SRI International’s Twin Research Registry is an active registry of fraternal and identical twins of all ages and backgrounds who are interested in learning more about twins and to participate in research studies to help advance science.

Registry Membership Updates

Brian Smith, a sophomore at Carlmont High School, is a member of the Twin Research Registry (TRR) who enjoys math, science and reading. Working with Ruth Krasnow, the TRR Data Manager, he looked at the TRR data. Below is his report.

In the last newsletter there were two pie charts showing the age and zygosity of the active members in the Twin Research Registry (TRR). These charts showed that the proportion of identical and fraternal twins was very different for twins younger than 18 and those older than 18. Using the data from the TRR, I made a graph for separate age groups (see chart). While 27-40% of the twins who are over age 20 are fraternal, more than 50% of the twins who are under 20 are fraternal. This pattern made me wonder what might have influenced the higher number of fraternal twins in the younger age groups.

The chance of conceiving fraternal twins naturally is about 1 in 89 (1.1%), while for identical twins it is 1 in 250 (0.4%). However, with the use of assisted reproductive technology (ART, such as in vitro fertilization or IVF) the chance of having fraternal twins increases dramatically. According to the Centers for Disease Control and Prevention, of all live in vitro births in 2000, 30.7% were twins and 4.3% were triplets. These data show that using in vitro methods increased the likelihood of having twins from 1 in 89 to almost 1 in 3, while triplets increased from 1 in 8000 to 1 in 25! The use of ART has greatly increased over the past few decades. In 1978 the first IVF baby was born, and by 2006 a total of 54,656 infants were born as a result of various methods of ART.

The TRR has a higher proportion of fraternal twins in the 0-20 age groups compared to the older age groups. Graph is based on 2,814 members of the registry (numbers vary by age group ranging from 38 individuals in the 81-90 age group to 516 in the 51-60 age group).

Twin Research Registry Questionnaire

More than 1300 Twin Research Registry members returned the questionnaire that was included with the 2010 newsletter. Thank you very much for your participation! The first page, developed at Washington University, estimates twin zygosity using a short set of questions. The other two pages were developed by Dr. Kari Nadeau at Stanford University for her Asthma Study (see Current Studies).

Of the 1300 twins, 71% were determined by the questionnaire to be part of an identical pair, and 29% part of a fraternal pair.

The questions about the difficulty various individuals had telling the twins apart were very good predictors of being identical (97% for teachers, 95% for parents). Of the twins who responded that they had the same hair color, eye color, and skin tone, 11% were identified as fraternal and 89% identical. The percentage of twins that had ever had a blood test to find out zygosity was 31%. If you have had a blood test to confirm zygosity and would like to share the results with us – please email us at twin@sri.com or call 800-SRI-TWIN. Having the blood test results will help ensure that we have the most accurate information in our database.
Results from SRI Twin Research

Pain Sensitivity Study
The Pain Study at Stanford has been completed and a paper about the methods of the study and some initial results was published in Twin Research and Human Genetics. Scores for pain threshold and tolerance of the "cold pressor test" (submerging the hand in ice water) were compared between two members of a twin pair. Overall, identical twins were more similar in their reports than were fraternal twin pairs, which indicates that there may be a genetic component to this type of pain sensitivity.

Pain study follow-up survey: Of the 219 twins who completed the Pain Study, 167 responded to a questionnaire about their participation (Thank you!). Most twins (96%) said that study expectations were met and they would recommend the study to others. The reactions to the medication were varied: less than 5% experienced disorientation or dehydration, but 14% were dizzy and 25% were nauseated. Our hope is that genetic information gathered in studies like these could be used to determine who should receive which pain medicine so that uncomfortable side effects can be minimized.

Recent paper – Nicotine metabolism
A paper published in Pharmacogenetics and Genomics found that there is a large amount of genetic variation in a biomarker of nicotine metabolism. This biomarker is known as the nicotine metabolic ratio (NMR) and it is predictive of successful smoking cessation in smokers who stop by using nicotine replacement therapy (such as the nicotine patch). Faster metabolizers do less well when using the patch. These results were from 110 identical and 29 fraternal twin pairs from the Registry who participated in our study at San Francisco General Hospital with our partner, the University of California at San Francisco.

Current Twin Studies

Study of Seasonal Flu Vaccines
Stanford University is investigating how the immune system responds to the current seasonal flu vaccines and how this response varies with age. The results could help in developing more effective vaccines or vaccination strategies. This study is ongoing and so far, more than 60 pairs of identical and fraternal twins have participated – thank you very much!

