

Hawai'i Neurotrauma Registry Update

State Traumatic Brain Injury Advisory Board

07/19/13

Goal I: Develop and administer a voluntary NT Registry.

The Hawai'i Neurotrauma Registry will assist the Department of Health in prioritizing activities to support the needs of neurotrauma survivors. The Hawai'i Neurotrauma Registry Project, hereafter referred to as "the project," complements the Hawai'i Department of Health, Healthy Hawai'i Initiative in areas of research, public and professional education, and evaluation. The Hawai'i Neurotrauma Registry, hereafter referred to as "the registry," shall include individuals who have sustained traumatic brain injury, stroke, or spinal cord injury.

Objective 1: Develop an Advisory Board of Stakeholders

The Hawai'i Neurotrauma Registry Advisory Board is intended to function as a selected membership that actively engages in forming the design, development, collection, and utilization of the data contained in the Hawai'i Neurotrauma Registry. The membership of this board should be stakeholders interested in what happens to people with neurotrauma injuries after they leave the hospital or rehabilitation. This advisory board will not duplicate the existing State Traumatic Brain Injury and Neurotrauma Advisory Boards.

The project will develop, coordinate, and document the activities of the Hawai'i Neurotrauma Registry Advisory Board.

To follow up from the last report on 05/17/13, the project's request to Dr. Linda Rosen for nominations was referred to Therese Argoud. Ms. Argoud responded that they would discuss the project's request sometime in July 2013.

The project also requested the involvement of Curtis Inouye, Department of Health, Developmental Disabilities Division, Outcomes and Compliance Branch. Curtis has agreed.

Objective 2: Conduct Research on Best Practices and Information contained in Voluntary Databases for Individuals with Neurotrauma Injuries

Project staff has an updated contact list of nationwide neurotrauma registries available at this time

Objective 3: Identify Data for the Hawai'i Neurotrauma Registry

The project is utilizing the Department of Health, DDD, NT Intake Survey at this time. Staff is identifying issues in implementation.

The intake survey will be revised in conjunction with the Hawai'i Neurotrauma Registry Board and research from other national registries.

Objective 4: Develop and Implement a Department of Health-Approved Registry Database and Process for the Hawai'i Neurotrauma Registry.

The Hawai'i State Department of Health will utilize the data for injury prevention and control activities, health care planning, evaluating the system of support for individuals with neurotrauma injury, and identify individual survivors of neurotrauma injury to facilitate their referral to and provide information about availability of needed services.

Twenty-two persons have completed or partially completed intake surveys. Intake surveys are available.

4.1. Develop Project Materials

Relocation of the Pacific Basin Rehabilitation Research and Training Center offices has necessitated a resubmission of previous project materials bearing the former address and contact information. The project is awaiting approval from the Committee on Human Studies, Institutional Review Board, for the following project materials:

1. Brochure
2. Orientation
3. Volunteer Application Form
4. Volunteer Screening and Interview Forms
5. Volunteer Training Sample ("What is Confidentiality?")
6. News Release Samples

4.2. Develop and Implement an Intake Process

The current intake process for the registry is as follows:

1. Recruit participants through referrals, community activities and events, or contacts to the project
2. Direct potential participants to the survey: phone, in person, online (<http://svy.mk/11SiAx3>).
3. Input intake survey responses into database.

The planned intake process for project volunteers is as follows:

1. Recruit volunteers from participants or contacts to office
2. Complete mandatory orientation.
3. Apply to become a Lehua Volunteer
4. Complete all required paperwork within one (1) month of application.
5. Complete interview.
6. Complete background checks.
7. Attend mandatory trainings:

- a. Expectations of Lehua Volunteers
 - i. Appropriate behavior while representing the project
 - ii. Understanding the goals and purpose of the registry
 - iii. Promoting the registry
- b. "What are Neurotrauma Injuries?"
- c. "What is Confidentiality?"

Objective 5: Develop a Comprehensive Implementation Plan for Statewide Recruitment

The project is informing others statewide about the start of the registry through Constant Contact (email marketing). The director continues to expand the project's network of supporters.

5.1. Promote Education and Awareness of Neurotrauma Injuries

Project staff began raising awareness of neurotrauma injuries and educating others through sharing updated research via Constant Contact and by participating in two (2) community events to date. See below.

5.2. Provide Community Outreach

The registry had a presence at the ESPN Sports Festival, 06/29/13, due to Hawai'i Concussion Awareness and Management's willingness to share their exhibitor's table with staff. The project dialogued with 83 individuals, passed out 95 fliers, and 50 referral forms. Staff dispersed 10 factsheets on high blood pressure relating to stroke 20 factsheets on stroke relating to heart disease and 30 factsheets on stroke nationwide. Staff supplied the web address for the Online Electronic Survey on both the fliers and the referral forms to encourage people to complete the online survey. Three (3) individuals requested follow-up copies of the project brochure when available.

