WASHINGTON STATE  TWIN REGISTRY

FY19 ANNUAL REPORT

FY 2019 at a glance

6
active projects

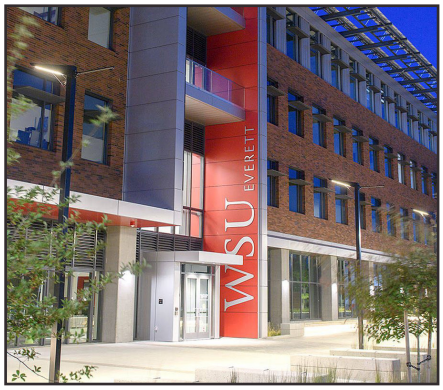
1,237
unique twins participated in a study

179
new twin pairs enrolled in the Registry

11
new peer-reviewed publications

About the Registry

The Washington State Twin Registry (WSTR) is administratively housed in the Department of Nutrition and Exercise Physiology, Elson S. Floyd College of Medicine, Washington State University Spokane.



The WSU Institutional Review Board (IRB) is responsible for the review and approval of all research activities involving human subjects including those of the WSTR. The WSTR IRB application is reviewed for continuing approval every April. Research staff are located on the WSU Spokane and Everett campuses, as well as the University of Washington campus.

Staff

Glen Duncan
Director

Elizabeth Blue
Assistant Director

Ally Avery
Scientific Operations Manager

Mike Oie
Research Study Coordinator

Shelby Tarutis
Research Study Assistant

Siny Tsang
Staff Scientist

Scientific Advisory Board

The advisory board consists of faculty selected by the Director and Assistant Director, and a pair of twins from the Registry.

Hans P.A. Van Dongen
Research Professor
Washington State University

Jack Goldberg
Research Professor
University of Washington

Naomi Chaytor
Associate Professor
Washington State University

Paul Whitney
Professor
Washington State University

Nicholas L. Smith
Professor
University of Washington

Eric Strachan
Assistant Professor
University of Washington

Eric Turkheimer
Professor
University of Virginia

Brent Lewis and Brian Lewis
Members
Washington State Twin Registry

Registry Construction

Since 1999, we've partnered with the Washington State Department of Licensing (DOL) to identify potential twins who reside in Washington State. Recruitment mailings are sent on a quarterly basis inviting these individuals to join the Registry.

DOL Partnership

Prior to September 2018, driver's license numbers in Washington State were generated using one's name and date of birth. Because twins typically share the same birth date and may have the same last name and first and middle initials, the DOL has historically asked all new applicants if they were a twin to avoid issuing duplicate numbers. In September 2018, the DOL moved to a new system that no longer generates license numbers based on one's name. However, the question on being a twin is still asked to help prevent identity theft.

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 such as triplets. Twin pairs are identified by matching last name, date of birth, and/or address.

During FY19, we received contact information for 3,281 unique individuals who indicated that they are a twin.

DOL Names Received per Month, January 2012 - June 2019

As part of our contract with the DOL, a data security audit was conducted to ensure that our systems comply with the security requirements outlined by the DOL. The audit reviewed data, network, access, application, and computer security, and verified that systems were securely encrypted. To ensure that our computer systems met the industry standard data security requirements, we worked with IT staff in the WSU College of Agricultural, Human, and Natural Resources to build out an Amazon Workspace, where all DOL data is now housed. Access to this workspace is limited to only the WSTR Scientific Operations Manager.

Invitation Mailings

We partner with the WSU Social and Economic Sciences Research Center (SESRC) to conduct recruitment mailings. The invitation contains 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. The SESRC sends follow-up mailings and enters data from returned paper surveys. At the end of a recruitment mailing, we receive a file that contains data from surveys completed both online and on paper. Once we receive surveys from both members of a twin pair, they are enrolled in the Registry.

In 2013, we modified our procedures to allow volunteers to request a survey to enroll, as we were being contacted by twins who had not been identified by the DOL. Volunteers request a survey invitation through our website and are sent an email with a link to complete the online version of the survey.

