

VETRegistry *Twin Times*

News for Participants in the Vietnam-Era Twin Registry

VOLUME TEN
AUTUMN 2016

1

WELCOME
SPOTLIGHT

2

VETR - WHAT

3

VETR - WHO

4

TWIN REGISTRIES

5

TWIN NEWS

6-7

FOCUS GROUPS

8-9

STUDY UPDATES

10

STAFF UPDATE

11

CONTACT UPDATE

PUBLISHED BY
Vietnam-Era Twin Registry

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The Vietnam Era Twin Registry is housed at the Seattle Epidemiologic Research and Information Center (ERIC) in Seattle, WA, and is sponsored by the Cooperative Studies Program (CSP).

WELCOME

Welcome to the 10th edition of the Vietnam-Era Twin (VET) Registry newsletter, the *Twin Times*. As the year winds down, we would like to take the time to reflect on the two years that have passed since the last edition of the newsletter. The VET Registry continues to thrive, with numerous collaborations with talented researchers and sustained support from members like you who have contributed to Registry studies and projects.

In this issue you will find information about current VET Registry studies, Registry focus groups, and Registry staff, as well as articles about the continued importance of twin research for scientific advances. We will also review what the Registry is, and the role that you play as a member. As always, we would like to hear from you. Our contact information can be found at the bottom of each page of the newsletter. Thank you for taking the time to read this issue.

RESEARCHER SPOTLIGHT

Dr. Pradeep Suri

Dr. Pradeep Suri is one of the many researchers who collaborates with the Registry. Dr. Suri is a Staff Physician at the VA Puget Sound Health Care System located in Seattle, Washington, and an Associate Professor of Rehabilitation Medicine at the University of Washington.

Dr. Suri studies chronic pain. Chronic back pain is a leading cause of disability for Veterans in the United States. However, little is known about many of the causes of this back pain. Dr. Suri hopes to improve the treatment and prevention of chronic pain syndromes that affect Veterans.

Currently, Dr. Suri has partnered with the Registry to conduct a study called, "A Twin Study of Chronic Back Pain and Associated Disability in Veterans". Dr. Suri's study uses previously collected data from a VET Registry research study called, "CSP #569: A Twin Study of the Course and Consequences of Post-Traumatic Stress Disorder in Vietnam-Era Veterans," and combines it with new data he collects from twin pairs in the VET Registry. The goal of the study is to learn about the biology behind chronic back pain and what can be done to prevent it.

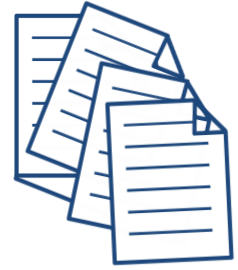
The Registry greatly values its collaboration with Dr. Suri, whose research helps to improve the health and lives of Veterans every day. This research is made possible by the membership of the Veterans and their family members in the VET Registry. In Dr. Suri's own words, "Thank you for being a part of this incredibly important contribution to science and public health."



Dr. Pradeep Suri, 2016

WHAT IS THE VET REGISTRY?

The VET Registry is database of **contact information**, called a “registry”, and a **collection of data**, called a “repository”. The repository contains data from more than 30 studies that VET Registry members have participated in, as well as some military and medical records. The VET Registry serves as a resource for researchers who are interested in studying the health and well-being of Vietnam-era Veterans and their families.



In 2002 the Registry established a Biorepository that includes **samples** of blood, DNA, and saliva. These samples are used in Registry studies. The biospecimens are stored securely at a state-of-the-art laboratory at the Boston VA Medical Center.

WHERE IS THE VET REGISTRY?



The VET Registry is a part of the Department of Veterans Affairs (VA). The VET Registry was based at the Hines VA near Chicago, IL, from the 1980s until 2001. Today, the home of the VET Registry and its data and biorepositories is the VA Puget Sound Healthcare System in **Seattle, WA**.

WHERE ARE THE STUDIES?

