Thank You! Thank You! Thank You! Thank You! Thank You! Thank You!

Hi! Welcome to the SRI International (formerly Stanford Research Institute) Twin Registry’s first ever newsletter. We’d like to take this chance to thank you all for the time and interest you have given in becoming a member of the Northern California Twin Registry (NCTR). The response has been fantastic! Your cooperation is invaluable and has the possibility of contributing significant information to research in the health sciences field.

In this, our first newsletter, we hope to provide you with some information about what it means to be a member of the NCTR, as well as a brief history of the registry. Included will be information about the history and population of the registry itself, upcoming studies and compensation for participation, and some of the most frequently asked questions. Another section will be devoted to other twin-related information that we thought you might find of interest, including your chance to become a published author.

We invite any comments or suggestions concerning our newsletter and any “twin” experiences that you might like to share with us. If you have any questions, please feel free to call us at 1-800-SRI-TWIN (1-800-774-8946). We hope that you find our first newsletter interesting and informative. As a small token of our appreciation, a refrigerator magnet has been included for registered members of the NCTR. We hope you enjoy it, and thank you again!!

History of the SRI International Northern California Twin Registry

Twins have long held a special place in medical science as a source of insight into human behavior and genetic links. As part of its scientific research and efforts to discover more about human behavior, SRI International launched the Northern California Twin Registry to develop a valuable scientific resource for studying human behavior and to respond to the need for better representation of ethnic, gender, and age diversity in health research involving twins. Northern California, with its large and diverse population base, provides an ideal location for the registry.

Currently, the NCTR is pleased to report that 604 complete sets of twins are registered members: 62% are female twins; 23% are male twins, and 15% are mixed-gender twins. The average age of NCTR twins is 40. Most (64%) are monozygotic twins, 31% are dizygotic, and 5% are not sure. Almost half of you (49%) are single, 45% are married, and 6% live with a partner.

Questions from NCTR Members

*What does it mean to be a member of the registry?*

The SRI NCTR is a collection of twin pairs who have indicated interest in taking part in health-related research projects. As a member of the registry, you will be contacted periodically and given the opportunity to participate in upcoming studies. However, you are not in any way obligated to take part in these studies. We will do our best to
keep you informed of the progress of our various studies via our newsletters, and we will contact you by telephone when opportunities arise for you to participate in one of our projects. Please contact us at our toll-free number, 1-800-SRI-TWIN (774-8946), if you have any questions regarding your membership in the registry.

Can participation in SRI studies take place through the mail?
The answer to this question depends on the type of study being conducted. It is most likely that mail-in questionnaires will be used primarily for gathering data during a follow-up phase to research projects that first involve more complicated methods of data collection.

Can I participate if my twin doesn’t?
Because many of our projects are based on comparisons of twin pairs, the answer to this question is no. We encourage those of you who are interested in being eligible for future studies to ask your twin to register as well if he or she has not already. It is not required that both twins appear at SRI at the same time. However, in previous studies, twins have often requested concurrent appointments so that they have a chance to visit together while taking part in activities at SRI.

Will my responses to questions and other personal information be kept confidential?
Absolutely! It is illegal for research institutions to release your personal information (including your name, address, and telephone number). Also, all data from our studies are reported only in coded or consolidated form; no names of participants appear in the studies’ published results.

Twin Research
Currently, the Center for Health Sciences at SRI is waiting for approval to begin a new research project, which we should receive before the end of the year. This and future studies that you may be invited to participate in will be related to the health sciences field. By studying twins, information relating to human habits and behavior — including smoking, drinking, overeating, and other behaviors — can be gathered and analyzed. SRI will be looking to see how genetic makeup influences a variety of health-related attributes, which may include:

- Blood pressure, obesity, and cholesterol levels.
- Diabetes.
- Relationship between diabetes, blood pressure, and cholesterol.
- Measures of aging, particularly as influenced by blood pressure, coronary artery disease (CAD), and diabetes.
- Use of alcohol and tobacco.

Compensation will be provided to those members who participate in our research studies. The amount will depend on how much twins are asked to do. Compensation will be less for simply filling out a questionnaire versus making an on-site visit.

Twins Restaurant
“A Restaurant Specializing in Twins”

Twins Restaurant is an eclectic downtown restaurant located in the upper east side of Manhattan. Twins is owned by identical twins Lisa and Debbie Ganz and actor Tom Berenger and is the only restaurant of its kind. It is staffed entirely by 37 sets of identical twins; each pair work the same shift, in the same section, and in the same kind of uniform. Twins usually get 10 to 20 sets of multiples each evening for dinner, and when multiples come in, they sign a twin guest book, get their picture taken (which goes on the wall), and get two-for-one drinks.

Twins Restaurants will be opening soon in Los Angeles and other locations, both nationally and
internationally. For more information, contact Twins Restaurant, 1712 Second Avenue, New York, NY 10128, 1-800-RU-TWINS.

Attention:
Here's Your Chance to Become a Published Author!

Lisa and Debbie Ganz (the creators of Twins Restaurant) are publishing a comprehensive and exciting book of stories and photos written by multiples of all ages from around the world.

They are soliciting your assistance by sharing with them your most memorable stories (happy, funny, endearing, and sad), along with photos.

These stories can be written by the multiples and/or their family members.

For more information, call 1-800-RU-TWINS or phone: 212-987-1111; fax: 212-987-3698; or e-mail: BILLYWONKA@AOL.COM.

Twin Facts and Figures

The fascination with twins is part of every culture and dates back centuries. Some interesting twin “facts and figures” include:

- In ancient times, doubleness in nature was often interpreted as a manifestation of the supernatural or intervention by the gods. That is why many gods in different religions are twins or super twins.

- In the Aztec, Babylonian, Zuni, and Ashanti cultural myths, twins took the form of warriors, builders, healers, and symbols of light, water, or thunder.

- Native American tribes in the Northwest believed that twins were actually salmon in human disguise.

- The frequency of twin births varies from country to country and ranges from 1 in 80 to 1 in 400.

- When it comes to phobias — like fear of heights, of closed spaces, or of open spaces — twins often respond similarly. More often than not, if one twin harbors an irrational fear, the other does too.


if you have any interesting facts about twins that you would like to share, please call us at 1-800-774-8946 and we’ll include the best submissions in our next newsletter.

Watch for our next newsletter in the spring of 1998.

In our next issue -

- Genetic research at SRI
- Twins in history
- Opportunities for participation in SRI twin studies
WANTED: MISSING TWINS
1-800-SRI-TWIN (774-8946)

THE NORTHERN CALIFORNIA TWIN REGISTRY IS STILL MISSING THE REGISTRATION QUESTIONNAIREFROM MANY TWINS, AND WE ARE ASKING FOR YOUR HELP!

HAS YOUR TWIN COMPLETED AND RETURNED THEIR QUESTIONNAIRE AND REGISTRATION FORM? IF THEY HAVEN'T, WE ARE ASKING THAT YOU ENCOURAGE THEM TO DO SO. IN ORDER FOR A TWIN TO BE ELIGIBLE FOR PARTICIPATION IN STUDIES, BOTH TWINS MUST BE REGISTERED MEMBERS.

YOUR ASSISTANCE WILL BE GREATLY APPRECIATED!

Affix magnet here

Thank you again for joining the NCTR!