#### REPORT TO THE THIRTY- SECOND LEGISLATURE

### STATE OF HAWAI'I 2024

### PURSUANT TO SECTION 321H-4 HAWAI'I REVISED STATUTES

# REQUIRING THE DEPARTMENT OF HEALTH TO PROVIDE AN ANNUAL REPORT ON THE ACTIVITIES UNDER THE NEUROTRAUMA SPECIAL FUND



PREPARED BY: STATE OF HAWAI'I DEPARTMENT OF HEALTH

December 2023

#### **EXECUTIVE SUMMARY**

In accordance with the provisions of Section 321H-4, Hawai'i Revised Statutes (HRS), "Neurotrauma," the Department of Health (DOH), Developmental Disabilities Division (DDD), Neurotrauma Program respectfully submits this annual report on the activities of the Neurotrauma Special Fund (NSF).

The NSF was established for the DOH to "develop, lead, administer, coordinate, monitor, evaluate and set direction for a comprehensive system for survivors of neurotrauma injuries." Since January 2003, the NSF is funded by surcharges from neurotrauma-related traffic citations that are deposited into the NSF. The Neurotrauma Program continues to work with neurotrauma survivors and their families to identify priorities for expenditure of moneys that are available in the NSF. The Neurotrauma Advisory Board (NTAB) and the Traumatic Brain Injury Advisory Board (TBIAB) provide stakeholder input into the Neurotrauma Program's activities. Additionally, NTAB offers advisory recommendations regarding the special fund. Based on the feedback received from neurotrauma survivors and stakeholders, the highest priorities of the NSF expenditures for fiscal year (FY) 2021-2023 are to educate survivors, caregivers, parents, and educators of youth on the signs, symptoms, resources, and effects of a neurotrauma injury.

In FY 2022 the Neurotrauma Program also obtained stakeholder feedback through the Data, Education, and Survivor Subcommittees to address the goals and objectives outlined in the FY 2021-2023 Neurotrauma Program Strategic Plan. During FY 2023, the Neurotrauma Program continued to work on meeting the goals and objectives of the Hawaii 2021-2023 Neurotrauma Program Strategic Plan (Attachment II). Program staff implemented activities to use the NSF in accordance with the mandate of Section 321H-4, HRS, in collaboration with the NTAB, TBIAB, Brain Injury Association of Hawai'i, families, survivors, and other community stakeholders.

Section 321H-4, HRS mandates the NSF be used for a "registry of neurotrauma injuries within the state". The purpose of the Hawaii Neurotrauma Registry (HNTR) is to gather information on the long-term service and support needs of survivors of neurotrauma injuries and their family members. A previous contract to administer the HNTR ended in May 2020. In FY 2022, the Neurotrauma Program Data Subcommittee explored different options for continuing the HNTR that would ensure the data collected is a valid representation of the needs of all survivors in Hawaii statewide. No viable options were identified, and subsequently, the Neurotrauma Program developed a Request for Information (RFI) to solicit information on other methods to implement the HNTR. Based on responses to the RFI it was determined that the Neurotrauma Program needed to consider alternative methods for the HNTR data collection. Until a new HNTR can be established, stroke and traumatic brain injury (TBI) data is being collected through the Behavioral Risk Factor Surveillance System. Due to the lack of Neurotrauma Program staff, the Data Subcommittee has not met in FY 2023. Community and stakeholder input continues to be gathered through NTAB, TBIAB, community partner discussions, and during community outreach events.

In FY 2023, the Neurotrauma Program explored available technology that would allow for building a sustainable HNTR while providing survivors and their caregivers a tool to support functions of daily living. Ensuing discussions with University of Hawaii staff included accessibility of the technology, support to users, and qualifications needed for an organization to launch, build, maintain, and sustain the HNTR. Going into FY 2024 the Neurotrauma Program will work with the University of Hawaii to create a Scope of Service for management of the day-to-day operations of the HNTR.

The Neurotrauma Program supported:

• Project RAPID Hawaii: A Statewide Collaboration on Acute Stroke Care with the Queen's Medical Center (QMC) to oversee and assist with the installation, implementation, and training of frontline staff on the RAPID Computerized Tomography (CT) perfusion (RAPID) software at six (6) acute care Hawaii hospitals. The most validated use of the RAPID software is to determine eligibility for a minimally invasive procedure called Mechanical Thrombectomy (MT) in patients experiencing large vessel occlusion (LVO) strokes. LVOs, if left untreated, have the highest rate of mortality or severe disability. Clinical trials demonstrated that MT dramatically increased chances of survival with independent level of function. The RAPID software can also be used to identify patients with wake-up strokes or strokes with unwitnessed onset who would be beyond the four and a half (4.5) hour treatment window from time-last-known-well for tissue plasminogen activator (tPA) treatment and to exclude tPA treatment in patients with suspected stroke mimics, such as those with seizure, complicated migraine, or psychogenic response.