Demographics

As of June 30, 2019, the Registry has 9,722 twin pairs (19,444 individuals). New pairs are enrolled on a quarterly basis. Twins pairs live throughout the US and in 43 countries around the world, however, 75% of the Registry lives in the Pacific Northwest.

Current Age Group (%)

9 and younger: 3.8
10-19: 1.7
20-29: 11.7
30-39: 26.8
40-49: 14.6
50-59: 13.0
60-69: 13.7
70 and older: 14.7

Zygosity/Sex (%)

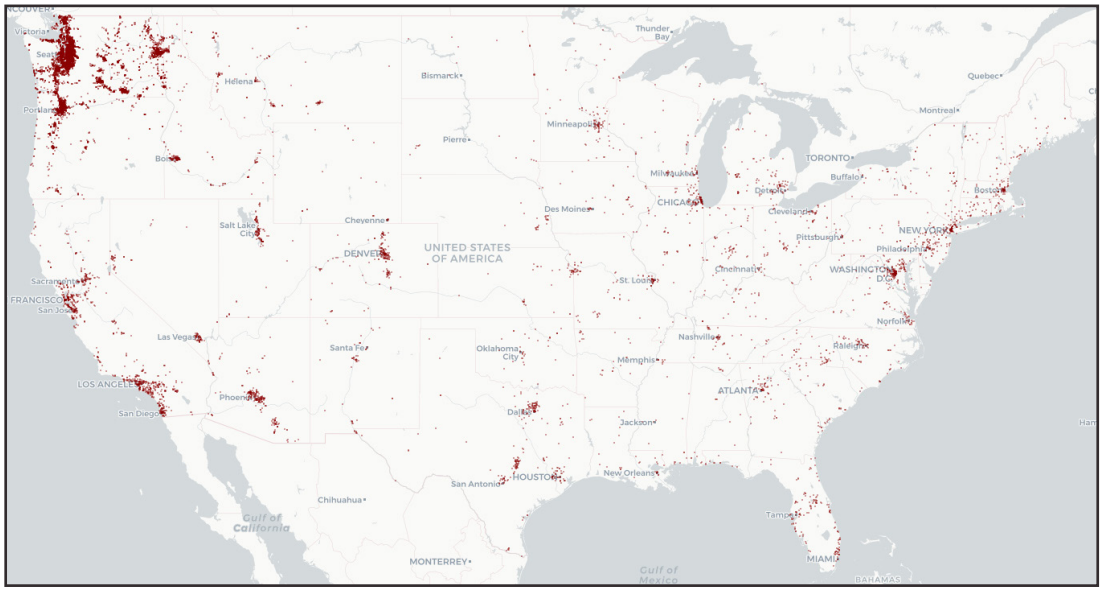
MZ male: 19.0
MZ female: 33.9
DZ male: 9.3
DZ female: 16.0
DZ male/female: 21.8

Ethnicity (%)

Hispanic/Latino: 4.0

Race (%)

White: 90.1
Black or African American: 2.0
American Indian or Alaska Native: 0.6
Asian: 2.4
Native Hawaiian or Pacific Islander: 0.4
Some other race: 1.4
Two or more races: 3.1



Active Studies

6 studies recruited twin pairs for participation during FY19, with 4 of those studies completing recruitment during the fiscal year.

A Continuing Study of Physical Activity in Twins
PI: Glen Duncan (WSU)
Funding: NIA R56 Award

The goal of this project is to understand how people interact in the built environment (BE) in which they live, work, and play daily. We focus on BE because health in a population is a function of macro-level or "big-picture" influences that affect the lives of all people, not just individuals. This study continues the work done during the first phase of this grant by measuring lifestyle behaviors in continuous time and space within and beyond individual residential locations (neighborhoods) of twins. 72 pairs of monozygotic (identical, MZ) twins who participated in the first phase of this grant were completed this follow-up study. All study materials were sent and returned by FedEx. Twins wore an Actigraph activity monitor and carried a GPS for one week. They completed questionnaires about their health and wellbeing, food consumption, and neighborhood, and completed a travel diary. They also measured their waist and used a soft brush to collect DNA from buccal cells, which will be used to investigate epigenetic changes related to obesity. Twins who completed the study received a $100 gift card. Outcomes of interest include the number of eating and activity events within and outside the home BE; longitudinal associations between the BE and physical activity and eating behaviors; and associations among the BE, lifestyle behaviors, and BMI by linking weight status with physical activity levels and food intake to determine if BMI is associated with the BE through these behaviors.