GIVE & TAKE

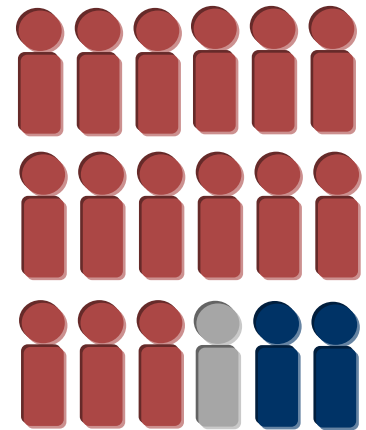
Researchers request to use Registry data or to contact Registry members for their studies. Then, those collaborators submit a copy of the data they collect back to the VET Registry for use by other Registry investigators.

Studies that include VET Registry members take place all over the country. Ongoing collaborations include researchers in **San Diego, CA, Boston, MA, and Atlanta, GA**.



WHO IS IN THE VET REGISTRY?

The **Vietnam-Era Twin Registry** is comprised of more than **7,000 twin pairs** who served in the military during the Vietnam era. It also includes some of the offspring of the twins, and the mothers of those offspring.



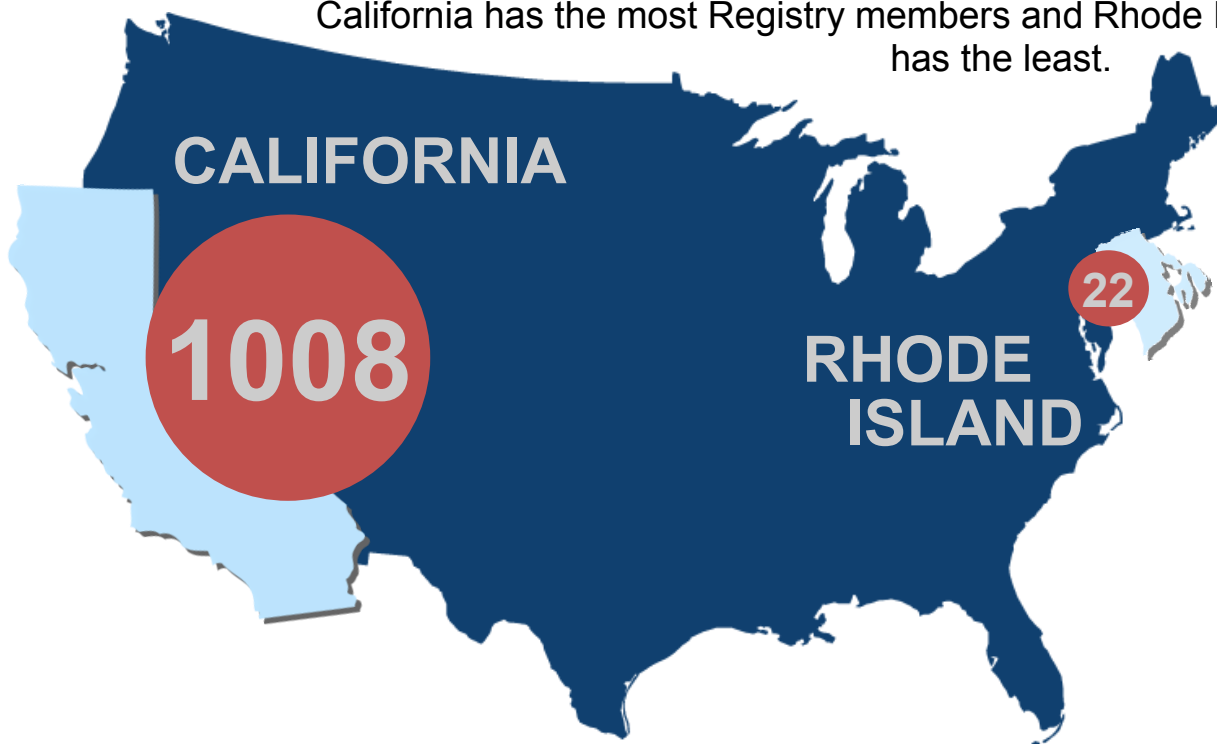
14,760 Twins
1,336 Mothers
2,251 Offspring
Population of the VET Registry

WHO ARE THE TWINS?

