Dear Parent,

Thank you for your interest in our Twin Research Registry! We would be pleased to have your twins as members of the first twin registry of its kind in northern California. This registry was developed by the Center for Health Sciences of SRI International, a not-for-profit, private institution that has done basic and applied research for government and industry for over 70 years. For the past 30 years, we have conducted research with twins and published over 100 scientific papers covering a wide array of topics, including the heredity of aging, heart, and lung disease, and risk factors for heart disease such as diabetes and smoking. We have also participated with researchers at Stanford University to look at the genetics of the body’s response to the seasonal flu vaccine, as well as genetic and environmental contributions to asthma and allergies. The participation of your twins in the Registry and in future studies will help us learn more about the influence of hereditary and environmental factors on children’s health.

By joining the Twin Research Registry, your twins are agreeing only to be placed on a list to receive annual newsletters and to be contacted regarding research opportunities. You and your twins will have the option to decide if you are interested in participating in studies that may require the completion of questionnaires and interviews at one of our research facilities.

Please complete the attached registration form, sign the consent forms (one for each twin) and return them to SRI by mail or e-mail. When we receive the completed forms, your twins will be members of the Twin Registry, and we’ll send you membership cards.

All information provided by you will be held strictly confidential and will be used by the Twin Research Registry staff only for the purpose of contacting you in the future. No other organization or individuals will have access to this information. If you have any questions about the enclosed materials or would like more information about our registry, please call us at 1-800-774-8946 (SRI-TWIN) or e-mail us at twin@sri.com. Our website www.sri.com/twin will be updated periodically with new information about studies.

Sincerely,

Ruth Krasnow
Coordinator, Twin Research Registry
Center for Health Sciences
As the parent or guardian granting permission for a child in this study the use of "you" may refer to you as well as your child or your ward.

You are invited to join the Twin Research Registry at SRI International.

What is a Registry? A registry is a research database that contains a list of potential research participants. If you agree to join the registry, this means that information you provide may be used to inform you about potential studies that you may be interested in joining.

Duration: Your twins’ participation in the Twin Research Registry will continue until they turn 18 and will not extend beyond the database. When your twins turn 18, they will be invited to join the Twin Research Registry as adults. Any future studies we inform you of will have their own research protocols that you would have to consent to separately. This means that while you can choose to be in this Registry, any actual research study you may participate in is entirely outside of this Registry and you can choose to quit either or both at any time.

If you decide to join, your active participation will total approximately 5-10 minutes to complete a short registration form (attached).

PURPOSE OF THE TWIN RESEARCH REGISTRY

The Twin Research Registry (TRR) was created in 1995 as a resource for scientists seeking to study the genetic contributions to a variety of medical and behavioral conditions.

The TRR is always seeking twins or multiples of any age. Although twins from all over the world may join, most of our research studies to date have involved participation in the San Francisco Bay Area.

VOLUNTARY PARTICIPATION

You do not have to join the TRR if you do not want to, and if you decide to join and later change your mind you may un-enroll at any time without any penalty or loss of any benefits to which you may be entitled. Should you decide to un-enroll, your information will be removed from the database.

PROCEDURES

If you choose to join, the Twin Research Registry study staff will add your name and contact information to our database. You will be sent birthday cards, an annual newsletter, and have the opportunity to be contacted about any research studies that are seeking to enroll twins of your age and twin type (fraternal or identical).

There are two ways to be informed about future research: (1) We can provide you with information so that you can personally reach out to the researchers to learn more about their studies, or (2) we will call you to let you know about specific research opportunities as they become available.

You are under no obligation to participate in any research studies that do not interest you.

POSSIBLE RISKS, DISCOMFORTS, AND INCONVENIENCES

There are risks, discomforts, and inconveniences associated with any research study. These deserve careful thought. There is a risk that your name and contact information will be discovered if there is ever an unauthorized access to the database. Many steps are taken to ensure this never happens (see Confidentiality below). When contacted by the Twin Research Registry staff regarding any research opportunities, you should let them know if you have any questions.
POTENTIAL BENEFITS

Being a member of the Twin Research Registry provides you the opportunity to participate in future research studies. These studies will each have their own potential risks and benefits.

The annual newsletters may provide you with interesting twin-related information.

We cannot and do not guarantee or promise that you will receive any benefits from being a member of the Twin Research Registry.

PARTICIPANT’S RIGHTS

You should not feel obligated to agree to join the Twin Research Registry. Your questions should be answered clearly and to your satisfaction. If you decide not to join, simply do not return this registration package.

CONFIDENTIALITY

All data will be kept in secured files on the SRI campus which is access-controlled. SRI computer systems are behind a monitored firewall using state-of-the-art security procedures. Your name will not be used by anyone other than authorized personnel, unless you specifically give us permission to do so, such as in our annual newsletters. Any report of the data collected will be in summary form, not identifying individuals.