Pair N sent invitations	Pair N completed study	Pair N not interested	Pair N ineligible
128	72	19	14

Differentiating Monozygotic Twins with DNA Methylation Technology

PI: Deborah Silva (Battelle Memorial Institute)

Funding: NIJ Award

Prosecuting cases with physical evidence from an identical twin remains a challenge in criminal justice because current genetic technology cannot differentiate persons with identical genomes. As the rate of twin births are on the rise, the incidence of forensic evidence samples originating from an MZ twin will likely also increase and result in further unsolved cases due to a lack of cost effective and accurate forensic analysis methods for MZ twins. Fortunately, new tools in genome analysis and bioinformatics are opening doors to explore the epigenetic landscape and may provide new biomarkers to the forensic community for challenging samples such as MZ twins. The aim of this study is to investigate one component of epigenetics, DNA methylation, in an applied research project to differentiate MZ twins of different ages and from evidence types of different tissue sources. The WSTR provided DNA samples for different age groups, and collected new semen samples from male twins who also had DNA from saliva and blood samples collected in previous studies. This research will statistically probe differentially methylated sites in the human genome, using deep coverage methylation profiling microarrays for identification of a panel of methylation markers with high association to MZ twin differentiation. The goal targets the discovery of methylation markers based on the analysis of over 850,000 CpG sites in samples collected from multiple twin pairs. Comprehensive statistical evaluation of these data across multiple parameters will result in a down selection to a target panel of markers (150-200 CpG sites). At the conclusion of the study, all laboratory methods and results will be made available as open source resources for the criminal justice community. Short Tandem Repeats (STRs) will likely always remain the gold standard in human identification. However, the epigenetic methylation markers and the laboratory methods discovered in this study could help resolve a vast number of cases involving MZ twins and open the door to further forensic genomic applications using epigenetics.

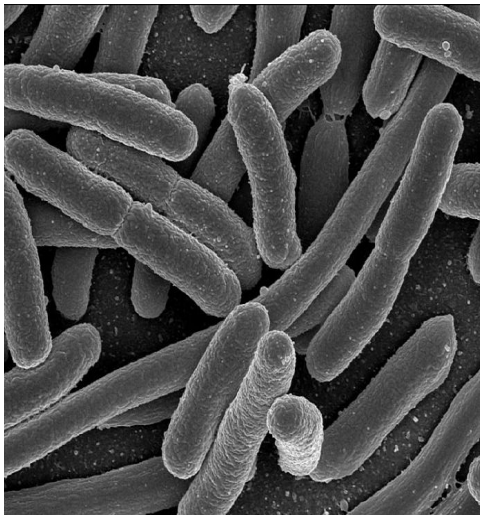
Pair N sent invitations	Pair N completed study	Pair N not interested	Pair N ineligible
26	5	2	3

Gene Expression and the Microbiome in Twins (GEMsTone)

PI: Glen Duncan (WSU)

Funding: WSU Strategic Reallocation Funding

The purpose of this pilot study is to catalyze new research on epigenetic and gut microbiota alterations associated with obesity by examining the gut microbiome of BMI-discordant twin pairs providing stool samples. A previous study in BMI-discordant identical twin pairs reported genome-wide DNA methylation and expression profiles in subcutaneous adipose tissue biopsies. Novel genes and pathways whose methylation and expression patterns differed within the twin pairs were identified, suggesting that the pathological adaptation of subcutaneous adipose tissue to obesity is, at least in part, epigenetically regulated. Twin studies of the gut microbiome suggest that it is highly heritable and linked to obesity and metabolic profiles. Both identical and fraternal twins participated in this study which was conducted entirely at home. Enrolled twin pairs collected a stool sample, provided DNA from buccal cells, and completed questionnaires about their health and wellbeing and food consumption.