- Fraternal or identical **twins**
- **Male-male** twin pairs
- Born between **1939** and **1957**
- Served on active duty for the United States during the **Vietnam-era** (between 1964-1975)

WHERE DO MEMBERS LIVE?

Members of the Vietnam-Era Twin Registry live in **all 50 states**. Some even live outside of the country. California has the most Registry members and Rhode Island has the least.



WHY TWINS?

THE CONTINUED IMPORTANCE OF TWIN RESEARCH

The very first scientific inquiries regarding twins appeared over 150 years ago, when Francis Galton published a paper entitled, “The history of twins, as a criterion of the relative powers of nature and nurture.”¹ In the time since then, hundreds of twin studies have been conducted. But why is twin research so important? The answer lies in their genes. Twins’ shared genes provide an opportunity to answer scientific and health questions that could not otherwise be addressed, helping other Veterans and future generations.

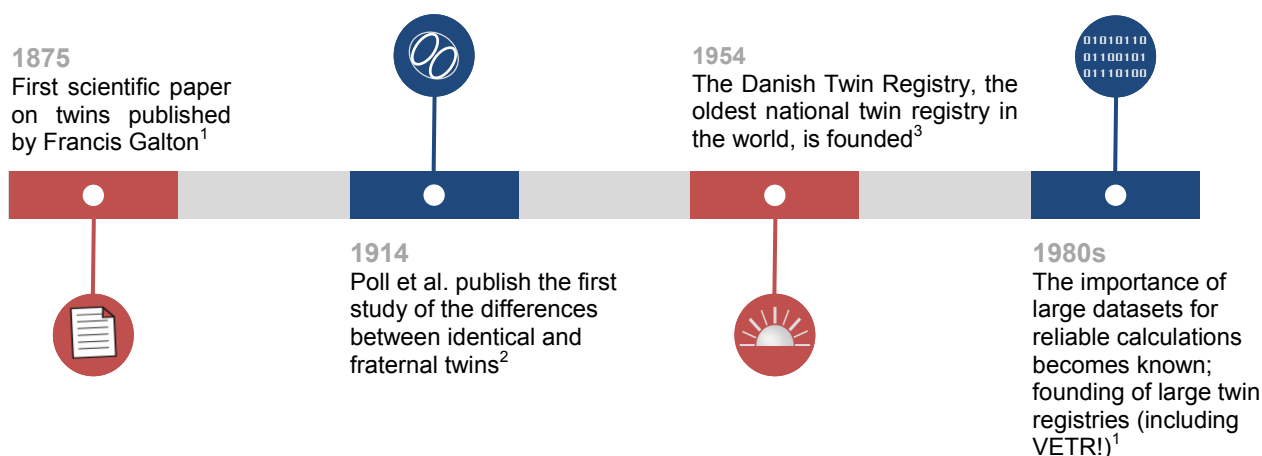
Twin’s shared genes provide an opportunity to answer scientific and health questions that could not otherwise be addressed, helping other Veterans and future generations.

Due to the importance of twin studies, many registries of twins have been formed in the last 60 years.² Not all twin registries are identical; however, most twin registries are a collection of contact information of hundreds of twin pairs. Researchers can use the registries as a resource for when they are conducting twin studies. Registries around the world have enlisted the help of twins who are willing to give their time and energy to help researchers and the public better understand the determinants of disease and health, and to improve the lives of not just twins, but their families, other Veterans, and entire populations.