Initial project implementation was delayed due to the COVID-19 pandemic. However, by FY 2023, the RAPID software was installed and is currently operating at all six (6) hospitals as was the goal of this project. All suspected stroke patients received a RAPID scan from the time of software implementation at each hospital. From the start of the contract to June 30, 2023, over four thousand (4,000) RAPID scans were successfully processed. In the final three (3) months of the contract, July 1, 2023, to September 30, 2023, RAPID software identified two (2) patients as eligible for MT, twenty-one (21) patients were given clot buster medications tPA or Tenecteplase (TNK), and ninety-six (96) patients were identified as not benefitting from MT and remained at their local hospital, avoiding an unnecessary transfer. The remaining patients either had completed strokes or were not eligible for MT or clot buster medications. The proportion of those identified as eligible for MT was as expected, given that fifteen percent (15%) of strokes are LVOs and only a fraction of those are eligible for MT.

• Project Head, Neck, Spine with the University of Hawai'i, Kinesiology and Rehabilitation Services Department (UH-KRS) developed, piloted, and launched an online educational health resource aimed at educating students in grades two (2) through twelve (12) on head, neck, and spine injuries, including recognition, awareness, and prevention. Outreach was extended to homeschooled students and families. The project has expanded by developing, piloting, and launching an online educational resource for educators on awareness and recognition of head, neck, and spine injuries, and "Return- to-Learn" protocol on how to appropriately support students as they return to the classroom after a head injury.

During FY 2024, the Neurotrauma Program will continue to gain community input through NTAB, TBIAB, and community organizations to meet the requirements of Section 321H-4, HRS. The Neurotrauma Program will continue its efforts to collect and analyze data, raise awareness to prevent disabilities, educate and disseminate information on traumatic brain injury (TBI), spinal cord injury (SCI), and stroke to survivors and their families. The Neurotrauma Program will also continue to improve the statewide system of services and supports for individuals living with neurotrauma in Hawai'i through activities consistent with the goals of the Neurotrauma Program Strategic Plan for FY 2021-2023 while the next strategic plan is being developed.

# REPORT TO THE LEGISLATURE IN COMPLIANCE WITH SECTION 321H-4. HAWAI'I REVISED STATUTES

#### Introduction

Pursuant to Section 321H-4, HRS, the DOH-DDD Neurotrauma Program respectfully submits this annual report on the activities of the Neurotrauma Special Fund (NSF) to the Thirty-Second Legislature.

Section 321H, HRS, mandates the DOH to "develop, lead, administer, coordinate, monitor, evaluate, and set direction for a comprehensive system to support and provide services for survivors of neurotrauma injuries;" to establish a Neurotrauma Advisory Board (NTAB); and to administer the NSF. The NSF began accumulating moneys from neurotrauma related traffic citation surcharges (speeding, drunk driving, not wearing seat belts, leaving the scene of an accident involving bodily injury) since January 1, 2003. This report is a status report on activities funded by the special fund for the period of July 1, 2022, to June 30, 2023.

#### Neurotrauma Advisory Board (NTAB) and Traumatic Brain Injury Advisory Board (TBIAB)

Section 321H, HRS was passed by the legislature in 2002. In compliance with the statute, the NTAB was established to advise the DOH on the use of the NSF to implement these statutes. In 1997, the legislature passed Act 333 that created the TBIAB to advise the DOH in the development and implementation of a comprehensive plan to address the needs of persons affected by disorders of the brain. As a subset of the NTAB, the TBIAB would continue to exist and advocate on behalf of the individuals affected by brain injury and would advise the DOH in consultation with the NTAB. In 2014, the Legislature amended Section 321H-3, HRS, to reduce NTAB membership from twenty-one (21) to eleven (11) members to obtain quorum while maintaining the same representation of members for the board. All members are appointed by the Director of Health and represent key stakeholder groups statewide. Board members participated in the development of the Neurotrauma Program Strategic Plan FY 2021-2023 to guide its work. Current members of the NTAB are listed in Attachment I.

#### Neurotrauma Program Strategic Plan FY 2021-2023

During FY 2023, the Neurotrauma Program worked to meet the goals and objectives defined in the Neurotrauma Program Strategic Plan for FY 2021-2023. Through NTAB and TBIAB, community members provided the Neurotrauma Program with input on strategies to meet goals and objectives. Data, Education, and Survivor subcommittees created in FY 2022 to implement the strategic plan were suspended in FY 2023 due to a lack of Neurotrauma Program staff. However, existing staff continue to focus on goals within the strategic plan. This Legislative Report provides highlights of how the Neurotrauma Program implemented activities to address the goals and objectives of the Strategic Plan during FY 2023.

#### Use of the Neurotrauma Special Fund

Section 321H-4, HRS, mandates that the NSF shall be used for:

- Education on neurotrauma:
- Assistance to individuals and families to identify and obtain access to services;
- Creation of a registry of neurotrauma injuries within the State to identifyincidence, prevalence, individual needs, and related information; and
- Necessary administrative expenses to carry out this section not to exceed two percent (2%) of the total amount collected.

#### (1) Educational activities:

Consistent with the Neurotrauma Program Strategic Plan Goals 1 and 2, the Neurotrauma Program, in coordination with community partners, provided education on neurotrauma to the public and providers to increase awareness of the effects of neurotrauma and how to respond to an injury and to improve service delivery and outcomes for survivors of neurotrauma.

