

Welcome to the Hawai'i Neurotrauma Registry!

Department of Health Neurotrauma Program
Consent to Participate in
Hawai'i Neurotrauma Registry Survey

Aloha,

This survey is for Hawai'i residents of all ages who have had at least one traumatic brain injury, stroke, or a spinal cord injury, which are known as neurotrauma injuries. It does not matter when or where the injury took place. Persons who provide care for those with these injuries may fill out the survey for someone who has had one or more brain injury, stroke, or spinal cord injury.

Per Chapter 321H-4, Hawaii Revised Statutes (HRS): The Neurotrauma Special Fund (NSF) to be used for creation of a registry of neurotrauma injuries within the State to identify incidence, prevalence, individual needs, and related information. The Department of Health (DOH) Neurotrauma Program will conduct this survey and reasons for collecting this information are to:

- Describe the health and service needs of persons with neurotrauma injuries
- Identify gaps in services and supports for persons with neurotrauma injuries
- Educate service providers
- Develop safety and prevention plans and policies

Time Commitment: The survey takes about 10 minutes to complete. Please note that it may take you more or less time to answer the questions. Staff from the DOH Neurotrauma Program may contact you in the future with additional questions and/or to update your information.

There are questions about you, your injury, and how the injury has affected you. The survey also asks about the services you receive and the ones that you need.

By completing this survey, you are helping us to identify and/or improve available services and resources for you, your family, and others with neurotrauma injuries in Hawai'i. You don't have to answer any question you don't want to, and you can decide to stop answering questions at any time.

Confidentiality and Privacy: Your participation and responses are kept strictly confidential to the extent allowed by law. All information is kept in a secure location. Only DOH staff affiliated with the Neurotrauma Registry have access to the data.

Any reports resulting from Hawai'i Neurotrauma Registry data will be about registry participants as a group and will not identify specific individuals who have contributed their information. Reports and the information will be used to assist the DOH Neurotrauma Program in learning what is needed to build a responsive system of supports for neurotrauma injury survivors.

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Consent to Participate

Voluntary Participation: Filling out this survey is entirely voluntary. If you decide not to participate, it will have no effect on any services you may receive now or in the future from the State of Hawai'i, Department of Health.

Questions and Accommodations: If you have questions or require accommodations, auxiliary aids, and/or services to complete the survey, please contact the DOH Neurotrauma Program:

Oahu: (808) 733-2155 (V)

(877) 447-5990 (TTY)

Toll Free: (833) 333-5133 (V)

(877) 447-5990 (TTY)

E-mail: ntrauma@doh.hawaii.gov

Mail completed survey to:

Dept. of Health Neurotrauma Program

3627 Kilauea Ave. #411

Honolulu, HI 96816

* 1. Today's date is:

Month, Day (today), and Year

MM/DD/YYYY

* 2. My birth date is (birth date of person with the injury):

Birth Month, Day, and Year

MM/DD/YYYY

* 3. I understand my involvement is completely voluntary and that my information will be kept confidential.

I understand that if I decide not to take the survey, it will have no effect on any services I may receive now or in the future from State of Hawai'i, Department of Health.

In the spaces below, provide the name and contact information of the person who has had a brain injury, stroke, and / or spinal cord injury.

If you are not the person who has had the injury, list your information in question 24 toward the end of the survey.

Name of neurotrauma survivor - First name, middle initial (if any), last name

Address

City or town

State

Zip code

Best phone number to reach you (if none, write "none")

Best e-mail address to reach you (if none, write "none")

4. Who is filling out this survey? (select the best option):

- Person with the traumatic brain injury, stroke, or spinal cord injury
- Spouse / Partner of person with the injury
- Child of person with the injury
- Sister or Brother of person with the injury
- Parent / Legal Guardian of person with the injury
- Other family member
- Other (please specify)
- Significant Other (such as a girlfriend or boyfriend, or a fiancé)
- Friend
- Paid caregiver
- Unpaid caregiver (not a family member)
- Social worker / nurse / other professional

Tell us about the neurotrauma injury or injuries.

Please read each question carefully and answer each question as best as you can.

If you are not the person with the injury, answer the questions about the person who has had the brain injury, stroke, or spinal cord injury.