REFERENCES

1. Van Dongen et al. 2012. “The continuing value of twin studies in the omics era.” Nature Reviews Genetics. Visit: www.nature.com/reviews/genetics
2. Mayo, O. 2009. “Early research on human genetics using the twin method: who really invented the method?” Twin Res. Hum. Genet. 12,:237–245
3. Skytthe et al. 2002. “The Danish Twin Registry: 127 Birth Cohorts of Twins.” Twin Research, 5,:352-357.

A TIMELINE OF TWIN REGISTRIES



THE GENETIC ORIGINS OF TWINS

Researchers in Amsterdam recently found variants in genes of mothers that are responsible for increasing the likelihood of having twins. Using data from the Netherlands Twin Registry, they found changes in the nucleotides – which are the building blocks of genes – in two genes that create proteins that influence ovulation in women. These changes were associated with an increased likelihood of having a fraternal twin pregnancy. Their finding provide biologic insights to what many already knew – the likelihood of having twins can be inherited.

REFERENCE

- Mbarek H, et al. 2016. “Identification of Common Genetic Variants Influencing Spontaneous Dizygotic Twinning and Female Fertility.” Am J Hum Genet. 5;98(5):898-908.



A pair of twins who are members in the Vietnam-Era Twin Registry

TWIN RESEARCH IN THE NEWS

RESEARCHING ZIKA



The outbreak of the Zika virus has dominated world headlines after the first confirmed Zika case in Brazil in 2015. In early 2016, the World Health Organization (WHO) declared the virus an international public health emergency. The virus is spread primarily through the bite of an infected *Aedes* species mosquito. Pregnant women are particularly vulnerable to the virus because of the risk to their unborn children. Zika can cause a serious birth defect called microcephaly, a condition where the baby's head – and brain — is much smaller than normal. Microcephaly has also been linked to seizures, developmental delays, intellectual disabilities, hearing loss, and vision problems.

Since the outbreak of the Zika virus, scientists have identified a handful of cases in which one twin was born with microcephaly and one without. Twins share the same environment until birth (the mother's womb) and may have nearly identical genetics which provides scientists with a unique opportunity to discover the specific factor that results in Zika-induced microcephaly. Scientists hope these infants hold the key to unlocking some of the most crucial answers in this international crisis.



TWINS IN SPACE



REFERENCES

<http://www.cdc.gov/zika/about/index.html>

<http://www.who.int/mediacentre/factsheets/zika/en/>

Recently even the *National Aeronautics and Space Administration (NASA)* has been dipping their toes into twin research. NASA's Human Research Program (HRP) and the National Space Biomedical Research Institute (NSBRI) have funded the "Twins Study" - a several year observation of astronaut Mr. Scott Kelly and his identical twin brother, retired astronaut Mr. Mark Kelly.

Mr. Scott Kelly recently returned home from a year-long mission to the International Space Station. During the mission, his twin brother continued to live his normal life in Arizona. The brothers underwent extensive medical testing to allow scientists to compare their results. Not only is this form of comparative research of astronauts the first of its kind, but the opportunity to study twins provides extraordinarily rich information because of their shared genetics - something that would be unavailable using any other pair of astronauts. The brothers have provided biospecimen samples such as blood, saliva, urine, stool, and cheek swabs. As time goes on, they may also undergo additional psychological or physical tests. NASA's goal is to analyze the human molecular response to physical, physiological, and environmental stressors exerted on the human body in space.

The goal of this ground-breaking research is to better understand the effects of how being in space - especially for long periods of time - affects the human body, which will benefit space exploration in the future. Although this is space research, this study is also applicable to humans who stay on earth. For example, during his mission Mr. Scott Kelly was exposed to radiation about 20 times greater than that of his brother here on earth. Understanding how high doses of radiation over extended periods of time affects the human body may help benefit cancer patients who undergo proton radiation treatments. Now that Mr. Scott Kelly has returned to earth, the results of this research are expected to emerge over the coming months and years as scientists continue to examine the Kelly twins.

