study to help identify and describe important factors of flu immunity, especially T-cell responses in the early stages of life. This knowledge will greatly improve our basic understanding of the genetic and environmental factors involved in shaping the immune system response in children, and may lead to the development of better vaccination strategies. Participants will receive an FDA-licensed influenza vaccine given as a flu shot. This is the same seasonal flu vaccine that is used for the public during the flu season. Participants must be able to come for three to four visits at Stanford to provide a small blood sample, and then return annually for up to three years during the fall flu season for annual vaccinations and blood samples. Compensation and parking vouchers are provided to study participants.

Smoke Exposure and Asthma:
Exposure to second-hand tobacco smoke (SHS) is associated with elevated life risk of asthma development and more severe asthma symptoms, suggesting that SHS exposure promotes a more severe form of asthma. Recent scientific findings suggest that there are many subtypes of asthma, and that specific therapies for each type of asthma may more successfully control asthma symptoms. Understanding how exposure to SHS affects the immune cells that contribute
to asthma is important for development of specific treatments for individuals with SHS-related asthma. Researchers Dr. Kari Nadeau’s laboratory at the Sean N. Parker Center for Allergy Research at Stanford University are conducting research to understand how exposure to SHS modifies the genetics, epigenetics, and function of immune cells in the blood from twin pairs with or without a history of SHS exposure or asthma. The use of samples from twins enables the researchers to more easily distinguish the effects of SHS exposure on asthma while controlling for genetics and other exposures during childhood (see additional information in the Results section below).

For this study, we seek identical and fraternal twins where one or both have been told by a doctor that they have asthma. Also needed: twin pairs who have been exposed to tobacco smoke (especially through exposure to SHS) with or without a history of asthma. Please call us or send us an e-mail if you are interested in participating!

Salivary Flow and Health Study: Dr. David Relman, a Stanford Professor and physician at the Veterans Administration Hospital in Palo Alto and his group seek twins to participate in a study aimed to determine the role that saliva plays in maintaining human oral health. All activities take place at the UC San Francisco Dental School. Click here for more information on the study. If you are interested, please contact Diana Proctor by email at hyposalivation@gmail.com or by phone at 650-485-3793.

Folic Acid Supplement Study: The role of supplemental folic acid on cancer risk is controversial. The goal of this study is to better understand the appropriate dose of supplemental folic acid and its relevance to cancer by conducting a dietary study in adult monozygotic (MZ) twins. Dr. Robert Haile of Stanford’s Cancer Institute has submitted an NIH grant proposal to conduct an intervention trial using vitamins with and without folic acid to determine the effects of this supplement on the body. If the study is funded, twins would be recruited in late 2016 to participate in the study at Stanford.
Smoke Exposure and Asthma: More than 90 twin pairs have volunteered for Dr. Kari Nadeau’s study so far. The research team is grateful for each pairs’ enthusiasm and commitment to research. The clinical staff looks forward to working with the twin pairs and seeing them interact—twins are truly a fun and unique group of participants like none other! Likewise, the twin pairs have enjoyed learning more about their allergies and breathing abilities in Dr. Nadeau’s state-of-the-art clinic. More information on the cutting-edge research being performed at the Sean N. Parker Center for Allergy Read more about the research here.

Identical Twins and Hair Samples: In our 2013 newsletter, we posted an opportunity for identical twins to participate in a study of their hair with UC Davis’ Forensics Department. The Davis team is grateful to the 10 twin pairs who participated. The study asked whether monozygotic twins can be distinguished by their hair protein profiles. Results show that often they can be distinguished (but not always); however, the hair protein profiles among unrelated individuals are much more distinctive. So far, their data support the possibility of establishing a protein database for distinguishing among unrelated individuals and between some monozygotic siblings. Once the study results are published, we will post them on our website to share with you.

Whole Biome Obesity: In our 2014 newsletter, scientists at Whole Biome (www.wholebiome.com) put out a call for twins to participate in study intended to gain insight into the role of the microbiome in obesity. Twenty-eight individuals responded to seek additional information (10 sets of twins); 19 individuals filled out the questionnaire supplied by Whole Biome (9 sets of twins); and 10 individuals qualified and were sent collection kits (5 sets of twins).

Only three people returned samples (one pair of twins, but one went on antibiotics during the study which made the results difficult to interpret).
Participation of Registry twins has supported unique studies of variation in the human immune system, and responses to vaccination against influenza and shingles. Following is information about the human immune system and results from studies in which twins from the Registry have participated.

Our immune system consists of two main parts: the innate and adaptive components. The innate immune system is the part of the immune system that is made up of the cells and mechanisms that help fight infection in a non-specific manner. This means that the cells of the innate system recognize and respond to pathogens (germs) in a generic way, but, unlike the adaptive immune system (which is found only in vertebrates), it does not provide long-lasting or protective immunity. Innate immune systems provide immediate defense against infection, and are found in all classes of plant and animal life.

The adaptive immune system is the part of the immune system that is composed of highly specialized, systemic cells and processes that eliminate or prevent pathogen growth. This acquired immunity creates immunological memory after an initial response to a specific pathogen, leading to an enhanced response to subsequent encounters with that same pathogen. This process of acquired immunity is the basis of vaccination. Learn more about the immune system on Wikipedia.

