



WASHINGTON STATE TWIN REGISTRY

**FY2018
ANNUAL
REPORT**

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This report summarizes the major achievements and activities of the Washington State Twin Registry (WSTR) from July 2017 to June 2018.

OVERVIEW

The WSTR has the potential to have a great impact on scientific growth and health-related research - from basic science to public health prevention and intervention efforts. Twins provide a unique resource and research tool for medical and scientific researchers to collaborate and use ground-breaking technologies such as genomic and proteomic tools and environmental geocoding.

Combining twin and molecular methods can dramatically impact public health by advancing fields such as pharmacogenomics, individualized medicine, and disease-specific treatments. Research focused on environmental contributions to disease may lead to better community-based approaches to disease as well as targeted interventions for individuals at highest risk.

LOCATION

THE WSTR IS A PARTNERSHIP BETWEEN WASHINGTON STATE UNIVERSITY (WSU) AND THE UNIVERSITY OF WASHINGTON, WITH THE GOAL OF BEING A STATEWIDE RESEARCH RESOURCE.

The WSTR is administratively housed in the Department of Nutrition and Exercise Physiology in the Elson S. Floyd College of Medicine (ESFCOM) at WSU Spokane. ESFCOM provides support for grant administration and budget and fiscal management, while WSU Spokane provides support for information technology and human resources. The Institutional Review Board (IRB) at WSU Pullman is responsible for the review and approval of all research activities involving human subjects. The WSTR IRB application is reviewed for continuing approval every April.



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SCIENTIFIC ADVISORY BOARD

The WSTR has an advisory board consisting of faculty selected by the Director and Assistant Director, and a pair of twins from the Registry.

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WSTR MEMBERS

RECRUITMENT

**ONLY TWIN PAIRS
IN WHICH BOTH
MEMBERS OF THE
PAIR COMPLETE
AN ENROLLMENT
SURVEY ARE
ENROLLED INTO
THE TWIN REGISTRY**

The Washington State Department of Licensing (DOL) is unique in that it encodes an individual's name and date of birth in the license number.

Based on this formula, twins have the potential to generate the same license number. To avoid issuing a duplicate license number, the DOL asks all individuals getting a new license or renewing their existing license if they are a twin. The month of birth is coded differently for the second twin. Since 2002, the DOL has been sending a list of these names to the WSTR on a weekly basis. DOL records are also used to update contact information for twins who are already in the Registry and still live in Washington State.

In the past, invitations to join the Registry were sent out on a monthly basis, but our current procedure is to send them quarterly. Invitation packets contain an introductory letter, an informational consent statement, a link to complete an online version of the survey, and a paper version of the survey with a business reply envelope. Once we receive a completed survey from both twins, the pair is enrolled into the Registry and eligible to be contacted for participation in studies.

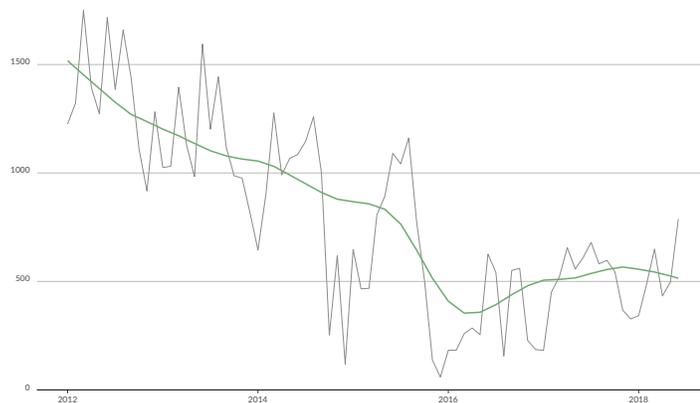
Beginning in September 2018, the DOL will be changing how they generate license numbers, which will no longer be based on name and date of birth. However, to avoid issues with identity theft, the DOL will continue to ask applicants if they are a twin, so the WSTR will continue to receive contact information for potential twins.



During FY18 we received contact information for 6,171 unique individuals.