REFERENCE

<https://www.nasa.gov/twins-study>

A FOCUS

Vietnam-Era Twin R

The Vietnam-Era Twin (VET) Registry is always looking for ways to engage with its members. Each Registry member has a unique perspective that can help the Registry to improve its service.

In the early days of the VET Registry in Illinois, the Registry held a focus group to receive direct input from its members. Focus groups are an in-person group discussion, usually led by a professional focus group moderator, where attendees share their thoughts and opinions on a predetermined topic. Focus groups are an excellent way to learn more about member's experiences by allowing attendees to freely express thoughts and ideas.

Nearly 30 years later, in the fall of 2015, the Registry had the opportunity to hold another focus group in Seattle, WA. Members who were part of a twin pair that both lived within 50 miles of the focus group location were invited to attend, and the group was a great success. After the Seattle group the Registry held three more focus groups in the spring of 2016: two in Chicago, IL; and one in New York, NY. A total of 43 members attended the four groups.

The feedback provided by attendees about VET Registry operations and membership will be invaluable in helping the development of the Registry and future research studies. The Registry hopes to hold more focus groups in other locations in the future; we would love to meet as many of our members as we can. The VET Registry would like to thank the members who attended these groups.



Participants at a Vietnam-Era Twin Registry Focus Group in Chicago, IL, 2016

ON TWINS

Registry Focus Groups



Participants at a Vietnam-Era Twin Registry Focus Group in New York, NY, 2016

WHAT WE LEARNED AT THE FOCUS GROUPS

- Nearly 2/3^{rds} of the members who attended the groups were retired.
- Members attending the groups wanted to know factual information about the VET Registry, such as:
 - “How many active members are there?” (*There are over 10,000!*)
 - “What percentage of us served in Vietnam?” (*35% served in theatre.*)
- VET Registry members who attended wanted to attend because they understood that the research they were participating in could benefit others.
- Members said they would be most likely to participate in telephone or paper survey research.
- And most importantly, we were reminded again how dedicated our members are to the Registry and its research.

THANK YOU The VET Registry would like to extend its sincere thanks to Dr. Tracy Wellens, PhD, of Gnosis Research for moderating the focus groups and for her invaluable contribution to their success.

STUDY UPDATES

VETSA

Vietnam Era Twin Study of Aging
Principal Investigators: Drs. Kremen & Franz

The third wave of VETSA kicked off at the beginning of 2016. The VET Registry is conducting recruitment by mailing invitation packets. This study is longitudinal, which means that researchers collect data from the same study participants at different time points. Study sites are located at Boston University and the University of California at San Diego. The VETSA researchers hope to better understand how genetic and environmental factors affect cognition as people age.

ETSF

The Emory Twin Study Follow-Up
Principal Investigator: Dr. Vaccarino

This year saw another launch of a second longitudinal study, ETSF, for which the Registry is also recruiting. The study site is located at Emory University in Atlanta, GA.

The ETSF researchers at Emory hope to better understand how stress may impact cardiovascular health.



VET REGISTRY PROJECTS

BIOREPOSITORY COLLECTION

One of the important parts of the VET Registry is its biospecimen repository. Biospecimens are extremely valuable to the VET Registry and the research world as a whole; data collected from testing them can help answer many of science's biggest health-related questions.

The VET Registry would like to expand our biorepository by collecting saliva from Registry members. DNA extracted from the saliva will be used in future VET Registry studies. Saliva will be collected via kits that are mailed to members throughout the next several years.



OFFSPRING MEMBERS & FUTURE RESEARCH

The VET Registry includes more than just twins from the Vietnam era. Many children (offspring), who are now adults, of VET Registry twins have generously participated in past Registry studies. Since it has been a few years since these studies, we would like to reconnect and update offspring contact information.

If (1) you are an offspring member, (2) both you and your sibling or cousin are members, or (3) your child or niece or nephew is an offspring member, you may receive a mailing or telephone call within the next several months asking for updated contact information for offspring members in your family. If you would like to ensure that we have accurate contact information for offspring members in your family, please contact the Registry at our toll-free number, 1-866-774-9647, or complete and mail the Contact Update Form on the last page of this newsletter.