Pair N sent invitations	Pair N completed study	Pair N not interested	Pair N ineligible
311	22	67	134

Google Timeline Feasibility Study

PI: Ofer Amran (WSU)

An important goal of the Twin Registry is to understand how genetics, lifestyle and environment determine health outcomes. A major challenge of doing this kind of research is the difficulty of measuring exposures to the environment, like air quality, exposure to green space, and access to neighborhood facilities. However, with the increasing use of mobile devices, it is becoming possible to better understand environmental exposures like never before. Using this type of data, we can better understand and measure the environmental exposures that may be important to one's health, and lead to tremendous impacts on our understanding of how environments influence the health of society. In order to advance this research, we assessed the feasibility of using this type of data in the Twin Registry by seeing how many members would be interested and eligible in participating in a study such as this. 500 pairs of twins reflecting the age and sex distribution of the Registry were sent an invitation by email to complete a brief survey. 168/500 (34%) pairs indicated that they would be interested in participating and willing to share their timeline data with our study team. Respondents were most interested in receiving air pollution exposure estimates.

Pair N sent invitations	Pair N interested	Pair N not interested	Pair N ineligible
500	201	31	13

Study of Environmental Exposure in Twins

PI: Glen Duncan (WSU) and Edmund Seto (University of Washington)

Funding: NIEHS R33 Award

There is a considerable amount of evidence to suggest that exposure to environmental toxins is associated with a variety of adverse health outcomes, such as cardiovascular disease and lung cancer. Most large studies have relied upon measurements made at central monitoring sites, and not within one's personal environment. Current personal environmental monitors are large and cumbersome, or very expensive. This study will utilize a new personal monitor (the PUWPM, built during the first phase) that can measure environmental exposures such as PM2.5 but is small, portable, and can be produced at a low cost. Twins attend an in-person study visit to provide clinical measures including blood pressure, height and weight, waist circumference, and lung function (spirometry), as well as biologic measures including inflammatory cytokines and cortisol. Data collection is done at home for two weeks using an activity monitor, a GPS, and the PUWPM. By using twin pairs we can study the associations between environmental exposures and health outcomes while controlling for genetic and shared environmental influences.

Pair N sent invitations	Pair N completed study	Pair N not interested	Pair N ineligible
166	31	65	35

Study of Affectionate Communication

PI: Kory Floyd (University of Arizona)

Funding: Internal funding

This questionnaire is being sent to twin pairs to understand how genetics, shared environment, and unique environment contribute to the tendency to communicate affectionately in close relationships.

Pair N sent invitations	Pair N completed study	Pair N not interested	Pair N ineligible
1,282	412	40	0

Service Center

Growth and maintenance of the Registry is supported by fees charged to investigators using WSTR twins or data in their research studies.

The following table summarizes estimated and actual spending and sales for the WSTR service center account during FY19.

	Estimated FY2019	Actual FY2019
Salary & Benefits	$21,114	$11,007
Goods & Services	$28,594	$14,880
Modernization	$0	$35
Total Spending	$43,017	$25,922
Carryforward from prior year	$7,741	$12,181
Total Sales	$27,876	$22,323
Balance	$4,165	$8,581

The differences between our estimated spending and actual spending were due to the way that the rates were set up for FY19. We created 3 rates - contact information, datasets, and biological samples - as this is how the service center had been originally set up when we were at the University of Washington. However, the only rate that we ended up charging for was contact information, so our estimated salary and benefit spending was much higher than what was actually spent. Our carryforward from FY18 into FY19 was also higher than we anticipated due to an invoice not being paid during the prior fiscal year.