#### **UH-KRS Educational Activities**

The Neurotrauma Program funded UH-KRS's Project Head, Neck, Spine. During FY 2023, Project Head, Neck, Spine launched their online educational resource for educators on awareness and recognition of head, neck, and spine injuries, and "Return-to-Learn" protocol on how to appropriately support students on their return to the classroom after a head injury. Additionally, UH-KRS onboarded five (5) new schools to utilize the online educational resource and expanded the outreach to homeschooled students and families. Over two hundred sixty-six (266) students and homeschooled students were educated on head, neck, and spine injuries, recognition, awareness, and prevention during FY 2023.

Since the project began in 2017 a total of twenty-one (21) elementary, middle, and high schools have utilized the resource. This includes fifteen (15) schools on Oahu, three (3) schools on Maui, one (1) school on Kauai, and two (2) schools on Hawaii Island. Multiple teachers have utilized the curriculum more than once with their new incoming classrooms. At this time a total of two thousand one hundred and sixty-two (2162) students have been educated. The middle and high school students had a pre-test average of sixty-five-point two percent (65.2%) and a post-test average of seventy-seven-point five percent (77.5%), indicating increased comprehension of the educational material. The upper grade level elementary students had a pre-test average of eighty-five percent (85%) and a post-test average of one hundred percent (100%). The lower grade level elementary students had a pre-test average of ninety percent (90%) and a post-test average of ninety-threepoint three percent (93.3%). Since the launch of the educators' curriculum a total of sixty-two (62) educators have fully completed the curriculum with an average summary score of eighty-eight-point two percent (88.2%). Elementary educators scored a pre-test average of seventy-six-point two percent (76.2%) and finished with a post-test average of eighty-three-point eight percent (83.8%), an increase of seven-point six (7.6) percentage points. Secondary educators scored a pre-test average of seventy-three percent (73%) and finished with a post-test average of eighty-seven-point five percent (87.5%), an increase of fourteen-point five (14.5) percentage points. Moving forward Project Head, Neck, Spine will continue to implement the online educational resource with additional educators, schools, students, and homeschooled students.

#### **QMC Educational Activities**

As a member of the Hawaii Stroke Coalition, QMC spearheaded and/or participated in education events to promote the recognition of the signs and symptoms of stroke and calling 9-1-1 to activate Emergency Medical Services. Educational outreach events included community presentations, health fairs, and the 2nd Hawaii Stroke Coalition Symposium. In recognition of stroke awareness month QMC participated in stroke events held at Hawaii's farmers markets, Wai Kai in Ewa Beach and the Filcom in Waipahu.

As part of Project RAPID Hawaii, providers were educated on implementing the RAPID software to improve stroke care. Twenty-four (24) physicians, thirty (30) Emergency Department staff, and two (2) stroke coordinators were trained. Training was also conducted at all the hospitals using the online RAPID University training modules. Additional information on Project RAPID Hawaii is discussed below.

#### Partnerships with Community Organizations and Neurotrauma Awareness Months

Consistent with Strategic Plan Objective 1.2, the Neurotrauma Program conducted activities to promote awareness of neurotrauma. Throughout FY 2023, the Neurotrauma Program partnered, participated, lead and supported sixteen (16) virtual and in-person events and presentations statewide. Special events were held to recognize nationally designated months for Trauma, Spinal Cord Injury, Stroke and Brain Injury Awareness. Event attendees were furnished with promotional products and educational materials related to neurotrauma. Information included education of signs, symptoms, and what to do when a TBI, SCI, or stroke occurs. At helmet events, attendees were educated on injury prevention, rules of the road, and offered a bicycle or multisport helmet free of charge. Over nine hundred (900) individuals from the general public as well as professionals received neurotrauma education through these events. Table one (1) includes additional information on the outreach activities.

Table 1. Community Outreach and Number Educated on Neurotrauma

Organization / Event	Education / Activity	Number Educated
Catholic Charities of Hawaii/Staff 1 year check in	Stroke presentation	30
Drowning and Injury Prevention Advisory Committee/ Water Safety Week	Injury prevention	unknown
Wahiawa Hongwanji	Stroke newsletters	15
Lanakila Senior Center	Stroke presentation	15
Ohana Senior Health Fair	Stroke education	100
Executive Office on Aging	Helmet education / safety	5
Kapiolani Medical Center for Women and Children  – Injury Prevention	Car seat safety checks	20
Queens Medical Center - Trauma		
Department of Education – Operation Driver Excellence	Traumatic Brain Injury prevention education	200
Leeward YMCA – Healthy Kids Day	Traumatic Brain Injury prevention education	150
Hawaii News Now interview	Traumatic Brain Injury prevention education	unknown
Public Health Nursing Talk Story	Neurotrauma resources	12
Hawaii Stroke Coalition at Wai Kai	Stroke education	150
Rollerskate Oahu Trauma Awareness Month	Helmet safety and head injury prevention education	10
Leeward Community Church	Stroke presentation	30
Queens Medical Center at Waipahu Health Fair	Stroke education	35
Queens Medical Center at Kailua Farmer's Market	Stroke education	35
Student Leadership Conference	Traumatic Brain Injury prevention education	100
TOTAL:		907+

The Neurotrauma Program kicked off Spinal Cord Injury Awareness Month by supporting the <u>Drowning and Aquatic Injury Prevention Advisory Committee</u> (DAIPAC) to celebrate Beach Safety/Lifeguard Appreciation Week, August 21-27, 2022. Governor Ige along with the mayors of Maui and Kauai, issued proclamations in honor of Beach Safety Week highlighting the heroic efforts of Hawaii's lifeguards. The Neurotrauma Program provided funding for beach week banners for the islands of Oahu, Hawaii, Maui and Kauai. Additional funding was provided to purchase lei for lifeguards who were honored for their outstanding work.