If you have any difficulty, please contact the DOH Neurotrauma Program:

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5. Tell us the **year** of your first or only neurotrauma injury. Provide your best estimate.

6. Tell us the **month** of your first or only neurotrauma injury. Provide your best estimate.

7. What was the **nature of the first injury or injuries**? Select all that apply.

- Acquired Brain Injury (occurred after birth)
- Traumatic Brain Injury/Concussion
- Stroke - Ischemic (clot or obstruction in a blood vessel supplying blood to the brain)
- Stroke - Hemorrhage (blood vessel burst inside the brain)
- Spinal Cord Injury
- Transient Ischemic Attack ("mini-stroke," "warning stroke")

Other (please specify)

8. What was the main cause of the first injury? Please select one.

- Assault
- Fall
- Motor vehicle crash
- Self inflicted injury
- Sports related injury
- Struck by an object
- Unknown

Other (please describe)

9. What was the primary diagnosis?

The diagnosis is the condition mainly responsible for your admission to the hospital, emergency room or another treatment center for care. If you do not remember the diagnosis, please select "Don't remember."

- | | | |
|---|--|---|
| <input type="radio"/> I never received care for my injury | <input type="radio"/> Hypoxic brain injury | <input type="radio"/> Stroke - hemorrhagic |
| <input type="radio"/> Don't remember | <input type="radio"/> Ischemia | <input type="radio"/> Stroke - ischemic |
| <input type="radio"/> Aneurysm | <input type="radio"/> Neck pain/injury | <input type="radio"/> Stroke - other |
| <input type="radio"/> Blood Clot | <input type="radio"/> Paraplegia | <input type="radio"/> Syncope |
| <input type="radio"/> Coma | <input type="radio"/> Quadriplegia | <input type="radio"/> Thoracic fracture |
| <input type="radio"/> Concussion | <input type="radio"/> Skull Fracture | <input type="radio"/> Transient ischemic attack (TIA) |
| <input type="radio"/> Endocarditis | <input type="radio"/> Spinal cord injury (SCI) | <input type="radio"/> Traumatic brain injury (TBI) |
| <input type="radio"/> Heart Attack | <input type="radio"/> Spine fracture | |
| <input type="radio"/> Other (please specify) | | |

10. What other health conditions do you currently have? Select all that apply.

- | | |
|--|--|
| <input type="checkbox"/> Arthritis | <input type="checkbox"/> Heart disease / heart problems |
| <input type="checkbox"/> Asthma / any kind of breathing problems | <input type="checkbox"/> High blood pressure |
| <input type="checkbox"/> Cancer | <input type="checkbox"/> High cholesterol |
| <input type="checkbox"/> Dementia / Alzheimer's Disease | <input type="checkbox"/> Mental health issues |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Substance abuse or misuse (alcohol, legal or illegal drugs) |
| <input type="checkbox"/> Other (please specify) | |

* 11. Have you ever had another neurotrauma injury?

- Yes
- No

Resources and Needs Questions

12. What is your current **living situation (the person who has the neurotrauma injury)**? Please select one.

- Home or apartment (own or rent)
- Family home or apartment (own or rent)
- Assisted living
- Nursing home
- Group home
- Halfway house

Other (please specify)

13. What is your **current employment situation**? Please select one.

- Employed full-time
- Employed part-time
- Self-employed
- Retired
- Unemployed
- Student only (no part- or full-time work)
- Do not know

Other (please specify)

14. What **medical insurance** do you have? (check all that apply)

- Private insurance (such as HMSA, HMAA, Kaiser, UHA, etc.)
- Medicare
- Medicaid / Quest Integration (AlohaCare, HMSA's Quest Plan, Kaiser's Quest Plan, United HealthCare, etc.)
- No insurance - self-pay (I pay for my medical care myself)
- No insurance - I do not get any medical care that I have to pay for
- Do not know the what kind of medical insurance I have or its name

Other (please specify)

15. What **benefits do you currently receive?** Select all that apply.

- I do not currently receive any benefits
- SNAP (Food Stamps)
- Section 8 or Section 8 Housing Choice Voucher Social
- Security Disability Insurance (SSDI)
- Social Security Retirement
- Social Security Supplemental Security Income (SSI)
- Temporary Assistance for Needy Families (TANF)
- Unemployment
- Worker's Compensation

Other (please specify)

16. What **services and supports** do you currently need, currently receive help with, or need more help with? Check all that apply. If you are not the person with the neurotrauma injury, please answer this question about their needs.

