



UNIVERSITY OF WASHINGTON INFORMATION STATEMENT UNIVERSITY OF WASHINGTON TWIN REGISTRY RESEARCHERS

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PURPOSE AND BENEFITS

We are asking you to be in a twin registry to study health and illness. Your participation in the registry will make a valuable contribution to science, but will provide no direct benefit to you.

PROCEDURES

If you agree to participate, here is what will happen:

You will be asked to complete a questionnaire that takes about 15 minutes. The questions ask about you and a short list of health conditions.

You will need to ask your twin about joining the Registry. If your twin agrees, you can give us your twin's name and contact information and we will send your twin information on joining the University of Washington Twin Registry. If your twin does not wish to participate, you will not be enrolled in the Registry.

As new questions arise about health and illness, we may contact you to collect more information for the Registry. This information could come from physical examinations, blood samples, and other tests or questionnaires. If you decide to provide the additional information, you will be given detailed information about the procedures and given a consent form describing the activities, which you can sign if you decide to participate.

We may also use information from public sources available to anyone such as birth records. This information will be kept along with all of your other information in the Registry.

We may contact you in the future about participating in specific scientific studies. You do not have to take part in any of these studies. If you choose to participate, you will receive detailed information about the study and given a consent form describing the study, which you can sign if you decide to participate. Only the University of Washington Twin Registry team, and no one else, will be able to contact you.

You will receive a newsletter from time to time updating you on the activities of the Registry. You will also receive birthday cards and contact information update requests. It is up to you if you want to respond to these requests.

RISKS, STRESS AND DISCOMFORT

You may consider some of the survey questions to be personal. You don't have to answer any question you don't want to answer.

We will ask for your social security number and your mother's maiden name but providing this information is optional. Your social security number can be useful in finding you if you move or lose contact with the Registry. Your mother's maiden name is how we will be able to know that you and your sibling are twins. All information you give to the Registry will be kept in locked cabinets and password protected computer files. Also, your social security number will be kept separately from the rest of the information to minimize the possibility of identity theft.

OTHER INFORMATION

Becoming a Registry member is voluntary. You may refuse to participate or may withdraw from the Registry at any time without penalty.

Providing information to the Registry or taking part in any research study is voluntary.

All information from the Registry and specific studies, including your name and contact information, will be kept indefinitely. If you withdraw from the Registry, the link between your name and data will be destroyed, but the data will be kept.

If you have any questions about the Registry, you may contact Bethany Osterman, the Project Manager or Dr. Dedra Buchwald, the Principal Investigator, toll-free at 1-888-223-0868. If you have questions about your rights as a research subject, you may contact the Human Subjects Division at (206) 543-0098.

Signature of Investigator

Dedra Buchwald, M.D.

Printed name of Investigator

April 18, 2007

Date

April 18, 2007

Date

For office use only:

Please take a moment to answer the following questions by using a dark pen to fill in the bubbles and boxes as clearly as possible. Some questions have multiple parts; be sure to answer each question completely.

Please complete answers like this ● using a blue or black ink pen.

1. Are you a twin, or triplet, or higher multiple birth?

- Twin Triplet or higher Neither

Continue with Question 2. Please stop here, fill in the contact information in Question 24 and return this survey.

2. When you were children, were you and your twin as alike as two peas in a pod or were you of ordinary family resemblance?

- Two peas in a pod
 Of ordinary family resemblance
 Don't know

3. How often, when you were children, did the following people have difficulty telling you and your twin apart?

- a. Your parents..... Never Rarely Sometimes Often
b. Other relatives..... Never Rarely Sometimes Often
c. Teachers..... Never Rarely Sometimes Often
d. Strangers..... Never Rarely Sometimes Often

4. Is your twin..... Alive Deceased Don't know

5. About the gender of you and your twin:

- a. I am a..... Male Female
b. My twin is a..... Male Female

6. In general would you say your health is:

- Excellent Very good Good Fair Poor

7. How often do you...

- a. have difficulty falling asleep or staying asleep?
 Never Sometimes Often Always

b. fall asleep during the day against your will?

- Never Sometimes Often Always

8. Over the past 4 weeks, how many days during a typical week did you exercise...

- a. vigorously for at least 20 minutes? Vigorous exercise causes heavy sweating or large increases in breathing or heart rate and includes such activities as running, lap swimming, aerobics and fast bicycling. 0 1 2 3 4 5 6 7

- b. moderately for at least 30 minutes? Moderate exercise causes only light sweating or slight to moderate increases in breathing or heart rate, and includes such activities as brisk walking, bicycling for pleasure, golf, and dancing. 0 1 2 3 4 5 6 7

9. What is your current...?

a. Height feet inches

b. Weight pounds

10. Have you...

- a. had at least one alcoholic drink in the past month? Yes No
b. smoked at least 100 cigarettes in your life?..... Yes No