Before we send recruitment invitations, the list of names we receive from the DOL is thoroughly examined to remove individuals who are already in the Registry, individuals who have requested to be removed from our contact list in the past, and individuals who would not be eligible to enroll in the Registry (higher order multiples). Twin pairs and higher order multiple sets are identified by matching last name, date of birth, and/or address.

DOL Names Received per Month, January 2012 - June 2018



The graph at left illustrates the trend in the number of unique individuals provided by the DOL each month since January 2012.

A photograph of two women standing in a field of purple lupines. They are holding large, vibrant bouquets of flowers that partially obscure their faces. The woman on the left is wearing a light-colored, vertically striped dress, and the woman on the right is wearing a light blue dress. The background is a soft-focus field of similar flowers under a bright sky.

**TO DATE, WE HAVE
ENROLLED 9,546
PAIRS OF TWINS,
REPRESENTING 9,107
ADULT PAIRS (OVER 18)
AND 439 JUVENILE PAIRS
(UNDER 18)**

We have members living in all 50 US states plus Washington DC, and around the world. Over 65% of our members live in Washington State, primarily in the Puget Sound region around Seattle.

DEMOGRAPHICS

Age	Percentage
9 years old and younger	3.6
10-19 years old	1.4
20-29 years old	14.4
30-39 years old	27.8
40-49 years old	15.0
50-59 years old	13.3
60-69 years old	13.7
70 years old and over	10.7
Ethnicity	
Hispanic/Latino	3.9
Race	
White	90.2
Black or African American	2.0
American Indian or Alaska Native	0.6
Asian	2.4
Pacific Islander or Native Hawaiian	0.4
Some other race	1.4
Two or more races	2.9
Zygoty/Sex	
Monozygotic male	18.9
Monozygotic female	33.5
Dizygotic male	9.4
Dizygotic female	16.4
Dizygotic opposite-sex	21.7

SERVICE CENTER

THE WSTR CHARGES FEES TO ALL INVESTIGATORS USING THE REGISTRY TO SUPPORT RECRUITMENT OF NEW TWINS AND RETENTION OF EXISTING MEMBERS.

01

Contact information

This rate supports recruitment of new twins into the Registry as well as retention of existing twins in the Registry. This rate is charged each month that a study is actively recruiting new twins for new data collection. This is our primary rate, as studies collecting new data have the highest need for twin pairs. Keeping the Registry up to date as well as adding new twins is essential for supporting recruitment into new data collection studies.

02

Datasets

This rate is charged to investigators wishing to use archived data for secondary data analysis. This rate supports a portion of recruitment for new twins (and therefore new survey data) as well as collection of new follow-up survey data.

03

Biological samples

This rate is charged to investigators wishing to use archived biological specimens for data analysis. This rate supports a portion of the FTE for the lab coordinator who oversees the organization and maintenance of the freezers where the specimens are stored, as well as sample shipping to the investigator requesting the samples. Most of our biological samples are processed DNA which can be used in epigenetic studies, but we also have saliva, urine, and blood available for use.

In addition to the rates listed above, we have hourly rates for research coordinators and research assistants to carry out new data collection for investigators.

AVAILABLE DATA

FOR OVER 15 YEARS, THE WSTR HAS COLLECTED DATA ON A VARIETY OF HEALTH-RELATED TOPICS



Survey data

All twins complete an enrollment survey to join the Registry, which asks about twin similarity, sociodemographics, sleep, physical activity, eating behaviors, health and medical history, pain and fatigue, mental health, and lifestyle behaviors. Every 2-3 years, we send a follow-up survey which contains questions from the same domains as the enrollment survey, as well as questions about caregiving, personality, and employment.

Environmental data

Since 2008, the residential address at the time of survey has been geocoded. This has allowed us to create environmental exposure measures that can be paired with survey data in order to better understand how the built and social environment impacts lifestyle behaviors and health. Current measures include walkability, neighborhood deprivation, normalized difference vegetation index (NDVI), and crime.

Biological samples

The WSTR has collected biological samples from twins participating in both at-home and in-person studies. The majority of our samples are DNA processed from saliva collected between 2010-2012, but we also have blood (processed DNA, whole blood, RNA, plasma, serum), saliva (buccal brush for DNA or salivary cortisol), and urine. Biological samples are located in freezers at WSU Spokane, and can be shipped within the US.