After the above effort, we plan to mail offspring members a *Your Opinion Matters!* survey asking for feedback. For example, what are offspring members' thoughts and opinions on health topics and areas of research where they think the Registry should focus.

HOW DOES **YOUR** STATE STACK UP?

The number of Vietnam Era Registry twin members living in each state.

STATE NUMBER	STATE NUMBER	STATE NUMBER	STATE NUMBER
CA 1008	NY 353	OR 199	NE 76
TX 782	WA 347	OK 196	UT 72
FL 547	GA 302	IA 186	MS 70
OH 526	WI 299	MD 169	SD 48
PA 523	VA 298	KY 166	MT 45
IL 413	MN 291	LA 151	ME 36
MI 403	IN 272	AL 134	ND 36
NC 391	TN 261	MA 126	DE 31
	MO 257	KS 124	HI 31
	AZ 239	NV 115	NH 31
	SC 219	AR 108	AK 30
	CO 215	WV 94	WY 28
	NJ 206	ID 77	VT 24
	CT 201	NM 77	RI 22

INTRODUCING

THE NVVLS REGISTRY

The Seattle Epidemiologic Research and Information Center (ERIC) is excited to announce that we are now home to another registry. The ERIC acquired stewardship of the National Vietnam Veterans Longitudinal Study (NVVLS) Registry in April of 2015. The NVVLS Registry is a closed cohort composed of approximately 1,450 male and female Veterans who served in the United States military during the time of the Vietnam War (1964-1975).

The Seattle ERIC looks forward to developing this registry and working with its members in the coming years.



EMAIL NOTIFICATIONS

In the future, the VET Registry plans to send periodic email notifications to all Registry members for whom we have email addresses on file. For example, an email notification may be sent to alert members that a newsletter, such as this fall 2016 Twin Times, was mailed. Please note that at this time, we cannot reply to email messages from VET Registry members due to VA institutional review board (IRB) policies that govern privacy protections for research subjects. Thus, we ask that Registry members do not reply to VET Registry notification emails as we will not be able to respond.

If you would like to update your contact information, or request another copy of the newsletter, please give us a call at our toll-free line, 1-866-774-9647, or complete and send in the contact information update form on the last page of this newsletter.

MEET OUR STAFF

Nicholas L. Smith, PhD

Dr. Smith is the Director of the Seattle Epidemiologic Research and Information Center (ERIC) and the VET Registry, and Professor of Epidemiology at the University of Washington. Dr. Smith provides overall leadership for the administrative and scientific goals of the Registry. He has been involved with VA-based epidemiologic and health services research for over 20 years.



Jack Goldberg, PhD

Dr. Goldberg is the Senior Epidemiologist for the VET Registry, Professor of Epidemiology at the University of Washington, and has more than 30 years of experience in the management and analysis of epidemiological studies. Dr. Goldberg has unique knowledge of the VET Registry, having worked with the Registry since 1983.

Cindy Liu, BA

Cindy is the VET Registry Project Manager. She is the main point of contact for the VET Registry.

