

# University of Washington

## Twin Registry Newsletter

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Dr. Dedra Buchwald

## Welcome Twins!

Welcome to the Registry! This is the first newsletter for the new University of Washington Twin Registry (UWTR). We'd like to update you on the Registry's progress, and inform you about research studies using the Registry. We want to let you know about how you, as a

twin enrolled in the Registry, are truly helping further medical research.

The articles that follow give you details about upcoming research studies, along with interesting facts about twins. We hope you enjoy our newsletter!

## Registry Results by Dedra Buchwald, MD

**Dedra Buchwald, MD is a Professor of Medicine at the University of Washington and Director of the UWTR.**

I would like to thank you for joining the Registry. We are very excited because the UWTR is one of the few twin registries in the United States. We are very grateful to you and your twin for being a part of it – a very important part! Already, the Registry is helping scientists learn more about health and illness.

There are 2 kinds of twins: identical, also known as monozygotic, and fraternal, also known as dizygotic. Identical twins share 100% of their genes, while fraternal twins share, on average, 50% of their genes. When scientists speak about the zygosity of a twin pair, they are referring to whether the twins are identical or fraternal.

In the survey you completed when you joined the Registry, we asked you questions about yourself and your health. Below are preliminary findings from this survey based on the first 1,000 pairs.

**Age**  
18-20 years old – 15%  
20-29 years old – 38%  
30-39 years old – 17%  
40-49 years old – 13%  
50-59 years old – 10%  
60 years old and over – 7%

**Race**  
87.9% White  
3.3% Hispanic/Latino  
3.2% Asian  
2.6% African American  
1.4% Native American  
1.6% Other

**Zygosity**  
56% identical  
40% fraternal  
4% undetermined

**Gender**  
27% male/male pairs  
56% female/female pairs  
18% male/female pairs

**Other**  
15 years of education (avg.)  
94% US born  
21 countries represented

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## Introducing the Registry Staff by Stephanie Hatzenbuehler

We are proud to introduce you to the dedicated staff of the UWTR. If you haven't had the pleasure of speaking with them already, you may be hearing from them in the near future. Our staff may be calling you to discuss your interest in participating in several research studies that are starting soon. They are very informed about details of these studies, including who is eligible. We encourage you to ask them questions!

Cindy Evanoff has been the Registry Manager since the UWTR was established in 1999. Cindy is our resident UWTR expert. Much of the Registry's success is due to her hard work, tireless commitment, knowledge,



**Kimberly, Karin, and Cindy**

and excellent work ethic.

Kimberly Mulvey, Research Coordinator, provides our team with boundless energy and enthusiasm. She has a background in psychology and has worked in several clinical research settings. Kimberly is looking forward to meeting the twins who will be participating in the studies.

Lastly, Karin Johnson, is

another UWTR Research Coordinator. Karin's great organizational skills and professionalism are matched only by her commitment to our work. Karin has also worked with both patients and participants in research studies.

Each of our staff members will be happy to answer any of your questions and appreciate any comments you may have regarding the UWTR. We have found that email has become a great way to correspond, particularly if you have moved and need to update your records. Please contact us to provide your current email address by sending an email to:

[uwtwins@u.washington.edu](mailto:uwtwins@u.washington.edu)

## Registry Information Update by Niloo Afari, PhD

**Niloo Afari, PhD is an Associate Professor of the University of Washington Department of Psychiatry and Associate Director of the UWTR.**

We have learned that there is much we don't know about the twins who are members of the UWTR. That includes information that would help describe our twins as a group and help answer new questions. As new questions arise about health and illness, we may contact you to collect more information. This information could come from questionnaires, physical examinations, blood samples, and other tests.

Of course, like everything else we ask of you, providing any such information is voluntary. If you agree, we will tell you about the survey or procedure and ask you to sign a consent form. We may also use information from public sources available to anyone, such as birth records. Please remember that all the information about you in the Registry is strictly confidential and will not be released to anyone without your written permission. 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.



Niloo Afari, PhD

## Preliminary Studies on Health by Dedra Buchwald, MD

All of the studies described below are based on the brief mailed survey you completed when you first joined the UWTR. In these studies, we use a concept called "concordance". Concordance is the percentage of twins who both have the same trait or condition. Concordance is one way of measuring how genetic a trait or condition is. To determine if a trait or condition is more or less genetic, we often compare the concordance in identical and fraternal twins. If a trait or condition is at least partly genetic, one would expect identical twins to be more concordant than fraternal twins. This is because identical twins share 100% of their genes and fraternal twins share only, on average, 50% of their genes. For example, let's say we are doing a study of pain and we start with 100 pairs of identical and 100 pairs of fraternal twins. We find that in 40 pairs of identical twins and in 20 pairs of fraternal twins both twin report pain. We would say the concordance for pain is 40% among identical twins and 20% among fraternal twins. Since identical twins are more concordant than fraternal twins, pain in our study appears to be under genetic influence.

One question we asked twins is if they had ever been diagnosed by a physician with **temporomandibular disorder** (also known as TMD or TMJ). This is a common condition of pain in the face and jaws. In total, 641 identical and 446 fraternal twin pairs participated in the study. The overall frequency of TMD was 4%. The identical and fraternal twin concordance rates for TMD were compared to determine the genetic influence on the condition. The concordance rate for TMD was 28% in identical twins and 9% in fraternal twins. This shows that temporomandibular disorder is at least in part affected by genetic factors.