For FY20 (July 1, 2019 to June 30, 2020), we simplified our service center rates to one Registry access rate. This new rate will ensure that we are accurately estimating our costs for the coming year and charging enough to break even. For studies recruiting twins for data collection, this rate will be charged monthly while the study is recruiting twins. For investigators requesting a dataset from archived WSTR data this rate will be charged one time. We have an internal rate for WSU investigators and an external rate for non-WSU investigators.

Registry Usage Rates for FY20

The Registry access fee for WSU investigators is **$1,658** and for non-WSU investigators is **$1,802**. Should new studies be funded during FY20, rates will be reviewed and adjusted to reflect the increase in use.

Available Data

All pairs enrolled in the Registry complete a baseline survey about health, lifestyle behaviors, and demographics. Follow-up surveys (HWB) have been sent every 2 to 3 years since 2010.

	Enrollment (2002)	Enrollment (2008)	Enrollment (2016)	HWB v1 (2010-13)	HWB v2 (2013-18)
Survey N (unique individuals)	5,724	12,172	394	9,142	4,659
Demographics	X	X	X	X	X
Self-report height and weight	X	X	X	X	X
Eating habits	-	X	X	X	X
Physical activity	X	X	X	X	X
Sleeping habits	X	X	X	X	X
Medical history	X	X	X	X	X
Drinking and smoking	X	X	X	X	X
Mental health	-	X	X	X	X
Personality	-	-	-	X	X
Employment	-	-	X	-	X
Military	-	-	-	-	X
Caregiving	-	-	-	X	X
Built environment	-	X	X	X	X

Publications

The following peer-reviewed articles were published during FY2019, and used data collected in WSTR studies.

1. 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 Sep;80(7):599-608.
2. Kim S, Wyckoff J, Morris AT, Succop A, Avery A, Duncan GE, Jazwinski SM. **DNA methylation associated with healthy aging of elderly twins.** Geroscience. 2018 Dec;40(5-6):469-484.
3. Strachan E, Zhao J, Roy-Byrne PP, Fowler E, Bacus T. **Study Design and Rationale for the Mood and Methylation Study: A Platform for Multi-Omics Investigation of Depression in Twins.** Twin Res Hum Genet. 2018 Dec;21(6):507-513.
4. Berkseth KE, Rubinow KB, Melhorn SJ, Webb MF, Rosalynn B De Leon M, Marck BT, Matsumoto AM, Amory JK, Page ST, Schur EA. **Hypothalamic Gliosis by MRI and Visceral Fat Mass Negatively Correlate with Plasma Testosterone Concentrations in Healthy Men.** Obesity (Silver Spring). 2018 Dec;26(12):1898-1904.
5. Duncan GE, Seto E, Avery AR, Oie M, Carvlin G, Austin E, Shirai JH, He J, Ockerman B, Novosselov I. **Usability of a Personal Air Pollution Monitor: Design-Feedback Iterative Cycle Study.** JMIR Mhealth Uhealth. 2018 Dec 21;6(12):e12023.
6. Zadro JR, Shirley D, Duncan GE, Ferreira PH. **Familial factors predicting recovery and maintenance of physical activity in people with low back pain: Insights from a population-based twin study.** Eur J Pain. 2019 Feb;23(2):367-377.
7. Telfer S, Bigham JJ, Sudduth ASM. **Plantar pressures in identical and non-identical twins.** J Biomech. 2019 Mar 27;86:247-250.
8. Ramchandani MS, Jing L, Russell RM, Tran T, Laing KJ, Magaret AS, Selke S, Cheng A, Huang ML, Xie H, Strachan E, Greninger AL, Roychoudhury P, Jerome KR, Wald A, Koelle DM. **Viral Genetics Modulate Orolabial Herpes Simplex Virus Type 1 Shedding in Humans.** J Infect Dis. 2019 Mar 15;219(7):1058-1066.
9. Goldfarb DS, Avery AR, Beara-Lasic L, Duncan GE, Goldberg J. **A Twin Study of Genetic Influences on Nephrolithiasis in Women and Men.** Kidney Int Rep. 2018 Nov 29;4(4):535-540.
10. Avery AR, Duncan GE. **Heritability of Type 2 Diabetes in the Washington State Twin Registry.** Twin Res Hum Genet. 2019 Apr;22(2):95-98.
11. Moudon AV, Huang R, Stewart OT, Cohen-Cline H, Noonan C, Hurvitz PM, Duncan GE. **Probabilistic walking models using built environment and sociodemographic predictors.** Popul Health Metr. 2019 Jun 3;17(1):7.