STUDIES COLLECTING NEW DATA

VALIDATION AND APPLICATION OF PORTABLE PARTICULATE DEVICE IN THE UW TWIN REGISTRY

PI: Edmund Seto (UW) and Glen Duncan (WSU)

Project number: R33ES024715

Funding agency: NIEHS

Project dates: 9/1/17-8/31/20

Now in the R33 phase of funding, this study seeks to understand how the environment influences human health by measuring environmental exposures in real-time using a portable particle monitor that was built and refined in the earlier R21 phase of the study. By studying twins, researchers will be able to assess the associations between environmental exposures and health outcomes while controlling for genetic and shared environmental influences. In this phase of the study, participants come in for collection of clinical measures including blood pressure, BMI, waist circumference, and lung function. They provide blood and saliva samples, and then collect data using the particle monitor, as well as an activity monitor and a GPS, for two weeks at home.

TWINSTUDY OF ENVIRONMENT, LIFESTYLE BEHAVIORS, AND HEALTH

PI: Glen Duncan

Project number: R56AG042176

Funding agency: NIA

Project dates: 9/30/17-8/31/18

The goal of this project is to determine how the built environment (BE) in which individuals live, work, and play in on a daily basis influences lifestyle behaviors and health. This funding continues a productive line of research by following up with 144 twin pairs that collected data from 2012-2015 and having them collect data for one week at home. Participants wear an activity monitor and carry a GPS, complete a travel diary, complete questionnaires, and collect buccal (cheek) cells for epigenetic analyses. By adding epigenetic analyses to the project, researchers have the potential to discover new and important insights linking epigenetic, environmental, and behavioral aspects of obesity and chronic disease.



GENE EXPRESSION AND THE MICROBIOME IN TWINS (GEMSTONE)

PI: Glen Duncan

Funding agency: WSU Strategic Reallocation Funding

Project dates: 2/1/18-1/31/19

The purpose of this pilot study is to catalyze new research on epigenetic and gut microbiota alterations associated with obesity in BMI discordant same-sex twin pairs. Previous studies of BMI discordant twin pairs have found that gene methylation and expression differed within twin pairs. Additionally, twin studies have found that the gut microbiome is highly heritable and linked to obesity and metabolic profiles. Twin pairs discordant for BMI (one is 'normal' weight, one is 'obese') and free of conditions or medications that impact the gastrointestinal tract and gut microbiome are sent collection materials to collect data at home. Participants complete questionnaires, provide a stool sample for gut microbiome analysis, and a buccal (cheek) sample for the epigenetic analysis.

STUDIES CURRENTLY ANALYZING DATA

Epigenetic Determinants of Major Depression: A Monozygotic Twin Study

PI: Jinying Zhao (University of Florida) and Eric Strachan (UW)

Project number: R01MH097018

Funding agency: NIMH

Secondhand Smoke and Asthma: Mechanistic Outcomes of DNA Methylation in T Cells

PI: Kari Nadeau (Stanford University)

Project number: R01HL118612

Funding agency: NHLBI

Neighborhood and Genetic Influences on Alcohol Misuse in a sample of twins

PI: Isaac Rhew (UW)

Funding agency: University of Washington Royalty Research Fund

Heritability of Preferences

PI: Martin Reimann (University of Arizona)

Funding agency: Departmental funding

Correlates of Resilient Coping with Health Behaviors

PI: Vaughn Sinclair (Vanderbilt University)

Funding agency: Departmental funding

Twin Study of Birth Weight and Reproductive Health

PI: Shayesteh Jahanfar (Central Michigan University)

Funding agency: Departmental funding

A Twin Study of Obesity Pathogenesis using FMRI

PI: Ellen Schur (UW)

Project number: R01DK089036

Funding agency: NIDDK

TWINStudy of Environment, Lifestyle Behaviors, and Health

PI: Glen Duncan

Project number: R01AG042176

Funding agency: NIA

*Follow-up data is currently being collected under R56AG042176



The Genetics & Epigenetics of Healthy Aging in Twins

PI: Sangkyu Kim (Tulane University)

Project number: P20GM103629-8393

Funding agency: NIGMS

PUBLICATIONS

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Eney AE, Tsang S, Delaney JA, Turkheimer E, Duncan GE. **Cross-sectional association between soda consumption and body mass index in a community-based sample of twins.** Nutr J. 2017 Aug 22;16(1):48.