# Hawai'i Lifeguard Appreciation Week





#### **Proclamation**

WIRERAK so come lifeguards are responsible for protecting the law of more than one million Rewal's residents and million or interest verbit reads resident in the Addition Research and the same of th







Ocean Safety staff from Kauai.

Additionally, the <u>Neurotrauma Program website</u> (<u>https://health.hawaii.gov/nt/spinal-cordinjury/</u>) included tips on SCI prevention, resources for survivors and family members, along with an activity page to increase knowledge on SCI.

For Brain Injury Awareness Month, the Neurotrauma Program participated in the Department of Education's (DOE) Operation Driver Excellence and YMCA's Healthy Kids Day. The DOE event, held at Aloha Stadium was attended by teens as new drivers. Using printed media and brain injury simulation activities, attendees were educated on the importance of wearing a seatbelt and minimizing distractions when driving.

The YMCA Healthy Kids Day was celebrated on April 1, 2023. With materials and training from Neurotrauma Program staff, Kalihi YMCA staff educated attendees on brain injury and conducted a simulation activity. Leeward YMCA hosted Neurotrauma Program, Queen's Medical Center, Kapiolani Medical Center for Women and Children, Hawaii Bicycling League, Brain Injury Association of Hawaii, and Leeward Pilots Club to hold a bike rodeo, offer free bike and multisport helmets, and related information. Attendees participated in activities to learn how difficult it is to do everyday things when a person sustains a brain injury.



Double click on this



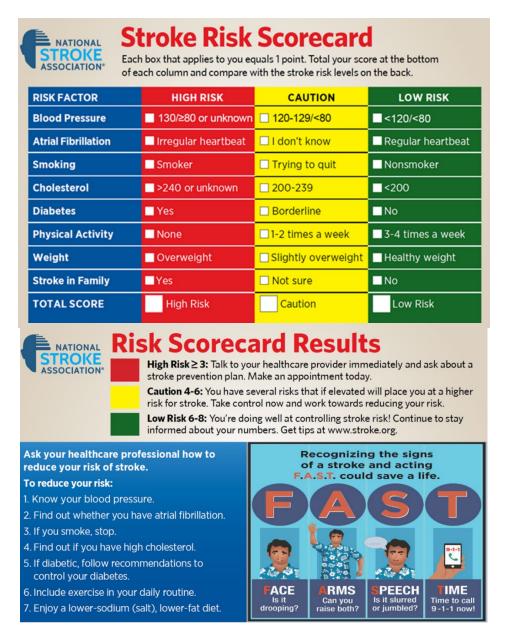
icon and select "Open" to view video footage of the bike rodeo.

Recognition of Brain Injury Awareness month continued with Hawaii News Now Sunrise, interviewing Brain Injury Association of Hawaii (BIHi) of which Neurotrauma Program staff is a board member. Besides brain injury statistics and facts, BIHi board members shared tips on preventing head injury and emphasized the collaborative efforts that made the Leeward YMCA bike rodeo successful.



In recognition of Trauma Awareness Month, the Neurotrauma Program teamed with Rollerskate Oahu to educate new skaters on the importance of proper fitting, use, and care of helmets. Attendees who did not have a helmet were furnished with a free multisport helmet. Rollerskate Oahu requires all students be helmeted during lessons.

The Neurotrauma Program recognized May 2023 as Stroke Awareness Month with a stroke awareness presentation to members of Leeward Community Church. Members learned about the most common causes of stroke, symptoms of stroke, what to do if you suspect someone is having a stroke and that almost all strokes are preventable. Members then used a "stroke risk scorecard" from the National Stroke Association, to self-assess their own risk level for having a stroke.





Click on the link below to go to the Neurotrauma Program website and learn more about stroke and self-assess your risk level for having a stroke: <a href="https://health.hawaii.gov/nt/news/stroke/stroke-symptoms-and-your-own-stroke-risk/">https://health.hawaii.gov/nt/news/stroke/stroke-symptoms-and-your-own-stroke-risk/</a>

In support of our stroke partners, Hawaii Stroke Coalition and QMC, the Neurotrauma Program participated in stroke outreach events at Wai Kai for Stroke Awareness month. While Neurotrauma Program staff were not able to attend additional stroke events at Waipahu Health Fair and Kailua Farmer's Market, each event was provided Neurotrauma brochures and promotional items with the phone number for the Neurotrauma Helpline. Stroke outreach activities not conducted in May include community education at Pearlridge Ohana Senior Fair, a one (1) year check-in with Catholic Charities Hawaii staff, sharing stroke resources with Public Health Nursing and stroke newsletters to members of Wahiawa Hongwanji.

