



ADULT CHANGES IN THOUGHT STUDY

## FALL - 2024 NEWSLETTER

### Your Precious Brain

As an ACT participant, you know the importance of brain health. Together with you, we are learning about how to keep our brains strong throughout life. But did you know that much of what we have learned about Alzheimer's Disease has come from studies of donated brain tissue at the time of one's death?

The ACT study has had a brain donation program since the study began in 1994. So far, over 1000 ACT participants have made this precious gift. Brain donation is especially valuable in the ACT Study because of the wealth of information participants have shared about their health, lifestyle, social experiences, family history and cognitive functioning while participating in ACT. Putting all this information together with the advanced technologies we now have for studying brain tissue provides an incredible resource for scientists worldwide to learn more about how to improve brain health in the future.

### What Have we Learned?

Our brain donation program has allowed ACT to make many important discoveries about what happens to the brain as we age.

Dr. Caitlin Latimer, a neuropathologist from the University of Washington who leads ACT's Neuropathology Core along with Dr. Dirk Keene, says that one of the most impactful discoveries we have made is that people can live long and cognitively healthy lives even when their brains show evidence of Alzheimer's disease or other forms of pathology. "This is why it is so important for us to receive brain donations from people who are cognitively healthy at the time of passing, as well as from people who had cognitive impairment."

These findings have led us, and others, to try to learn about why some people are more resilient than others to pathologies that can cause dementia, with the hope that we can help more

people avoid developing dementia. "Another important thing we have learned through our brain donation program," Dr. Latimer reported, "is that there are many different diseases that can occur together in the brain as we get older." Because many people, including ACT participants, do develop a combination of multiple diseases in the brain with age, understanding how these diseases interact and contribute to cognitive decline is an important question that the ACT brain donation program will help us answer. These are just a few of the ways the ACT study is helping scientists learn more about what causes these diseases so that we can learn how to prevent them.

### How Does ACT Brain Donation Work?

Cathy Hutchison, an ACT research coordinator, has helped participants and their families learn more about ACT's brain donation program for the past 10 years. All participants receive an information packet about the program at their first study visit that has Cathy's contact information.

Participants who volunteer for the program are given a number for their family to contact at the time of their passing. The program then arranges for the body to be picked up and to be returned to the family for funeral or cremation services after the brain is removed. "One of the most common questions I get is whether volunteering for the brain donation program would require a closed-casket funeral, and I assure them that it would not. The team is very careful to minimize any sign of the brain donation process," said Cathy.

After Dr. Latimer or her associates examine the brain, the family receives a research report describing the findings. Families can request to tour the lab and even discuss the brain findings with Dr. Latimer or Dr. Keene.

Cathy regularly hears from family members that



The Adult Changes in Thought Study and its newsletter is a collaboration between Kaiser Permanente Washington Health Research Institute and the University of Washington.

their loved one was very proud to be part of ACT and that they were very committed to donating their brain so that they could keep contributing to research. "I always tell families that this truly is the gift that keeps on giving!"

### **Brain Donation: A Gift for Future Generations**

Each precious gift of brain donation can make a significant impact for the study of Alzheimer's disease and other causes of dementia, potentially providing information for hundreds of research studies. Brain donation can help researchers learn how the brain is affected by diseases and how we might better treat and prevent them. Discoveries made possible by tissue donation provide hope to families affected by brain disease.

You can learn more about why people donate their brains for Alzheimer's research, the process of brain donation, and how to talk with your family about this decision at this website created by the National Institute on Aging, the organization that funds the ACT study:

<https://www.nia.nih.gov/health/brain-donation/brain-donation-faqs-gift-future-generations>.

You can also learn more about brain donation by visiting Dr. Keene's UW Biorepository and Integrated Neuropathology (BRain) Laboratory website: <https://dlmp.uw.edu/research-labs/keene/BRain-lab>

### **For more information about ACT's brain donation program, please contact:**

#### **Cathy Hutchison**

Research Coordinator

Kaiser Permanente/ University of Washington  
Adult Changes in Thought (ACT) Study

150 Nickerson St., Suite 201

Seattle, WA 98109

[hutchc2@uw.edu](mailto:hutchc2@uw.edu)

[Tel: 206-543-8787](tel:206-543-8787)



## Be the **brain** behind the **breakthroughs**.

One donated brain makes a huge impact.



#braindonation



The Adult Changes in Thought Study and its newsletter is a collaboration between Kaiser Permanente Washington Health Research Institute and the University of Washington.