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Schur E, Carnell S. **What Twin Studies Tell Us About Brain Responses to Food Cues.** Curr Obes Rep. 2017 Dec;6(4):371-379.

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Rhew IC, Kosterman R, Duncan GE, Mair C. **Examination of Cross-Sectional Associations of Neighborhood Deprivation and Alcohol Outlet Density With Hazardous Drinking Using a Twin Design.** J Stud Alcohol Drugs. 2018 Jan;79(1):68-73.

Melhorn SJ, Askren MK, Chung WK, Kratz M, Bosch TA, Tyagi V, Webb MF, De Leon MRB, Grabowski TJ, Leibel RL, Schur EA. **FTO genotype impacts food intake and corticolimbic activation.** Am J Clin Nutr. 2018 Feb 1;107(2):145-154.

Cohen-Cline H, Beresford SA, Barrington W, Matsueda R, Wakefield J, Duncan GE. **Associations between social capital and depression: A study of adult twins.** Health Place. 2018 Mar;50:162-167.

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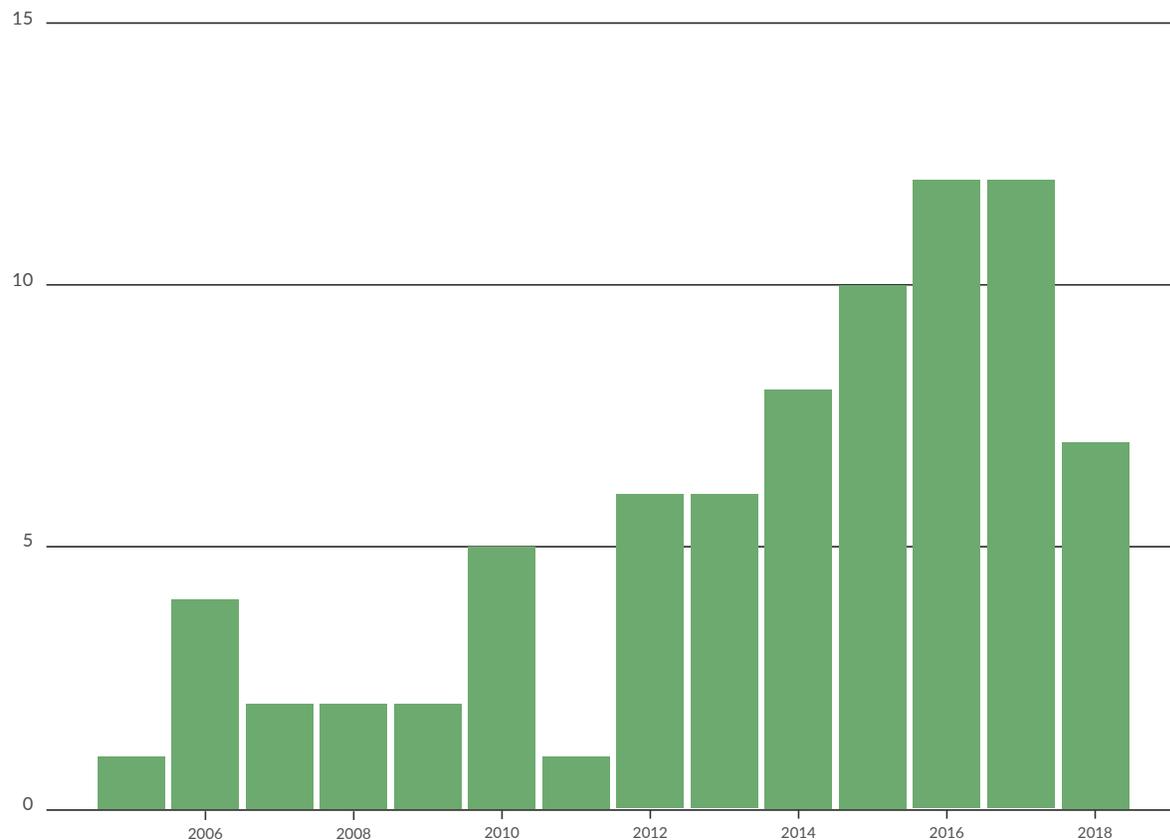
Cook DJ, Duncan G, Sprint G, Fritz R. **Using Smart City Technology to Make Healthcare Smarter.** Proc IEEE Inst Electr Electron Eng. 2018 Apr;106(4):708-722.