#### (2) Assistance to individuals and families to identify and obtain access to service activities:

#### Project RAPID Hawaii: A Statewide Collaboration on Acute Stroke Care

October 2021 began the final year of a three (3) year contract with QMC to oversee and assist with the installation and implementation of the RAPID CT perfusion software at six (6) acute care Hawaii hospitals and training of frontline staff at these hospitals to use the software. The six (6) hospitals include Wahiawa General Hospital, Kona Community Hospital, Kauai Veterans Memorial Hospital, Hilo Medical Center, Castle Medical Center, and Kuakini Medical Center. The contract also funded the software licensing fees for each hospital from the installation date through September 2022. The hospitals have assumed funding the licensing fees after the DOH contract and funding ended.

Until 2015, the only proven treatment for ischemic stroke, which occurs when a blood vessel supplying blood to the brain is blocked by a clot, was intravenous (IV) tissue plasminogen activator (tPA), also known as clot buster medication. However, treatment with IV tPA alone has only a ten to thirty percent (10%-30%) success rate at fully restoring blood flow to the brain with large vessel occlusions (LVOs). LVOs, if left untreated, have the highest rate of mortality or severe disability. In 2018, several landmark clinical trials demonstrated that manual removal of the blockage within twenty-four (24) hours of symptom onset through a procedure called mechanical thrombectomy (MT) dramatically increases the chance of survival with independent level of functioning when patient eligibility is determined by advanced imaging studies that measure blood flow to the brain. The RAPID software can also be used to identify patients with wake-up strokes or unwitnessed onset, who would be beyond the four and a half (4.5) hour time window from time-last-known-well for tPA treatment and to exclude tPA treatment in patients with suspected stroke mimics, such as seizure, complicated migraine, or psychogenic response.

The goals of this project were to improve access for eligible patients at the six (6) remote hospitals to receive MT at tertiary hospitals that can perform this procedure; reduce the time and cost associated with on-site processing of RAPID CT perfusion imaging; and reduce the delay in treatment times for patients.

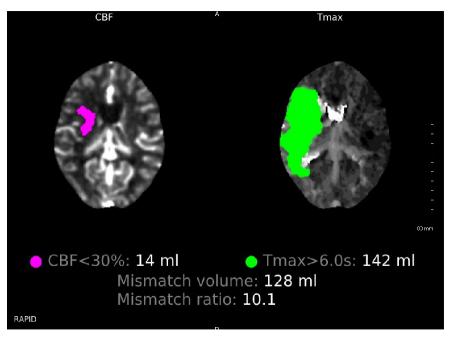
Despite initial implementation delays due to the COVID-19 pandemic, the RAPID software was installed and is operational at all six (6) hospitals. The participating hospitals include Wahiawa General Hospital, Kona Community Hospital, Kauai Veterans Memorial Hospital, Hilo Medical Center, Castle Medical Center, and Kuakini Medical Center.

In FY 2023 a total of five hundred thirty (530) RAPID scans were successfully processed including seventy-four (74) from Wahiawa General Hospital, two hundred seventy- six (276) from Hilo Medical Center, nine (9) from Kauai Veterans Memorial Hospital, one hundred twenty-four (124) from Castle Medical Center, forty seven (47) from Kona Community Hospital, and zero (0) from Kuakini Medical Center. In the final three (3) months of the contract, July 1, 2023 to September 30, 2023, the use of RAPID software resulted in the identification and provision of treatment to two (2) patients eligible for MT and twenty-one (21) eligible for tPA or TNK. Furthermore,

ninety-six (96) individuals were identified as patients who would not benefit from MT and remained in their local hospital and community instead of being unnecessarily transferred to QMC. Although a relatively small proportion of individuals are identified as eligible for MT, the impact of the RAPID software and a successful MT procedure is life-changing, evidenced by the following case scenario.

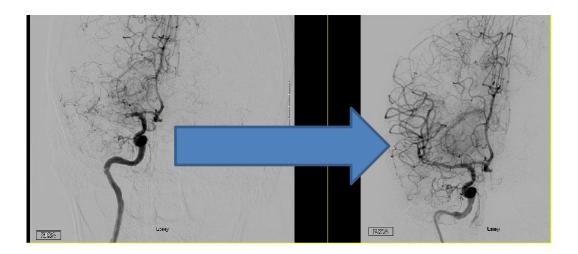
The patient presented to the medical center at 12:00 PM with left sided paralysis, slurred speech, left visual field cut, and right sided gaze deviation. The patient was last seen normal at 11:00 PM the previous night and had unwitnessed onset of stroke symptoms. The patient was seen by the Queen's neurologist using telemedicine at 12:05 PM and RAPID scans were obtained. The patient was not eligible for treatment with tPA (clot buster medication) because the patient was outside the four-point five (4.5) hour time window (last seen normal thirteen (13) hours prior to presentation). The RAPID CT perfusion scan shown below demonstrates one hundred forty-two (142) mL of brain tissue that is not getting adequate blood flow (ischemia, shown in green) and fourteen (14) mL of brain tissue that is already permanently damaged (stroke, shown in purple). The mismatch volume of one hundred twenty-eight (128) mL represents the volume of brain tissue that can still be salvaged but only if the patient can have a successful clot removal (mechanical thrombectomy) fast enough.