FINANCIAL CONSIDERATIONS

Payment: You will not be paid to join the Twin Research Registry. Many of the research studies that twins may participate in offer compensation however.

Costs: There is no cost to you to join the Twin Research Registry.

SRI International is providing financial support for the Twin Research Registry.

CONTACT INFORMATION

Questions, Concerns, or Complaints:

If you have questions about the Twin Research Registry, please contact us at twin@sri.com. You may also call us at 1-800-SRI-TWIN.

Independent Contact: If you are not satisfied with how the Twin Research Registry is being conducted, or if you have any concerns, complaints, or general questions about the Registry or your rights as a member, please contact the Institutional Review Board at SRI International by calling 650-859-4022 or e-mailing IRB@SRI.com.

Signing your name means you agree to join the Twin Research Registry and that you will receive a copy of this signed and dated consent form.
Principal Investigator: Lisa Jack  
Protocol Title: Development and Maintenance of the Twin Research Registry

Assent of Minor: I agree to join the Twin Research Registry.

Printed Name of Minor

__________________________________  _________________________________
Signature                   Date

Parental Consent to join the Twin Research Registry: Your children’s participation in the Twin Research Registry is voluntary. If you choose not to have your children join or wish to withdraw your children from the Registry at any time, there will be no penalty of any kind.

By signing this form, you give permission for your child to participate in the research study described above.

Printed Name

__________________________________  Authority to Act for participant
Signature of Legally Authorized Representative (LAR) (parent, guardian, or conservator)  ____________________________  Date
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Signing your name means you agree to join the Twin Research Registry and that you will receive a copy of this signed and dated consent form.
Principal Investigator: Lisa Jack
Protocol Title: Development and Maintenance of the Twin Research Registry

Assent of Minor: I agree to join the Twin Research Registry.

Printed Name of Minor

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Signature                   Date

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By signing this form, you give permission for your child to participate in the research study described above.

Printed Name                                                                                      Authority to Act for participant

___________________________________________                                                 _________________
Signature of Legally Authorized Representative (LAR)                                         Date
(parent, guardian, or conservator)
Twin Research Registry at SRI International
REGISTRATION FORM

Date Form Completed by Parent: _____/_____/_____  

Name of Parent Completing Form: ___________________________________________________________  
First          Middle          Last  

Address       City       State       Zip  
( )   ( )   ( )  
Home Telephone   Work Telephone   Cell Telephone  

Email address:  

General Instructions: For each question, either circle the appropriate number or fill in the appropriate box. Thank you for completing this registration form. By completing this form, your twins become eligible (but under no obligation) to receive a regular newsletter describing opportunities to participate in health research. The information you provide here will remain strictly confidential, known only to staff of the Twin Research Registry at SRI International.

Please give us your twins’ names and gender below  

Name: ________________________________________  1 Male  2 Female  
First          Middle          Last  

Name: ________________________________________  1 Male  2 Female  
First          Middle          Last  

Please give your twins’ date of birth: _____/_____/______  
Month Day Year  

Assigned by SRI  
ID# ____________  
ID# ____________  
Pair # ____________  

1. Are your twins:  
   “As alike as two peas in a pod” . . . . . . 1  
   Of only ordinary family resemblance . . . . . . 2  

2. Do you and your family or teachers and friends  
   Have trouble telling your twins apart?  
   No. . . . . 0  
   Yes. . . . . 1  

3. As far as you know, are your twins:  
   Fraternal. . . . . 1  
   Identical. . . . . 2  
   Don’t know. . . . . 3
4. How close do you feel your twins are compared to the closeness between ordinary siblings?

   - Less close than ordinary siblings . . . . . 1
   - As close as ordinary siblings . . . . . 2
   - Somewhat closer than ordinary siblings . . . . . 3
   - Much closer than ordinary siblings . . . . . 4

5. How much time do your twins spend together?

   ______ Hours per day
   ______ Days per week

6. What grade in school are your twins? ____________

7. What is the ethnic group of your twins?

   - Black, non-Hispanic . . . . . 1
   - White, non-Hispanic . . . . . 2
   - Hispanic . . . . . 3
   - Asian . . . . . 4
   - Other . . . . . 5

8. How did you hear about the Twin Research Registry at SRI International?

   - 1 … Newspaper (specify): ______________________
   - 2 … Radio
   - 3 … Friends or relatives
   - 4 … Mothers of Twins
   - 5 … Other (specify): _________________________

9. Have your twins participated in other research studies?

   - No … 0
   - Yes … 1

Thank you for completing the Twin Research Registry registration form.

The information you have provided will be held in strict confidence.

Twin Research Registry
SRI International
333 Ravenswood BN129
Menlo Park, CA 94025