Outreach

As a land-grant university, WSU has an obligation to serve the citizens of Washington State through teaching, community engagement, and research. The WSTR aims to support this mission by engaging twins in research and by reaching out to twins in the community via our website, Facebook page, appreciation mailings, and in-person get togethers.

Thank You Mailing

In November 2018 we sent out a thank you card to every member of the Registry, which included a decal with the WSTR logo, and a contact information update form with business reply envelope. As an incentive to return the contact information update form, we conducted a raffle for an 23andme Ancestry kit. When both members of a twin pair submit their DNA samples to 23andme, they can learn if they are identical or fraternal twins. 23andme is a CLIA-certified laboratory, which means zygosity results can be used for medical purposes if needed. 5,052 individual twins updated their contact information, and 5 pairs of twins were selected as winners of a DNA kit.

The contact information update form included a write-in box for suggestions about a potential twin event. Over 1,700 people provided suggestions for an event. When looking at word pairings, activities such as wine tasting, golf, and happy hour were frequently suggested. We are planning a larger event that will serve as an annual gathering for twins statewide, and several smaller events for twins local to WSU campuses.

The top 5 suggested locations were Seattle, Spokane, Tacoma, Portland (OR), and Everett.

Twins Get Together

The contact information update form sent out during the thank you received many responses from twins indicating that they wanted an event where they could meet other twins and learn about research being done by the WSTR. On June 19, we held the first Twins Get Together event at WSU Everett. 47 twins (21 complete pairs) attended this free evening event. Food was provided, and twins had the chance to talk with other twins and read about our research studies. We gave a short presentation about why twin studies are important, our past and present research, and addressed some of the frequently asked questions that we receive from twins, such as questions about zygosity (whether twins are identical or fraternal). Finally, we played a fun game of twin-themed BINGO which led into time for the twins to share stories with each other about their unique experiences as a twin.

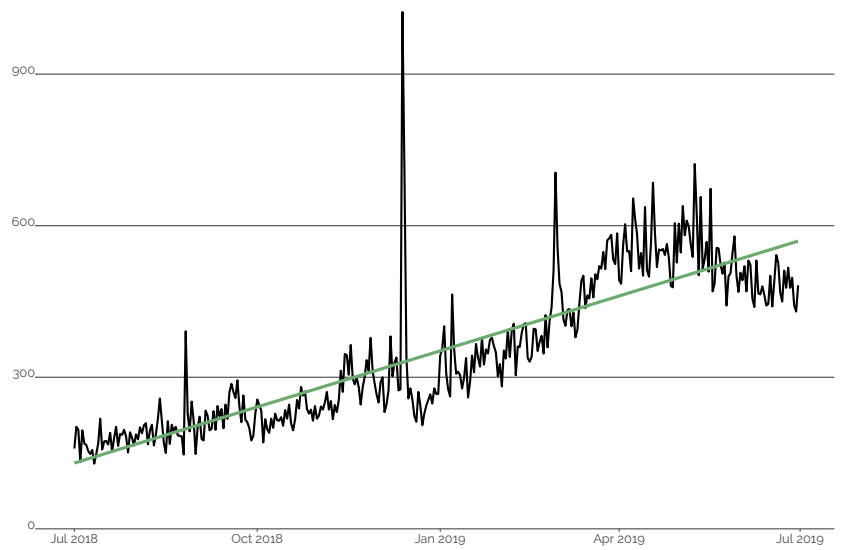
We received positive feedback and will be planning similar get togethers for twins living near other WSU campuses. We are also in the early planning stages of a large celebration of twins to take place in the summer of 2020.