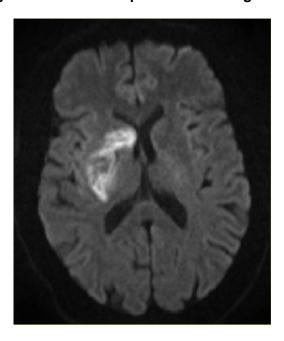
Based on the RAPID CT perfusion scan, the patient was transferred to QMC and arrived at 3:50 PM. Patient then underwent a cerebral angiogram (shown below) which demonstrated persistent blockage of the right middle cerebral artery which was then treated using MT for successful removal of the clot that was blocking blood flow. The procedure concluded at 5:12 PM.

Figure 2. Cerebral Angiogram Showing Occlusion Pre-MT and Reperfusion Post-MT



An MRI the following day (shown below) showed a stroke in the distribution that was originally predicted by the RAPID CT perfusion scan, but the remaining brain tissue was salvaged. The patient was able to start full time physical therapy in an acute rehabilitation hospital to recover from the stroke and return home.

Figure 3. Patient MRI post-MT Showing Small Stroke



This case illustrates the use of RAPID CT perfusion to expand treatment eligibility for patients with severe strokes who would not be eligible for clot buster medications. It also illustrates how RAPID can be used to triage patients for inter-island transport in order to undergo lifesaving treatments that are not available on the neighbor islands.

#### DOH Neurotrauma Program Information and Resource Referral

The Neurotrauma Helpline provides information and resource referrals to survivors of neurotrauma, family members, and professionals assisting survivors in identifying and obtaining

access to services and supports. During FY 2023, the Neurotrauma Program provided information and resource referral assistance fifty-one (51) times. Twenty-six (26) contacts were initiated by professionals, seventeen (17) by family/caregivers, six (6) by survivors, and the remaining two (2) were friends of the survivor. Traumatic brain injury was the primary diagnosis in nineteen (19) requests for assistance. Twenty-two (22) requests, primarily from professionals, were for assistance with a study, queries for a research project, job opportunities, and available neurotrauma resources in Hawaii. As in years past, survivors and caregivers indicated a high need for case management services, one (1) source providing a direct link to needed supports.

The time needed to manage each request varies from a few minutes to dedicating hours of staff time to ensure everyone who contacts the Neurotrauma Program receives proper attention. One assistance request from this past year stands out from all others. The individual indicated a background with a strong work history until they became injured. At the time of the call, the individual had been on pain medication for more than two (2) years. The call to the Neurotrauma Helpline was prompted by their inability to obtain their pain medication. Additionally, the caller's spouse was encountering issues having their own health needs met. Over the course of the year Neurotrauma Program and support staff have managed more than fifty (50) contacts and countless hours with or on behalf of the individual. The caller's issues ranged from an inability to secure a new primary care provider, medical interference from past primary care providers, uncooperative insurance companies, threats from medical staff, and police brutality. The situation was exacerbated by a lack of support in the home to complete activities of daily living. During one call, desperation drove the caller to mention suicide as an option to their difficulties. Successful measures were taken to safeguard the individual to prevent self-harm. While the individual finds the resources provided to be inadequate for their needs, they say they continue to contact the Neurotrauma Program because the staff listens to them when no one else will and are helpful in facilitating communication with existing providers.

### (3) <u>Development of a registry within the State to identify incidence, prevalence, individual needs, and related information of survivors of neurotrauma injuries:</u>

Section 321H-4, HRS, states the NSF shall be used for the "creation of a registry of neurotrauma injuries within the State to identify the incidence, prevalence, individual needs, and related information." Incidence of TBI, SCI, and stroke are collected via the Hawaii Trauma Registry and the Hawaii Stroke Registry, and prevalence is collected via the Behavioral Risk Factor Surveillance System. The goal of the Hawaii Neurotrauma Registry (HNTR), consistent with Goal 4 of the Neurotrauma Program Strategic Plan, is to identify the individual needs and service gaps of survivors of neurotrauma injuries after they transition back into the community from acute care and rehabilitation. The data obtained from the HNTR shall be used to make data-driven decisions to improve the system of services and supports for survivors of neurotrauma where most needed.

The HNTR is not a mandated registry and thus, our efforts focus on ensuring the data collected is a valid representation of the needs and service gaps for survivors statewide. In FY 2021 the Neurotrauma Program developed a Request for Information (RFI) to identify potential methods for developing and implementing the HNTR in the State of Hawaii. Based on responses to the RFI it was determined the Neurotrauma Program needed to consider alternative methods of data collection for the HNTR. In FY 2022 the Neurotrauma Data Subcommittee, in partnership with community partners and stakeholders, explored different methods of data collection for the HNTR.

During FY 2023, the Neurotrauma Program worked with the University of Hawaii to lay the groundwork for use of an application that would allow neurotrauma survivors to register for the HNTR and receive ongoing benefits by digitally tracking and managing their own symptoms.