This research study takes place at the Stanford University Medical Center. At the first visit twins will give their consent to enroll, have blood drawn and will be given a flu shot. At the second and third visits, twins will talk briefly with the study nurse then have their blood drawn. The blood samples will be analyzed for various indicators of immunologic activity.

We will resume recruiting for the study in summer 2011 and appointments will occur between late August/early September and December 2011. The study is open to twin pairs in various age groups. Participating twins will be compensated and zygosity (fraternal or identical status) will be determined and shared with the twins. If you would like to take part in this study, you can contact Jill Rubin at any time at 1-800-605-3645 and you will be added to the list of twins to be contacted.

Zoster Vaccine Study
Shingles is caused by the varicella zoster virus, the same virus that causes chickenpox, and currently will affect about 1 out of every 3 people in the US. After a person recovers from chickenpox, the virus stays in the body in a dormant (inactive) state. For reasons that are not fully known, the virus can reactivate years later, causing shingles. About half of all cases occur among men and women 60 years old or older.

In collaboration with Stanford University, we are about to begin recruitment of identical twin pairs for two zoster-related studies. In one study, twins between the ages of 40-49 will be asked to come to Stanford for a single visit to provide a blood sample. In another study, identical twins age 50 or older will receive, at no charge, the Zostavax® vaccine to protect against an outbreak of shingles and its associated pain. The vaccine, now available at pharmacies for more than $200, is approved by the FDA for use in adults aged 50 years and older. There will be 5 study visits during the one month of study participation. The information from these studies could lead to an improvement in vaccination strategies and identification of ways to improve vaccine responses in older individuals. If you are interested, please call Jill Rubin at any time at 1-800-605-3645 and you will be added to the list of twins to be contacted for this study. Enrollment is expected to begin in August or September.

Asthma Study
In collaboration with Stanford University physicians, this study was designed to help identify twins who are at risk for allergies or asthma. Recruiting has ended but so far more than 50 twins pairs have participated! Awesome!
Donald J. – “Two years ago I had rotator cuff surgery in Indiana. As part of the procedure, a sticky piece of plastic is placed on the scar to keep it from puckering. The last Thursday in September I told my therapist that I would stop to say goodbye before heading to Florida. Unbeknownst to her, my twin brother came to town and the next day I placed the sticky bandage on his right arm and sent him in to see the therapist. He told her, “A miracle, my scar is gone!” She took off the bandage and began to rub thinking I had put makeup on it. Since that didn’t work, she proceeded to look at his other shoulder but then knew it wasn’t right. By this time, my brother was doubled over with laughter and the therapist said, “There is something screwy going on!” I walked in. Good thing I didn’t need any more therapy for she may have killed me!”

Lloyd S. – “Larry and I have put together a Web album of almost 70 years of twin photos with 589 photos so far. Luckily our parents took a lot of photos. Below is the link to see them all.”
http://picasaweb.google.com/Lsmithtwin/TwinsLloydLarrySmith1940To#

Jim B. – Check out Channel 7 News for Idaho “Two brothers and 30 years of running the race to Robie” about the Robie Creek Mountain Half-Marathon, reputed to be the most grueling in the northwest. See link at KTVB.com.

Ed W. – “In December 1946 my twin Roger and I flew home to North Illinois from Stanford for Christmas. Our parents wanted us to get new suits from them as Christmas gifts. We went separately, on different days, to nearby Rockford to buy the new suits. When the suits arrived a few days later lo and behold we had unknowingly both gone to the same store and bought the same suits.”

Anabel S. – “We both have cystic fibrosis (a genetic lung disease) and both had double lung transplants that saved our lives. We wrote a memoir about our family experiences called "The Power of Two: A Twin Triumph over Cystic Fibrosis" which was published in 2007. This memoir is about two lives, two cultures, two life-saving transplants from two amazing donor families. Currently, our book has inspired the making of a documentary film, a project to promote Cystic Fibrosis Awareness and Organ Donation Awareness. Spearheaded by Academy Award nominated producer Marc Smolowitz ("The Weather Underground," "Trembling Before G-d"), THE POWER OF TWO movie will engage and inspire people around the world by conveying a fundamental truth: there is a miracle in every breath.”

Meet Bob and Dick, TRR members since 2009.