Kevin Clark, The Herald

Ally Avery, WSTR

Website

Website visits per day, July 2018 - June 2019



During FY19, we had over 127,000 visits to our website, a nearly three-fold increase from FY18. 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 92% of all visits; returning users also spent less than one minute on the website, a decrease from FY18. 82.4% of referrals to our website are from search engines, while 17.6% are from other websites, an increase from FY18. The NIH Genetics Home Reference website continues to be our top referral source for other websites. Our second highest referral source was our survey platform, Qualtrics. We used Qualtrics to send a reminder email with a link to a contact information update form as part of the thank you mailing. After updating their information, participants were redirected to our website. The website for the DOL continues to refer a modest number of visitors to the website.

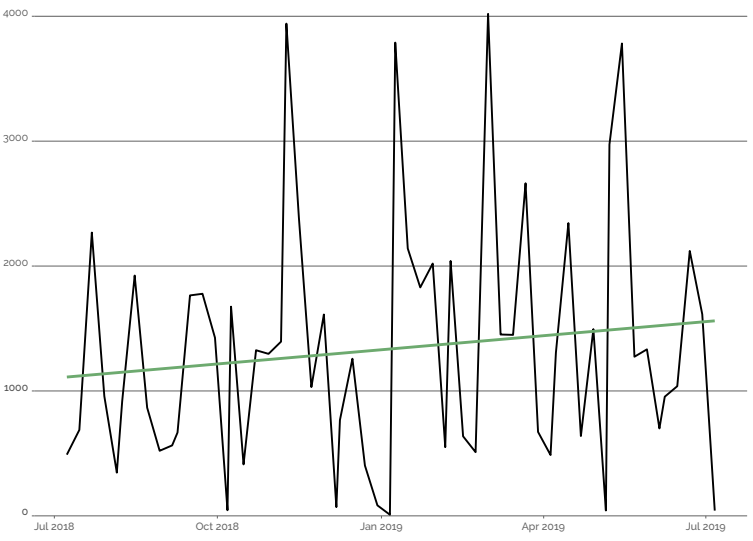
The Registry website is located at www.wstwinregistry.org

Facebook

The Registry Facebook page continues to grow organically, primarily through links on our website and by our followers interacting with our page and posts. During FY19, our Facebook page gained 80 new page likes, and as of June 30, 2019 we have a total of 1,260 page likes. Our page reached over 78,000 people during FY19. The graph at right shows the total reach for each 7-day period between July 1, 2018 and June 30, 2019. There is a modest increasing trend in the number of people that our Facebook page reaches.

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

Total reach by 7-day period, July 1, 2018 to June 30, 2019



Plans for FY2020

As the Registry enters its 18th year of active recruitment, we look forward to working on the following projects in the coming months.

Health and Wellbeing wave 4

The 4th wave of our follow-up questionnaire will be sent out beginning in July 2019. Nearly 7,000 twin pairs are eligible for this mailing. We will start with emailed invitations and follow up with a mailed paper survey in the fall. The 23andme Ancestry kit raffle was quite popular in the thank you mailing, so we will be holding another raffle to win an Ancestry kit as the incentive for completing this survey.

Improving Diversity

Nearly 91% of the WSTR is non-Hispanic White, a limitation that has been well-documented in genetics research generally. Up until 1985, around 90% of all twin births in the state of Washington were classified as White. Since then, the percentage of births classified as White has been steadily decreasing, with increases in Hispanic/Latino and Asian racial groups. Improving minority representation will likely require different methods for different groups, and this is one of our major initiatives in the new fiscal year.

20,000 in 2020

As of June 30, the Registry has 9,725 pairs of twins enrolled, with 8,957 pairs still actively participating. Our goal for 2020 is to reach 10,000 pairs of actively enrolled twins (20,000 individuals) in the Registry through DOL recruitment, volunteer recruitment, and community outreach.

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?

Are you a student who would like to use twin data for a research project?

Do you have a question about twin studies?

Do you want to provide feedback about the annual report?

Let us know! Send an email to ws.twinregistry@wsu.edu or call 1.833.432.8720.

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