5.3. Develop and Implement a Referral Process

Staff and friends of the project are dispersing referral forms. Copies of this referral form have been sent to individual service providers, interested organizations, and persons known to support people with neurotrauma injuries. Staff also distributes these referral forms to attendees of community events and activities to recruit for participants in the registry.

To date, the project has had four (4) referrals. Staff has succeeded in receiving one response. This individual elected to complete the online intake survey. Staff will continue to contact the remaining referrals.

Objective 6: Development a Volunteer Program

The project has a plan for its Lehua Volunteer program. The project recruits potential Lehua Volunteers from referrals, participants in the registry, and contacts to the project.

6.1. Develop Volunteer Training

Lehua Volunteers will attend a mandatory Orientation before proceeding to three (3) following trainings. The project has completed and piloted a “What is Confidentiality?” training; however, the project is waiting for approval from the Institutional Review Board for both the Orientation and training mentioned.

6.2 Involve Volunteers in Community Outreach, Recruitment, and Intake

Staff submitted the Lehua Volunteer Application and the Volunteer Screening and Interview Forms to the Institutional Review Board. The project is unable to involve volunteers until these project materials are reviewed and approved. However, several Hui Malama Po’o members (formerly Ho’oikaika volunteers) offered their help in seeking participants for the registry as individuals advocating for persons with neurotrauma injuries.

Staff and the Director of Insights to Success are working on establishing a Service Agreement for Research Corporation of the University of Hawai’i to provide background checks for Lehua Volunteers. Background checks will include electronic fingerprinting and four (4) background checks: FBI, State Criminal History, Adult Protective Services, and Child Abuse and Neglect.

Objective 7: Provide and Document Information and Referral

Update from May 2013:

Table: Information and Referral, Contacts and Results

Date	Contact	Result of Contact
06/10/13	Private vocational rehabilitation counselor	Given information about the project; emailed flier and referral forms
06/17/13	Vocational rehab counselor	Emailed flier and referral forms; Obtained a referral for TBI assessment
06/17/13	Individual seeking support for TBI	Provided O’ahu Resource Listing, referred to Hawai’i Disability Rights Center, Brain Injury Association of Hawai’i, Hui Malama Po’o. Individual joined Hui Malama Po’o and wishes to volunteer for Hawai’i Neurotrauma Registry Project.
07/09/13	Former Ho’oikaika Volunteer	Referred to Communication Sciences and Disorders Department for help in fluency

7.1. Conduct Statewide Webinars to Share Community Resources

The project will address this objective in future quarters.

7.2. Develop and Maintain a Database of Contacts to the Hawai’i Neurotrauma Registry Project

Table: Contacts to Hawai'i Neurotrauma Registry Project and Results

Date	Contact	Reason for Contact	Result
12/10/12	Individual	Wanted information on TBI	Informed about registry
01/17/13	Individual	Called about TBI	Informed about registry
04/02/13	Individual	Wanted help with spouse's aftermath of stroke	Referred to Aloha Independent Living Hawai'i, Neurotrauma Helpline, Hawai'i Disability Rights Center
04/25/13	Individual	Referred by Hawai'i Disability Rights Center	Desire to advocate for others with TBI Informed about registry
05/01/13	Private Case Manager	Wanted to find a support group for client with TBI in addition to BIA—HI	Referred to Hui Malama Po'o as client is interested in crafts
05/29/13	Individual	Wanted to volunteer	Referred to registry
05/30/13	Individual	Saw STRIDE listing on AUW	Wants to volunteer for registry after move to neighbor island from mainland
06/10/13	Private Vocational Rehabilitation Counselor	Referred by colleague to registry	Informed about registry for client
06/17/13	Vocational Rehabilitation Counselor	Advocate for persons with disabilities	Wanted to refer a physician who has a database regarding neurotrauma injuries. Will refer appropriate clients to registry.
06/17/13	Individual	Saw Ho'oikaika listing in magazine	Wanted information about TBI symptoms. Wants to volunteer for registry. Sent O'ahu Resource Listing. Referred to Hui Malama Po'o. Joined the Hui.

Goal 2: Develop and disseminate an effective PSA and social media campaign

Collaborate with Developmental Disabilities Division, State Traumatic Brain Injury Advisory Board, and State Neurotrauma Advisory Board to assist in the development of the PSAs.