Peng H, Zhu Y, Strachan E, Fowler E, Bacus T, Roy-Byrne P, Goldberg J, Vaccarino V, Zhao J. **Childhood Trauma, DNA Methylation of Stress-related Genes, and Depression: Findings from Two Monozygotic Twin Studies.** Psychosom Med. 2018 May 17. [Epub ahead of print]



The following graph shows the number of publications per year since 2005, when the first peer-reviewed article using data from the Twin Registry was published. As of 6/30/18, we have published more than half the number of articles that were published in 2017, and we expect to meet or exceed the final 2017 publication count by the end of the calendar year.

WSTR Publications by Year as of June 30, 2018

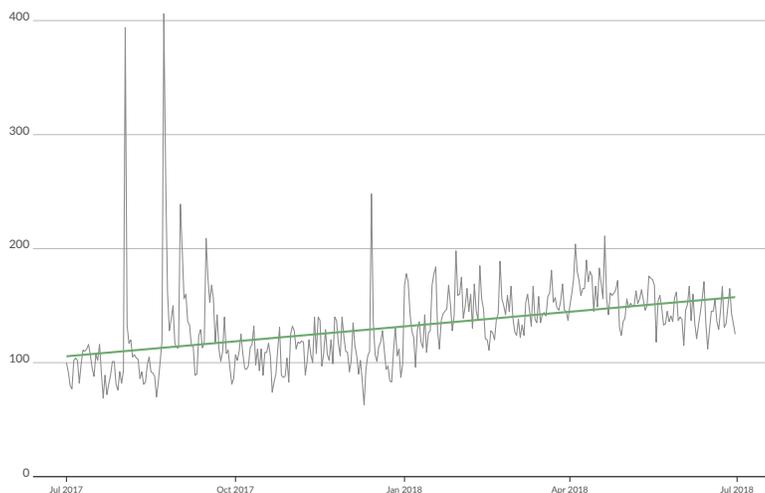


OUTREACH

WEBSITE

During FY18, we had over 45,000 visits to our website. Daily visits increased over the duration of the year, continuing the trend from FY17. New visitors spent less than one minute on our website and represented 90% of all visits, while returning visitors spent an average

Daily website visits July 2017 - June 2018



of one minute and twenty seconds, a decrease from FY17. 74% of referrals to our website are from search engines, while 14.4% are from other websites. The NIH Genetics Home Reference website is our top referral source for other websites. Our second highest referral source was our survey platform, Qualtrics. In August 2017, we sent emailed invitations for a new survey built on the Qualtrics platform (Twin Study of Birth Weight and Reproductive Health). At the completion of the survey, participants were redirected to our website, which thanked them for their participation and provided links to summaries about our research. The website for the DOL continues to refer a modest number of visitors to the website.

The Registry website is located at www.wstwinregistry.org

FACEBOOK

The Registry Facebook page has continued to grow organically, primarily through links on our website and by our followers interacting with our page and posts. During FY18, our Facebook page gained 168 new page likes, and as of June 30, 2018 we have a total of 1,180 page likes.

The Registry Facebook page is located at www.facebook.com/wstwinregistry

Cumulative new Facebook likes by month, July 2017 - June 2018



GET IN TOUCH

We want to hear from you!

Do you have ideas for research topics?
Would you like to collaborate on a research project?
Do you have a question about twin studies?
Want to provide feedback about the annual report?

Visit our website or Facebook page,
send us an email, or give us a call!



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