



NATIONAL VIETNAM VETERANS LONGITUDINAL STUDY (NVVLS) REGISTRY NEWSLETTER

Welcome to the second issue of the NVVLS Registry Newsletter!

The first issue, mailed in 2017, was part of a welcome packet describing the background of the National Vietnam Veterans Longitudinal Study (NVVLS) Registry, who we are at the Seattle Epidemiological Research and Information Center (ERIC), and how you can be involved. If you have not received a welcome packet and would like to be mailed one, please contact us at 1-800-329-8387 ext. 61965.

In this issue you will find information about current and upcoming NVVLS Registry studies. Your participation in the NVVLS Registry helps researchers make scientific advances to better inform the health care of Veterans like you.

We hope you enjoy this edition of the annual newsletter. Thank you for your participation in the NVVLS Registry!

Maintaining Contact

One of the ways we maintain the NVVLS Registry is by updating our database with the latest and most accurate contact information on Registry members like you. With the correct contact information, we can mail you invitations to participate in research studies and send you updates like those described in this newsletter. To help us locate Registry members, we may use information from public databases. If we have an unreliable address, the U.S. Post Office may forward to us the next best address according to their records. We may also contract with a professional service to locate you by searching for a best match in public records.

If you recently had a change of address or phone number, please update and return the Contact Update Form on the back of this newsletter.

NOT INTERESTED? You may decide to withdraw your membership in the Registry now or at any time in the future. To opt-out, contact us toll free at 1-800-329-8387 ext. 61965.



NATIONAL VIETNAM VETERANS READJUSTMENT
STUDY

1984-1988



NATIONAL VIETNAM VETERANS LONGITUDINAL
STUDY

2012-2013



2015-present

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CURRENT PROJECTS

VA Brain Bank

The Seattle ERIC is planning to collaborate with the National Posttraumatic Stress Disorder Brain Bank (PTSD Brain Bank), which is part of the VA Biorepository Brain Bank (VABBB). A brain bank collects, processes, stores, and shares research specimens from donors for scientific studies. Donations are made after a person's passing with the permission of the donor and their family. Brain banks are essential resources for research on brain disorders, including identifying risk factors for diseases such as amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease).

The PTSD Brain Bank is directed by Dr. Matthew Friedman from the VA National Center for PTSD's Executive Division in White River Junction, Vermont. The PTSD Brain Bank is enrolling both Veterans and non-Veterans with PTSD. The VABBB, which is led by Neil Kowall, MD at the VA Boston Healthcare System, also oversees and operates two other brain banks: one focusing on ALS, and one on illnesses related to

service during the 1990-91 Gulf War. The ALS and Gulf War Brain Banks only enroll Veterans. Any Veteran living in the US may enroll in the VABBB. Participants are asked to complete questionnaires about their health every 6-12 months and to donate their brain after their death.

The Seattle ERIC may send you an invitation to participate in the VA Brain Bank in the next few months. If you have questions, call 1-800-329-8387, ext. 61965 to talk to a NVVLS Registry staff member.

Survey of the NVVLS Registry

The Seattle ERIC is planning to conduct a Registry-wide survey of health in 2019 as the latest data collection point in the longitudinal series consisting of the 1988 National Vietnam Veterans Readjustment Study (NVVRS) and its 2013 follow-up, the National Vietnam Veterans Longitudinal Study (NVVLS). Every member in the NVVLS Registry will be mailed an invitation to participate. The survey should take about 30-45 minutes to complete, and you will receive monetary compensation for your time.

The purpose of the survey is to better understand the longitudinal course of PTSD and its consequences into late life. In addition to questions about changes

in your physical and mental health, the survey will include 9 questions on the topic of moral injury. Like psychological trauma, moral injury describes extreme and unprecedented life experiences that may damage one's moral or ethical beliefs and values (1). While the concept behind moral injury is not new, more research is needed to further assess the concept and explore its potential health effects. For more information regarding moral injury, please visit <https://www.ptsd.va.gov/professional/articles/article-pdf/id33165.pdf>

1. https://www.ptsd.va.gov/professional/treat/cooccurring/moral_injury.asp

Did You Know?

March 29th is nationally observed as
Vietnam War Veterans Day.

The Seattle ERIC would like to thank you for your service.

FOCUS GROUPS

The Seattle ERIC is always looking for ways to engage with its NVVLS Registry members. Each Registry member has a unique perspective that can help the ERIC improve its operations and services.

A focus group is an in-person group discussion where attendees share their thoughts and opinions on a topic of interest to the organizers. Focus groups allow the ERIC staff to obtain direct input from Registry members about their experiences, by allowing attendees to freely express their thoughts and ideas. We collaborate with a professional focus group moderator- someone with experience working with Veterans to help facilitate the group discussion.

The Seattle ERIC conducted its first annual focus group with NVVLS Registry members in April 2017 in Torrance, CA. Registry members who lived within 50 miles of the focus group location were invited to participate. Out of the 52 members who were mailed an invitation, 6 NVVLS Registry members attended the focus group.

The feedback provided by attendees is invaluable in steering the development of the Registry and its future research projects and studies. The ERIC plans to hold more NVVLS Registry focus groups in other locations in the future; we would like to meet as many Registry members as we can.

WHAT WE LEARNED

- All 6 NVVLS Registry members who attended the focus group had served during the Vietnam-era. Among the attendees, there was a mix who had been deployed in Vietnam and those who had not.
- Attendees wanted to participate in the focus group because they understood that the research they were participating in could benefit others.
- When asked about which type of research study they would participate in, focus group attendees expressed that they were willing to participate in most types of research including paper surveys or studies that involved in-person visits; attendees were least interested in web-based surveys.
- Focus group attendees stated they were interested in participating in studies that are relevant to their own particular health concerns and situations.
- Although many years ago, most attendees remembered participating in previous study timepoints that focused on PTSD and alcohol and drug use – the 1988 National Vietnam Veterans Readjustment Study (NVVRS) and its 2013 follow up, the National Vietnam Veterans Longitudinal Study (NVVLS).

The Seattle ERIC would like to extend its sincere thanks to the 2017 focus group attendees and to Dr. Tracy Wellens, PhD of Gnosis Research, for moderating the focus groups and for her invaluable contribution to its success.

The Seattle ERIC conducted its second annual focus group with NVVLS Registry members in September 2018 in Springfield, NJ. Please stay tuned for a summary report on our findings in the next issue of this newsletter.



2017 LA Focus Group Attendees

Seattle ERIC
National Vietnam Veterans
Longitudinal Study Registry
VA Puget Sound Health Care System
1660 South Columbian Way | S-152-E
Seattle, WA 98108



ADDRESS SERVICE REQUESTED

CONTACT UPDATE FORM: *Please update your information*

TITLE _____ FIRST NAME _____ MI _____ LAST NAME _____

Address 1: _____ City: _____ State: _____

Zip: _____ - _____ Country: _____

Address 2: _____ City: _____ State: _____

Zip: _____ - _____ Country: _____

Home Phone: _____ - _____ - _____ Cell Phone: _____ - _____ - _____

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

Email 1: _____

Email 2: _____



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