Two other items on the survey asked about difficulty (falling and staying asleep) and

sleepiness. The 500 identical and 355 fraternal twins who provided information were, on average, 29 years old and 49% were female. The overall rate of insomnia was 19% and the rate for daytime sleepiness was 3%. The concordance for insomnia was 64% in identical pairs and 18% in fraternal pairs. Moreover, insomnia did not seem to be due to environmental factors shared between twins. For daytime sleepiness, 31% of identical and 27% of fraternal twins were concordant, respectively. In contrast to insomnia, common environmental effects did account for some of the daytime sleepiness experienced by the twins. This shows how studies of twins can be of unique value in pointing to the potential genetic and non-genetic causes of health problems. Lastly, we examined the genetics of asthma. The 435 identical and 377 fraternal twins who provided information were, on average, 29 years old. The overall frequency of self-reported asthma was 15% and was slightly higher in women than men. Twin concordance rates for asthma were 59% in identical pairs and 30% in fraternal pairs. This indicated that the genetic influence on asthma was strong. Although common environmental effects were small, environmental effects unique to the twins (that is environmental exposures not shared by the twins) accounted for the remaining likelihood of developing asthma. One message from this study is that genetic factors are important in the etiology of asthma.

Taken together, these studies show how simple questions can lead to complex but very useful answers about common problems.

### UW Twin Registry

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*"Identical twins share 100% of their genes and fraternal twins share 50%."*

## Herpes Simplex Virus Research by Corey Casper, MD, MPH

Together with researchers from the Infectious Disease Division at the UW, the UWTR is conducting a study to understand why some people have more frequent or severe herpes outbreaks than others.

Over half the population in the US is infected with herpes simplex virus-1 (HSV-1). This virus is the cause of most cases of oral herpes (cold sores) and some cases of genital herpes. On the other hand, about 25% of Americans are infected with herpes simplex virus-2 (HSV-2), the most common cause of genital herpes. Infection with these viruses is life-long, yet people vary widely in the number of

outbreaks with either virus they will have over their lifetime. Similarly, the symptoms of an outbreak often differ between people and even the same person can have very different symptoms with each outbreak. Yet surprisingly, the reasons for these differences are not known. Experts believe the differences may reflect the function of a person's immune system or the specific type of herpes virus with which they are infected.

We hope to compare how similar the immune system is in pairs of twins infected with oral herpes. This study may provide important information to develop new treatments for herpes simplex in the future.



*The Space Needle  
Seattle, Washington*

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*"This study may provide important information to develop treatments for herpes."*

## Lung Disease Research by Mark Wurfel, MD

Every year in the United States, thousands of people die from an overwhelming infection known as 'sepsis'. Sepsis begins with a small infection that spreads and activates a person's entire immune system. This then sets off a chain reaction of events that can lead to uncontrolled inflammation in the body. The whole-body response to infection produces changes in temperature, blood pressure, heart rate, white blood cell count, and lung function. The body's white blood cells combat germs, such as bacteria, but in the process also cause inflammation. This inflammation is believed to play an important role in the development of sepsis.

Dr. Thomas Martin and Dr. Mark Wurfel from the University of Washington Division of Pulmonary and Critical Medicine are leading a study to determine the genetic and environmental factors that control inflammation caused by infection. This study

will test how normal human white blood cells react to bacteria. In each pair of identical and fraternal twins, we will compare one twin to the other twin by testing the amount of inflammation generated by their white blood cells. This will allow us to estimate how much of a role genes and environment play in determining someone's response to infection.

Information learned from this study may eventually help in the development of new ways to diagnose and treat sepsis.

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## Jack's Facts by Jack Goldberg, PhD



**Jack Goldberg, PhD is a Research Professor at the University of Washington and Director of Research for the UWTR.**

The number of twin pairs varies widely across the world. The highest twinning rate is

45 per 1000 births and is found in the West African country of Nigeria among the Yoruba tribes. Among the Yoruba twin births are considered a great blessing and the Yoruba celebrate twins in art and song. Much lower rates are found in Japan with a rate of twins of only 8.3 per 1000 births. In the United States the rate of twinning is increasing and is now at 29 per 1000 births; in 2003 more than 125,000 twins were born.

The rate of twin births for identical twins is 4 per 1000

births and is virtually constant across the globe. This rate does not seem to be effected by where a person lives, what they eat or any other factors. This is not the case for fraternal twin births where the rate varies both within and between countries. On a global basis the rate of fraternal twinning is about 23 per 1000 births. But this rate is effected by fertility treatments, where a person lives, and mothers age at birth-older mothers are much more likely to have fraternal twins.

### FOR MORE INFORMATION ON TWINS

see these websites...

[www.twinsworld.com](http://www.twinsworld.com)  
[www.twindays.org](http://www.twindays.org)  
[views.vcu.edu/twinreg](http://views.vcu.edu/twinreg)

### Win a gift by sending an email!

Email is a very fast and easy way for us to communicate with twins in the UWTR. To encourage the use of email, we are holding a contest. The first 100 twins enrolled in the UWTR to contact

us with their email address will receive a beautiful cream colored UWTR canvas bag with a Northwest Indian design. You can win by sending us an email by May 15, 2004 to [uwtwins@u.washington.edu](mailto:uwtwins@u.washington.edu)

### About Our Organization...

The University of Washington Twin Registry is supported by the National Institutes of Health. For more information, please contact us toll-free at 1-888-223-0868 ext. 1 or email us at [uwtwins@u.washington.edu](mailto:uwtwins@u.washington.edu). Thank you!



University of Washington  
Twin Registry  
Harborview Medical Center  
325 9<sup>th</sup> Avenue, Box 359780  
Seattle, WA 98104