The chosen application will have a history of proven success, be Health Insurance Portability and Accountability Act (HIPAA) compliant and contain data points from the current HNTR survey. <a href="https://health.hawaii.gov/nt/files/2020/07/Neurotrauma-Survey DOH Neurotrauma Program rev.-06-25-20.pdf">https://health.hawaii.gov/nt/files/2020/07/Neurotrauma-Survey DOH Neurotrauma Program rev.-06-25-20.pdf</a>

In FY 2024 the Neurotrauma Program will partner with the University of Hawaii to facilitate the process of acquiring and implementing use of the health monitoring application, recruiting eligible users to register for the HNTR, and introduce the benefits of utilizing the application. The application will be furnished to users free of charge.

#### (4) Necessary administrative expenses to carry out this Section:

In FY 2023, a total of \$ 462,802 was deposited into the funds from traffic surcharge collections. The total expenditure as of June 30, 2023, was \$408,324. As of July 1, 2023, there was an available cash balance of \$645,149. A projected FY 2024 budget for the NSF is provided in Attachment III.

The Neurotrauma Program, with input from the TBIAB, NTAB, and other community constituents plans to utilize the NSF in accordance with Section 321H-4, HRS, by supporting:

- **Hawaii Neurotrauma Registry** Engage in preparatory activities to determine the most effective method to create, implement, maintain, and sustain the HNTR.
- HCAMP BrainSpace Create new and update existing education, information, and resources on concussions, geared specifically for students, parents, athletes, coaches and educators.
- Education & Dissemination of Information by providing opportunities for education on neurotrauma to the public and providers that are in line with the Neurotrauma Program Strategic Plan objectives 1.1, 1.2, 1.3, and 2.2. Dissemination of information will be through verbal and written information (e.g., TBI, SCI and Stroke Discharge packets; conferences; events; presentations; the Neurotrauma Program Helpline; etc.) and information on the DOH Neurotrauma website. The website allows the community to access the most up-to-date information and resources on neurotrauma in real time.

#### **ATTACHMENT I**

#### **NEUROTRAUMA ADVISORY BOARD**

#### Section 321H-3, HRS

VOTING MEMBERSHIP	TERM REPRESENTATION

Molly Trihey Neurotrauma Injury Survivor

Spinal Cord Injury

Angie Enoka Neurotrauma Injury Survivor

Traumatic Brain Injury

Rita Manriquez TBIAB Member

Neurotrauma Injury Survivor Traumatic Brain Injury

Dr. Eugene Lee, M.D. Private Sector

Rehabilitation Hospital of the Pacific

Leilani Nutt Trauma Center

Queen's Medical Center

VACANT Brain Injury Association of Hawaii

Representative

Matthew Wells Trauma Services

Pali Momi Medical Center

Milton Takara At-Large

Neurotrauma Injury Survivor Traumatic Brain Injury

Scott Sagum Chair

Neurotrauma Injury Survivor

Stroke

Stella Wong At-Large

Catholic Charities Hawaii

Valerie Yamada At-Large

Neurotrauma Injury Survivor Traumatic Brain Injury & Stroke

#### ATTACHMENT II

#### **NEUROTRAUMA PROGRAM STRATEGIC PLAN**

#### **FISCAL YEARS 2021-2023**

<u>Goal 1:</u> In coordination with community partners, expand educational opportunities to the public sector on all neurotrauma injuries to increase awareness on the effects of neurotrauma and how to respond to an injury.

#### **Objectives:**

- **1.1:** Provide survivors and caregivers with awareness of how a neurotrauma injury can affect a person's life immediately following an injury and throughout their lifetime.
- **1.2:** Educate the public on the signs, symptoms and what to do when recognizing a TBI, SCI or Stroke.
- **1.3:** Coordinate public education efforts to maximize the impact and ensure efforts are not being duplicated.

<u>Goal 2:</u> In coordination with community partners, connect providers to educational opportunities to increase awareness of neurotrauma and improve service delivery and outcomes for the survivors they serve.

#### **Objectives:**

- **2.1:** Provide social workers and medical providers with insight on survivors' experiences and methods for effective communication to improve collaboration between patient and provider.
- **2.2:** Work with administration and staff involved with educating youth to establish and implement a Return-to-Learn protocol for students exhibiting signs of a TBI, including the identification of TBI signs and symptoms and how to discuss with parents.

## **Goal 3:** Expand survivors', family members', and caregivers' connections to available resources in Hawaii.

#### **Objectives:**

- **3.1:** Work with hospital staff and interested stakeholders to develop and implement an effective way to share information and resources with survivors to increase access to services and supports.
- **3.2:** Provide guidance for members of the neurotrauma community to gather in a safe space to share thoughts, ideas and resources on a regular basis.

# <u>Goal 4:</u> Use data to identify the needs and service gaps for survivors of neurotrauma and family members/caregivers.

#### **Objectives:**

- **4.1**: Develop and implement a plan for obtaining generalizable data.
- **4.2**: Develop and implement a plan to analyze data and identify service gaps to direct program activities.