Cleo Faraone, MPH

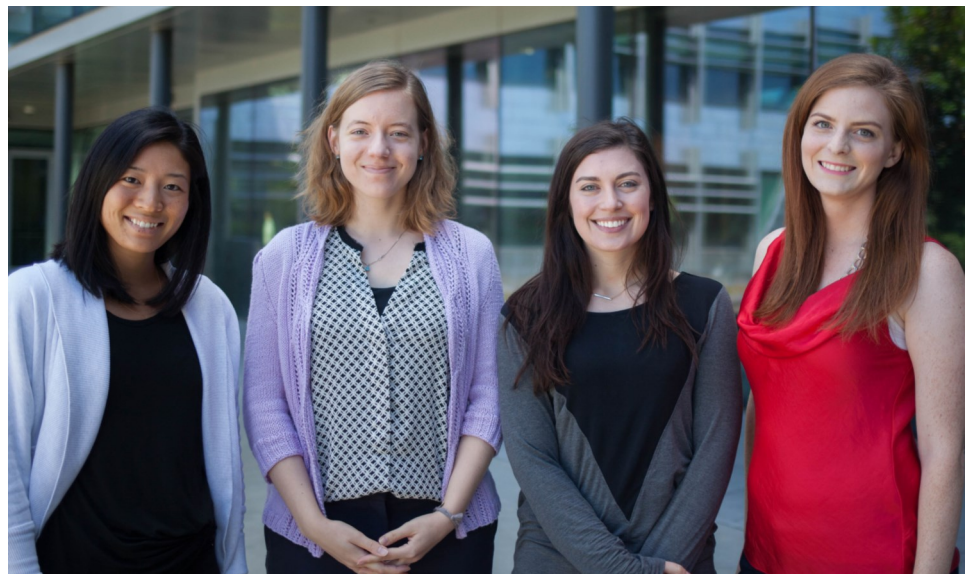
Cleo is a VET Registry Research Assistant.

Emily Wing, BS

Emily is the VET Registry Research Coordinator.

Bailey Clopp, BS

Bailey is a VET Registry Research Assistant.



ACKNOWLEDGMENTS

We would like to acknowledge the following Seattle ERIC staff who contribute to the overall functioning of the VET Registry.

- **Jennifer Sporleder, BS** – Associate Center Director, RO
- **Mary Jo May, BA** – Administrative Specialist
- **Kathryn Moore, PhD** – Senior Programmer/Data Manager
- **Alexandra Fox, MSIS** – Research Data Specialist
- **Chris Forsberg, MS** – Biostatistician
- **Heli Venkov, BS** – ERIC Core Project Coordinator, NVVLS
- **Emily Ashmore, BS** – ERIC Core Project Coordinator
- **Isaac Purton, MA** – ERIC Core Research Coordinator

THANK YOU

The VET Registry would like to thank **Melyssa Tsai** and **Alaina Mori** (former Research Coordinator and Project Manager, respectively) who recently departed the Registry. Both Melyssa and Alaina spent many years contributing their knowledge, skills and enthusiasm to the VET Registry and its studies. We wish them the best of luck on their new ventures.

CONTACT UPDATE FORM

Please update your contact information by filling out and returning the form below (tear at marked line & mail to address listed).

TITLE _____ FIRST NAME _____ MI _____ LAST NAME _____

I'm a (Check One): VETR Twin Offspring of a VETR Twin Mother of VETR Offspring

Address 1: _____ Address 2: _____

City: _____ State: _____ City: _____ State: _____

Zip: _____ - _____ Country: _____ Zip: _____ - _____ Country: _____

Home Phone: _____ - _____ - _____ Personal Email: _____

Cell Phone: _____ - _____ - _____ _____

Work Phone: _____ - _____ - _____

Other Phone: _____ - _____ - _____ Phone Type: _____



MAIL TO

Seattle ERIC
Vietnam Era Twin Registry
VA Puget Sound Health Care System
1660 S Columbian Way | S-152-E
Seattle, WA 98108

BY PHONE

If you prefer to update your contact information by telephone, please give us a call, toll free, at **1-866-774-9647**.



NOT INTERESTED?

You may decide to withdraw your membership in the Registry now or at any time in the future. If you withdraw, this means you will not be invited to participate in any future studies or receive further contact from the Registry. Note that data and samples that were previously collected while you were a member may still be used for research. As always, the VET Registry will keep all samples and data confidential, secure, and protected. To opt-out, contact us toll free at (866)-774-9647.

ADDRESS SERVICE REQUESTED

VA Puget Sound Health Care System
Vietnam Era Twin Registry
1660 South Columbian Way (S-152-E)
Seattle WA, 98108