“We volunteer for twin research for the same reason that we volunteer to donate blood. It’s a gift that a person can give to another that is priceless. We look upon the twin studies in the same way. As identical twins, we have a unique gift to give – exactly the same DNA and genes that can be used in scientific research that can benefit others and we learn more about ourselves in the process. Priceless!”

Do you feel like Two Peas in a Pod?
“Yes, we always have been very close and are interested in the same type of things – physical fitness, bike tours, swimming teams, etc. We grew up never wanting to be apart in school and always had the same group of friends.”

What about your voice and mannerisms?
“People are amazed that two individuals could sound so similar and have the same gestures! Our Mother could never tell us apart over the phone. We have not lived together since 1962 yet we still speak the same, act the same, and yes, our wives can confirm “you do that just like your brother” or “just because your brother does that, doesn’t mean you have to do it too” (not necessarily a compliment!).”

What about your professional choices?
“We are both entrepreneurs – we are the most comfortable having the freedom to work as much or as little as we like and not having to answer to management! We both joined the US Navy Reserve on the same day in 1961 as seamen recruits and eventually retired as senior officers. Dick went into naval aviation and Bob served in the nuclear submarine force upon graduation from college and being commissioned as ensigns.”

What about right side vs. left side brain strengths?
“The one difference that holds true throughout life is Dick is more linguistically oriented and Bob is more mathematically oriented.”

We wish to thank Bob and Dick again for sharing their wonderful story and for being so generous with their time.
Ashlee and Andrea B. – My identical twin sister was diagnosed with breast cancer 2 yrs ago. I had recalled reading about how identical twins could donate organs and even tissue without the risk of rejection and jokingly mentioned to her that if she ever needed some skin or tissue that I still had a little tummy from my pregnancy that I'd happily donate to her. During her preliminary reconstruction stage she was told by multiple surgeons that there was really nothing that could be done for her in terms of creating a modest or pleasing size of breast because she was so thin and the tissue so damaged from radiation. She asked surgeon after surgeon about the possibility of using donated tissue but they all seemed greatly intimidated either by the idea or the process of getting the insurance approval. She was undaunted and finally found an amazing plastic surgeon who was able to see that what she was asking actually wasn't that big of a deal. We had the gene testing done and confirmed we are true identicals. We were then both asked to gain weight in preparation for the surgery. Almost exactly one year ago we were both prepped for surgery and operated on simultaneously. They did tummy tucks on both of us and used the fat and tissue to create beautiful breasts for her. It was an extraordinary experience to be able to truly give her something so special and to see the end result on her and the happiness it brought her. Needless to say, we were extremely close before, and we are even closer now.

Jim Barker’s habit of rescuing abandoned hats was written up in the San Jose Mercury News (see article at http://www.mercurynews.com/scott-herhold/ci_17759937?IADID). The interesting part of the story is that his twin brother Ron had independently starting doing the same thing 700 miles away in Idaho!

Other Twin-Related Items

Dr. Gary Swan gave a talk titled “How Twin Studies Help Advance Health Research”. A link to the podcast and other twin-related news items can be found at: http://sri.com/policy/healthsci/twin/ithenews.html


A book by twins: Logan and Noah Miller wrote “Either You’re in or You’re in the Way: Two Brothers, Twelve Months, and One Filmmaking Hell-Ride to Keep a Promise to Their Father” and produced a movie “Touching Home” about their own life stories. For more information about both go to http://www.inorintheway.com/index.php

Feedback

Tell Us Your Twin Story!
If you have an interesting, fun story about being a twin, e-mail it to twin@sri.com and you may be featured in our next newsletter! Please include permission for us to share your story.

We’re Going Green
Would you prefer to receive our newsletter via email? Email us at twin@sri.com All information is kept confidential and not shared with anyone else. Many twins have already shared their email addresses with us – thank you!

You can see all of our newsletters on our website at http://www.sri.com/policy/healthsci/twin/newsletter.html

How to Contact Us

✓ You can visit our website at http://www.sri.com/twin/ for more information. Adult twins interested in registering can do so on this website.

✓ Check out the SRI Twin Research Registry page on Facebook.

✓ Follow us on Twitter at @twinSRI

✓ You can 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 1-800-SRI-TWIN (1-800-774-8946). We check for messages daily, and will return your call as soon as possible.

✓ For information about study opportunities, call Jill Rubin at 1-800-605-3645