11. Has your doctor ever told you that you have any of the following conditions? Answer Yes or No for each condition.

- a. High blood pressure/hypertension..... Yes No
b. Heart attack..... Yes No
c. Diabetes..... Yes No
d. Blood clots in legs or lungs..... Yes No
e. Breast cancer..... Yes No
f. Asthma..... Yes No
g. Herniated or slipped disc..... Yes No
h. Low back pain..... Yes No
i. Kidney stones..... Yes No
j. Gastroesophageal reflux disease (GERD)..... Yes No
k. Irritable bowel syndrome..... Yes No
l. Chronic sinus problems..... Yes No
m. Seasonal allergies or hay fever..... Yes No
n. Migraine headaches..... Yes No
o. Chronic tension headaches..... Yes No
p. Chronic fatigue syndrome..... Yes No
q. Fibromyalgia..... Yes No
r. Temporomandibular joint disorder (TMJ)..... Yes No
s. Depression..... Yes No
t. Panic or anxiety attacks..... Yes No
u. Attention deficit/hyperactivity disorder (ADHD) Yes No
v. Post traumatic stress disorder..... Yes No
w. Hearing loss..... Yes No
x. Speech or language problems..... Yes No
y. Seizures or epilepsy..... Yes No

12. Have you been tired, fatigued, or exhausted?

- Yes, for less than a month Yes, for months **or** years No

For office use only:

13. Have you ever...

- a. had persistent or recurrent bothersome thoughts, images, or dreams after a stressful or traumatic event?..... Yes No
- b. been hospitalized for an infection?..... Yes No
- c. seen a doctor for a lung disease other than asthma?..... Yes No
- d. had genital herpes?..... Yes No
- e. had cold sores or fever blisters?..... Yes No

14. Have you...

- a. had **2 weeks or more, in the past year**, during which you felt sad, blue or depressed?..... Yes No
- b. had **2 weeks or more, in the past year**, during which you lost all interest or pleasure in things that you usually cared about or enjoyed?..... Yes No
- c. had **2 years or more in your life** when you felt depressed or sad most days, even if you felt OK sometimes?... Yes No

15. In the **past 3 months**, how many visits have you made to:

- a. a medical doctor?..... 0 1 2 3 or more
- b. a psychiatrist or other mental health practitioner?
 0 1 2 3 or more
- c. an alternative practitioner (for example, an acupuncturist or massage therapist)?..... 0 1 2 3 or more

16. In the **past 3 months**, have you had...

- a. back pain that lasted for at least one day?..... Yes No
- b. back pain that travels into one or both legs?..... Yes No
- c. pain in the midback?..... Yes No
- d. abdominal pain relieved with bowel movements, or associated loose stools or constipation?..... Yes No
- e. persistent or recurrent pain in the face, jaw, temple, in front of the ear, or in the ear?..... Yes No
- f. chest pain?..... Yes No

17. How many headaches have you had in the **past 3 months**?

- Less than 5 5-15 16-30 More than 30

18. Do any of the following accompany your typical headache?

- a. Feeling sick to your stomach or vomiting?..... Yes No
- b. More sensitive to light and/or noise?..... Yes No
- c. A throbbing feeling in your head..... Yes No
- d. Pain on only one side of your head..... Yes No
- e. A decrease in your normal daily activity..... Yes No
- f. A preceding warning such as problems with vision, sensation, or strength..... Yes No

19. In the **past 3 months** have you had pain in your muscles, bones, or joints lasting at least **one week** in your:

- a. shoulders, arms, or hands?..... Yes No
- b. legs or feet?..... Yes No
- c. neck, chest, or back?..... Yes No

20. During the **past 7 days**, how often did the following occur when you thought about an event that was upsetting in your life?

Not at all Rarely Sometimes Often

- a. I thought about it when I didn't mean to.....
- b. I avoided letting myself get upset when I thought about it or was reminded of it.....
- c. I tried to remove it from memory.....
- d. I had waves of strong feelings about it.....
- e. I had dreams about it.....
- f. I stayed away from reminders of it.....
- g. I tried not to talk about it.....
- h. Other things kept making me think about it.....
- i. I tried not to think about it.....
- j. Any reminder brought back feelings about it.....
- k. My feelings about it were kind of numb.....

21. Are you currently...?

- Single, never married Separated Divorced
- Widowed Married Living with partner

22a. Do you consider yourself to be Hispanic or Latino?

- Yes No

b. What race do you consider yourself to be? Choose one or more of the following.

- American Indian or Alaska Native Asian
- Black or African-American White
- Native Hawaiian or Pacific Islander Other

23. What is the **highest** level of education you have completed?

(Choose only one.)

- Never attended school or only attended kindergarten
- Grades 1-8
- Grades 9-11
- Grade 12/High school graduate/GED
- Some college (no degree)
- Associate's degree
- Technical or vocational degree
- Bachelor's degree
- Graduate or professional degree

24. To make sure we have your correct information, please complete the following:

Your full first name:

Your middle name:

Your last name:

Number and street address:

Address line 2:

City:

Zip:

E-mail address:

Your date of birth (MM/DD/YYYY):

Your social security number (Optional):

25. With your twin's permission, please provide us with your twin's name, current address and phone

Twin's full first name:

Twin's middle name:

Twin's last name:

My twin lives out of the United States No Yes

Twin's number and street address:

Address line 2:

City:

State:

Zip:

Twin's telephone number:

Twin's e-mail address:

26. To help us tell you and your twin apart from other pairs of twins, please provide us with your mother's maiden name (her name before she was ever married):

Mother's first name:

Mother's maiden last name:

27. To help us reach you in the future, please give us the contact information for someone (not including your twin or spouse) who will always know where you are:

Contact's full first name:

M.I.:

Contact's last name:

Number and street address:

Address line 2:

City:

State:

Zip:

Contact's telephone number:

Please read the information statement that is attached to this survey and mail this entire form in the enclosed envelope.

If you have any questions, feel free to contact us toll free at 1-888-223-0868, ext. 3 or 206-543-2932.

Thank you for your participation!