Response to the Flu Vaccine: Every year, five to 20 percent of the U.S. population gets the flu. More than 200,000 people are hospitalized from flu-related complications and about 36,000 people die from flu-related causes. Seasonal flu shots work 67 percent of the time, but this depends on how well the vaccine matches the version of the virus being transmitted. For a Stanford-led study on the influenza vaccine, 210 healthy Registry twins between 8 and 82 years of age donated blood and other samples. These samples were tested for 204 different immune system markers, including, for example, the number and variety of certain cells each person has. Based on the study results, nearly 60% of the immune markers were almost totally defined by nongenetic factors—in other words, by the environment. And some of the markers became increasingly defined by nongenetic factors with age. Study results highlight the largely reactive and adaptive nature of the immune system in healthy individuals, and these important findings were published in the journal *Cell.*
Response to the Shingles Vaccine:
One out of every three people in the U.S. will develop shingles, and half of the cases affect adults over age 60. Anyone who has had chicken pox is at risk for developing shingles. Although the shingles vaccine is effective in reducing outbreaks and the related pain, vaccination use is very low in people 65 and older. A Stanford-led study of monozygotic twins from the Registry who received the shingles vaccine shows that genetic traits strongly influence some features of the immune response, while other aspects of the immune response are not well matched in twins. Some responses to the shingles vaccine were found to be unique to each individual. Results were published in the journal Proceedings of the National Academy of Sciences.

Twin Stories and Photos

Rachel and Rebecca: How They Handle Living So Far Apart

Rachel (China): Even though I now live halfway around the world from California, my twin and I are still very close. We are SO thankful for things like Skype, email, and the phone, which helps us feel like we are just blocks away from each other instead of thousands of miles. We are identical twins and our hobbies and interests are almost identical, too. I love to take pictures and so does Becky. In fact, Becky’s husband calls her the “momarazzi” because she takes so many pictures of her kids! WE love the same TV shows (including “Downton Abbey,” which we watched together via Skype.
last year) and both enjoy writing books. We have been able to read over, critique, and give each other advice about books and projects we are both working on. Speaking of which, we should write a kid’s story about twins since we LOVE being twins!

**Rebecca (California):** As Rachel mentioned, life as twins across the globe is a challenge, but technology makes communication a breeze. We e-mail, call, or Skype each other about everything (even down to what is planned for dinner!). In 2014, Rachel gave birth to her first son; her pregnancy and delivery story has glaring similarities to my first child’s birth despite the fact that her son was born in China and mine in California, two years apart. Both our pregnancies went very smoothly, neither of us had morning sickness (thankfully!) and our water broke at our homes at the same time (7-8PM). We both went through labor without any pain killers and our sons were born almost at the same time: 1:50AM and 2:05AM. Nowadays, my kids call both Rachel and me “Mom” when we Skype because they cannot tell us apart. They look to me and say “Mom” and then to the computer screen and call their Aunt Rachel “Mom”. It is hilarious. We’ll have to see if her son thinks he has “two moms” when he begins to talk.

**Twins on Track**

Identical twins Alyssa and Alex were featured on Chapman University’s Athletics website last spring. The picture is from a meet where their time for the 200m race was EXACTLY the same, down to the hundredth of a second, even though they ran in different heats.

**2000 Twin Party at SRI**

Time sure does fly: This year, we are celebrating the 15-year anniversary of a twin get-together hosted at SRI in Menlo Park, CA. The party, which marked the fifth anniversary of the Northern California Twin Registry, captured the attention of local media. News teams from three local TV stations and teams of reporters from local newspapers interviewed some of
the more than 200 twins who attended. Highlights included the opportunity for twins to meet other twins, a magic show, a group photo, door prizes, and presentations by Gary Swan (the Registry’s founder), a senior VP, and SRI’s president. If you attended, we’d love to hear from you!

Web Links of Interest

- **News from Dr. Jeff Craig** of the University of Melbourne’s Australian Twin Registry: “You can get identical twins that look and behave quite differently….29% of fraternal twins were led to believe that they were identical.”

- *The New York Times Magazine* wrote about two sets of identical twins that were switched at birth and raised as fraternal twins.

- **Northern California Mothers of Twins Club (NCA)** is a nonprofit organization founded in 1971 to unite all Mothers of Twins Clubs in Northern California in a central organization. NCA currently has 20 clubs in its organization. It assists in forming new clubs and helps established groups through sharing of procedures, ideas, and educational information. NCA members participate in research, mainly through projects sent by the National Mothers of Twins Club (also known as **Multiples of America**). Two convention-style meetings are held each year in spring and fall. Meetings are hosted each time by one of the clubs and include entertainment, meals, keynote speakers, workshops, booths selling twin-related items, and prize drawings.
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, and include pictures!

Green is good! Join the more than 3,000 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 kept confidential and not shared without your permission.

Past newsletters are archived at www.sri.com/twin.

Is your contact information 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!
We’re enormously grateful for our twins who have participated in studies, both on location and via email surveys, which have led to important scientific findings and published papers.

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.

Check us out on Facebook at www.facebook.com/TwinSRI.

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