### **ATTACHMENT III**

### PROJECTED BUDGET FOR THE NEUROTRAUMA SPECIAL FUND FY 2024

Beginning Cash Balance as of 7/1/23	\$ 645,149
Estimated Revenues FY 2024	\$ 500,000
FY 24 Estimated Expenses	
Contract Encumbrances:	
Website Maintenance	\$ 10,000
2. BrainSpace	\$ 20,000
Behavioral Risk Factor Surveillance System Data	\$ 6,000
Get with the Guidelines Stroke Data	\$ 6,315
NASHIA Membership	\$ 1,250
Education and Awareness Activities	\$ 24,000
Personnel	\$ 257,664
Total Expenses	\$ 325,229
Estimated Ending Cash Balance as of 6/30/2024	\$ 819,920

#### [CHAPTER 321H] NEUROTRAUMA

#### Section

- 321H-1 Definitions
- 321H-2 Neurotrauma system
- 321H-3 Neurotrauma advisory board
- 321H-4 Neurotrauma special fund
- 321H-5 Rules

[§321H-1] **Definitions**. As used in this chapter, unless the context requires otherwise:

"Board" means the neurotrauma advisory board established under section 321H-3.

- "Department" means department of health.
- "Director" means the director of health.

"Neurotrauma" means a severe chronic disability of a person that is attributable to an injury to the central nervous system, such as traumatic brain injury and spinal cord injury, and likely to continue indefinitely. Neurotrauma can include other neurological dysfunctions but does not include substance misuse and abuse, Alzheimer's disease, or the infirmities of aging. Neurotrauma or other neurological deficits result in substantial functional limitations in two or more of the following areas:

- (1) Self-care;
- (2) Speech, hearing, or communication;
- (3) Learning;
- (4) Mobility;
- (5) Self-direction;
- (6) Capacity for independent living; and
- (7) Economic sufficiency. [L 2002, c 160, pt of §2]

[§321H-2] Neurotrauma system. The department of health shall develop, lead, administer, coordinate, monitor, evaluate, and set direction for a comprehensive system to support and provide services for survivors of neurotrauma injuries. [L 2002, c 160, pt of §2]

- §321H-3 Neurotrauma advisory board. (a) There is established within the department a neurotrauma advisory board to advise the director in implementing this chapter.
- (b) The board shall consist of eleven members to be appointed by the director. The director shall designate a member to be the chairperson of the advisory board. The director or a designee shall serve as an ex officio, nonvoting member of the advisory board. The director may also appoint up to three state and county representatives whose work relates to

neurotrauma to be ex officio, nonvoting members of the board. The members shall serve for a term of four years; provided that upon the initial appointment of members, two shall be appointed for a term of one year, three for a term of two years, three for a term of three years, and three for a term of four years. In establishing the advisory board, the director shall appoint:

- (1) Two survivors of neurotrauma or their family members (one for traumatic brain injuries and one for spinal cord injuries);
- (2) One member of the Brain Injury Association of Hawaii;
- (3) One member representing the state traumatic brain injury advisory board;
- (4) Two members representing private sector businesses that provide services for neurotrauma survivors;
- (5) One member representing trauma centers that provide services for neurotrauma survivors;
- (6) One representative for persons with stroke; and
- (7) Three at-large members.
- (c) The members shall serve without compensation but shall be reimbursed for actual expenses, including travel expenses, that are necessary for the performance of their duties.
- (d) The number of members necessary to constitute a quorum to do business shall consist of a majority of all the voting members who have been appointed by the director and have accepted that appointment. When a quorum is in attendance, the concurrence of a majority of the voting members in attendance shall make any action of the board valid. [L 2002, c 160, pt of \$2; am L 2014, c 191, \$1]
- §321H-4 Neurotrauma special fund. (a) There is established the neurotrauma special fund to be administered by the department with advisory recommendations from the neurotrauma advisory board. The fund shall consist of:
  - (1) Moneys raised pursuant to the surcharges levied under sections 291-11.5, 291-11.6, 291C-12, 291C-12.5, 291C-12.6, 291C-102, 291C-105, and 291E-61;
  - (2) Federal funds granted by Congress or executive order, for the purpose of this chapter; provided that the acceptance and use of federal funds shall not commit state funds for services and shall not place an obligation upon the legislature to continue the purpose for which the federal funds are made available; and
  - (3) Funds appropriated by the legislature for the purpose of this chapter.
- (b) The fund shall be used for the purpose of funding and contracting for services relating to neurotrauma as follows:

- (1) Education on neurotrauma;
- (2) Assistance to individuals and families to identify and obtain access to services;
- (3) Creation of a registry of neurotrauma injuries within the State to identify incidence, prevalence, individual needs, and related information; and
- (4) Necessary administrative expenses to carry out this chapter not to exceed two per cent of the total amount collected.
- (c) Moneys in the neurotrauma special fund may be appropriated to obtain federal and private grant matching funds, subject to section 321H-4(a)(2).
- (d) In administering the fund, the director shall maintain records of all expenditures and disbursements made from the neurotrauma special fund.
- (e) The director shall submit to the legislature an annual report on the activities under the neurotrauma special fund no later than twenty days prior to the convening of each regular session. [L 2002, c 160, pt of §2; am L 2006, c 129, §6]

[§321H-5] Rules. The director may adopt rules under chapter 91 necessary to carry out this chapter. [L 2002, c 160, pt of §2]