The project will address this goal in future quarters.

Objective 1: Provide Education and Awareness of Neurotrauma Injuries

Produce and broadcast two (2) thirty (30) second local PSAs to be disseminated via television, radio, and the PBRRTC website. This objective will be addressed in future quarters.

The project, however, has been providing education and awareness of neurotrauma injuries through Constant Contact on a statewide basis as some recipients on the project's email list reside on Kaua'i, Maui, and Hawai'i. The project sent 27 educational items to 296 active contacts. The average open rate was 16%. The smallest open rate was 9% for a forward of Brain Injury of Hawai'i Meetings Schedule and the greatest open rate was 26% for "The Psychological Effect of Stroke."

Table: Educational Information Sent, June 7, 2013—July 10, 2013

Category/Type of Information	Number of Emails Sent
Disability Issues	9
Brain Injury	5
Stroke	2
Spinal Cord Injury	1
Injury Prevention	2
Veteran-Related	4
Employment	2
Technology Assistance	1
Neighbor Island Training	1
	Total: 27

2.1.1. Produce and Broadcast a Television PSA

2.1.2. Produce and Broadcast a Radio PSA

2.1.3. Develop a Project Website

Objective 2: Encourage Voluntary Participation in the Hawai'i Neurotrauma Registry

2.2.1. Develop and Implement a Social Media Campaign

- **Develop a Face Book Site**
- **Link the Face Book Site to Twitter**
- **Use Constant Contact to Promote the Project**

The project has sent invitations to participate in the registry twice on June 7, 2013, and a third time on June 14, 2013 to email recipients on the Constant Contact lists. The project sent notice of office relocation on July 3, 2013. Staff has received three contacts from service providers inquiring about the registry as a result of Constant Contact.

2.2.2. Advertisement Campaign

- **Develop Print Advertisements**
- **Produce Radio Advertisements**

Goal 3: Develop and Implement an Evaluation Process to Assess the Goals and Objectives of the Hawai'i Neurotrauma Registry Project

The project will address Goal 3 in future quarters.

Objective 1: Conduct Participatory Formative Evaluation on the Development and Implementation of the Project

Objective 2: Conduct Summative Evaluation of the Effectiveness in Attaining the Goals and Objectives of the Project

Objective 3: Provide Recommendations for Planning Post-Project Continuation and Sustainability of the Neurotrauma Registry

Goal 4: Reporting

Objective 1: Report and Update Project Progress to the Following Organizations

4.1.1. Neurotrauma Advisory Board

The project updated the Neurotrauma Advisory Board on June 21, 2013.

4.1.2. State Traumatic Brain Injury Advisory Board

The project updated the State Traumatic Brain Injury Advisory Board on May 17, 2013.

4.1.3. State Department of Health, Developmental Disabilities Division, Outcomes and Compliance Branch

The project had its first meeting with members of the Department of Health on June 5, 2013. Staff discussed the Department of Health intake form, the creation of a Hawai'i Neurotrauma Registry Advisory Board, collaboration with the University of Hawai'i Concussion Management Program and Project, and background checks for the project, hereafter called "Lehua Volunteers."

Monthly meetings will be on the second Wednesday of each month.

Objective 2: Health Insurance Portability and Accountability Act of 1966 (HIPAA) Compliance

The Hawai'i Neurotrauma Registry Project staff have completed and received Curriculum Completion Certificates for the following HIPAA trainings:

- Social and Behavioral Research—Basic Refresher Curriculum
- Social and Behavioral Responsible Conduct of Research

Objective 3: Quarterly Reports to State Department of Health

The quarters for the Hawai'i Neurotrauma Registry Project contract period are as follows:

- Quarter 1: March 21, 2013—June 21, 2013
- Quarter 2: June 22, 2013—September 21, 2013
- Quarter 3: September 22, 2013—December 21, 2013
- Quarter 4: December 22, 2013—March 21, 2013

4.3.1. Provide Electronic Intake Data

The project has provided the Hawai'i State Department of Health results of eight (8) online intake surveys on July 10, 2013.

4.3.2. Project Progress Reports

The project has updated the State Traumatic Brain Injury on May 17, 2013, and July 19, 2013.

The project has updated the Neurotrauma Advisory Board on June 27, 2013.

Objective 3: Provide Annual and Final Report to State Department of Health

The annual report covers the first twelve (12) months of progress for the Hawai'i Neurotrauma Registry Project. The final report concludes the Contract. Both reports include documentation to show fulfillment of the Contract. An original and one (1) copy is submitted to the Hawai'i State Department of Health, Developmental Disabilities Division, Outcomes and Compliance Branch.