	I need help with this	I currently have paid or unpaid help with this	I need more help with this
Assistive technology (eyeglasses, hearing aids, canes, crutches, wheelchairs, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I need help with this	I currently have paid or unpaid help with this	I need more help with this
Chore assistance (house cleaning, minor repairs, yard work, laundry, trash removal, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Companionship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day program (nonresidential program with daytime activities)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employment assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home-delivered meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home health care / visiting nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical assistance (Physician referral, help paying for medications, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal assistant services (help with bathing, toileting, eating, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite (provide caregivers with short-term breaks from caregiving)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social activities (community events, game nights, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social networks (including family or other support, support groups, and faith groups)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transportation services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us a little bit about yourself (the person with the neurotrauma injury).

17. What is your **gender**? Please select one.

Female

Male

Other (please specify)

18. What is your **ethnicity**? Select all that apply.

African American

Caucasian

Chinese

Filipino

Hawaiian

Hispanic

Japanese

Korean

Micronesian

Samoan

Tongan

Vietnamese

Other (please specify)

19. What is your current **marital status**? Please select one.

Single

Married

Divorced

Separated

Widowed

20. What is your **primary language**? Please select one.

- English
- Chinese
- Hawaiian
- Ilocano
- Japanese
- Korean
- Samoan
- Spanish
- Tagalog

Other (please specify)

21. Please select the one that best describes you:

- U.S. Citizen
- U.S. National
- Permanent Resident
- Citizen of a Freely Associated State (i.e., Micronesia, Republic of the Marshall Islands, and Palau)
- Other (please specify)

22. What is your **military status**? Please select one.

- Active military (including Reserves)
- Veteran
- Never in military service

Other (please specify)

23. What is the **highest level of school** you've completed? Please select one.

- Less than high school diploma
- High school diploma or equivalent (e.g., GED)
- Some college but no degree
- Associate degree
- Bachelor degree
- Graduate degree
- Don't know

Other (please specify)

24. For neurotrauma injury survivors: Who can we **contact as a "backup"**? Please provide a name and contact information.

If you are filling this out for someone else who has a neurotrauma injury, please enter your name and contact information below.

Name	<input type="text"/>
Company	<input type="text"/>
Address 1	<input type="text"/>
Address 2	<input type="text"/>
City/Town	<input type="text"/>
State	<input type="text" value="-- select state --"/>
Zip	<input type="text"/>
Country	<input type="text"/>
Best Email Address (if none, write "none")	<input type="text"/>
Best Phone Number (if none, write "none")	<input type="text"/>

25. How did you find out about the Hawaii Neurotrauma Registry? Select all that apply.

- Conference (type in name of Conference in Other box below)
- Family or Friends
- Information and Referral
- Internet / online
- Newspaper / Newsletter
- Hospital / Clinic (type in name of hospital or clinic in Other box below)
- Medical Professional (doctor, nurse, etc.)
- Presentation (type in name and / or location of presentation in Other box below)
- Radio
- Support group (type in name of Support Group in Other box below)
- Table at Public Event (type in name and / or location of Event in Other box below)
- Television

Other (please specify)

26. Is there anything else you'd like to share?

27. We offer a free information and referral service to Hawai'i residents who have had a brain injury, stroke, and / or spinal cord injury, and their families, friends, and other supports. Please select "yes" if you would like us to contact you for information and referral support. You can also contact us at any time for information and referral services.

- Yes, please contact me about information and referral services
- No, I am not interested at this time

Thank you!

Thank you for participating in the Hawai'i Neurotrauma Registry and completing the survey. Your information is very important in documenting needs, services and planning for the future so persons with neurotrauma injuries can be better helped. Staff will contact you to follow up with additional information and resources as needed. Mahalo!

Mail your completed survey to:

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Honolulu, HI 96816