

# Hawaii Neurotrauma Registry Project

## Final Report, March 2013 – June 2020



Pacific Disabilities Center, John A. Burns School of Medicine, University of Hawaii at Manoa  
December 2020 and January 2021

# Three Main Goals

1. Educate the public and professionals about neurotrauma injuries (spinal cord injuries, stroke, traumatic brain injuries) and about the Hawaii Neurotrauma Registry Project (aka “outreach”)
2. Provide an information and referral service for residents of Hawaii
3. Recruit voluntary participants (neurotrauma injury survivors and caregivers) to take the Hawaii Neurotrauma Registry Project survey for the purpose of identifying their needs

# Outreach Summary

<b>Location</b>	<b>Number of Presentations, Events, and Meetings</b>	<b>Number of Attendees or Packets of Information Distributed</b>
Hawaii	45	2,527
Kauai	15	1,546
Lanai	10	160
Maui	28	2,586
Molokai	9	144
Oahu	330	24,137
<b>Totals</b>	<b>437</b>	<b>31,100</b>

# Information and Referral Services

<b>Attempt and Outcome</b>	<b>Frequency</b>	<b>Percentage</b>
Initial I&R request, connected	755	52.5%
Initial I&R request, could not reach	336	23.3%
Initial I&R request, refused help	101	7.0%
6 month follow-up, connected	31	2.1%
6 month follow-up, could not reach	59	4.1%
6 month follow-up, refused help	17	1.1%
12 month follow-up, connected	23	1.5%
12 month follow-up, could not reach	99	6.8%
12 month follow-up, refused help	27	1.8%
<b>Totals</b>	<b>1,448</b>	<b>100.0%</b>

# HNTR Survey Participation

Contract Year	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6	Year 7 <sup>2</sup>	Totals
Number of Unique Persons	37 6.6%	58 10.3%	44 7.8%	55 9.8%	51 9.1%	59 10.5%	258 45.9%	<b>562</b> <b>100.0%</b>
Number of Surveys <sup>1</sup>	37 6.3%	59 10.2%	45 7.8%	55 9.5%	54 9.3%	67 11.6%	262 45.2%	<b>579</b> <b>100.0%</b>

<sup>1</sup>Some individuals took the survey more than once over the years

<sup>2</sup>A power bank (portable device charger) incentive worth approximately \$10 was offered in Year 7

# Residence and Gender

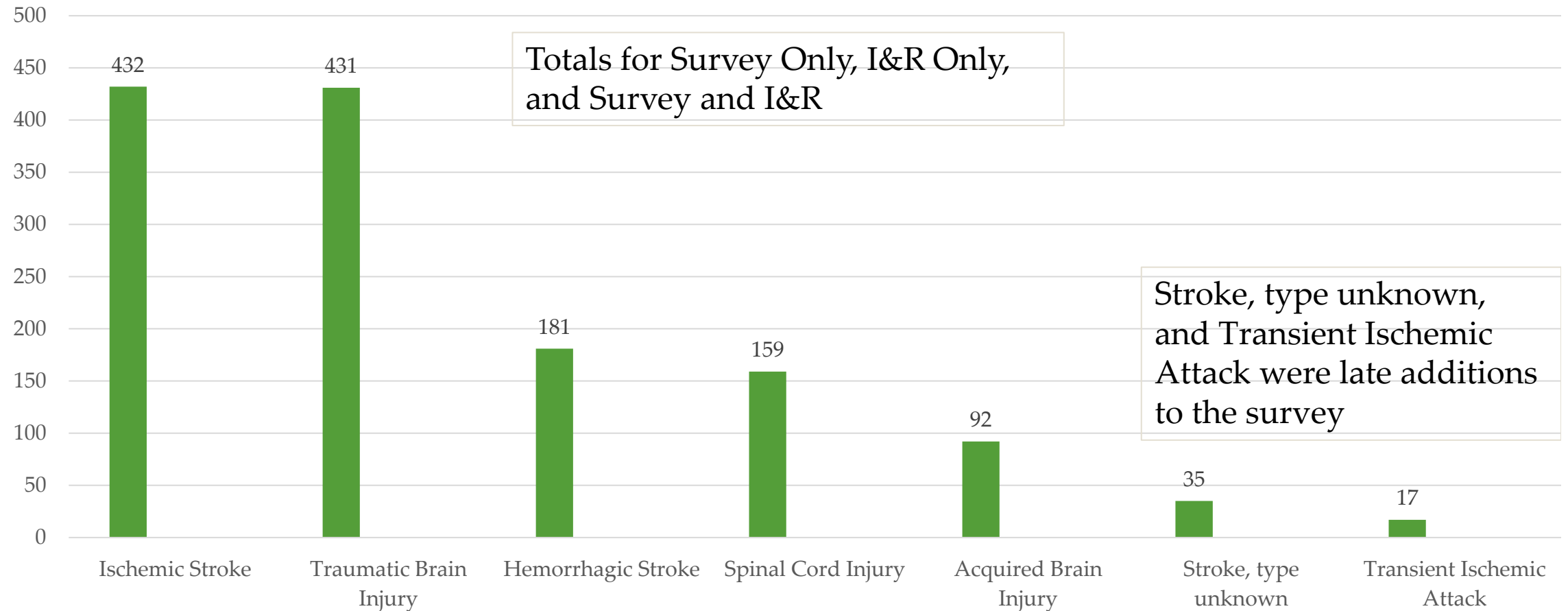
<b>Residence</b>	<b>Survey Only</b>	<b>Survey and I&amp;R</b>	<b>Total # Surveys</b>	<b>I&amp;R Only</b>
City & County of Honolulu	210	112	322	225
Hawaii County	59	41	100	26
Maui County	39	29	68	36
Kauai County	21	12	33	10
Outside of State	8	1	9	7
Missing	25	5	10	371
<b>Totals</b>	<b>362</b>	<b>200</b>	<b>562</b>	<b>675</b>
<b>Gender</b>	<b>Survey Only</b>	<b>Survey and I&amp;R</b>	<b>Survey and I&amp;R</b>	<b>I&amp;R Only</b>
Women	184	105	289	239
Men	167	94	261	170
Missing or Not Applicable	11	1	12	266
<b>Totals</b>	<b>362</b>	<b>200</b>	<b>562</b>	<b>675</b>

# Age and Marital Status

**Age Statistics for all groups – Survey Only, I&R Only, Survey and I&R**  
Age Range in Years: 0 (under 1 year old) – 100 years old  
Average age: 58.5 years old

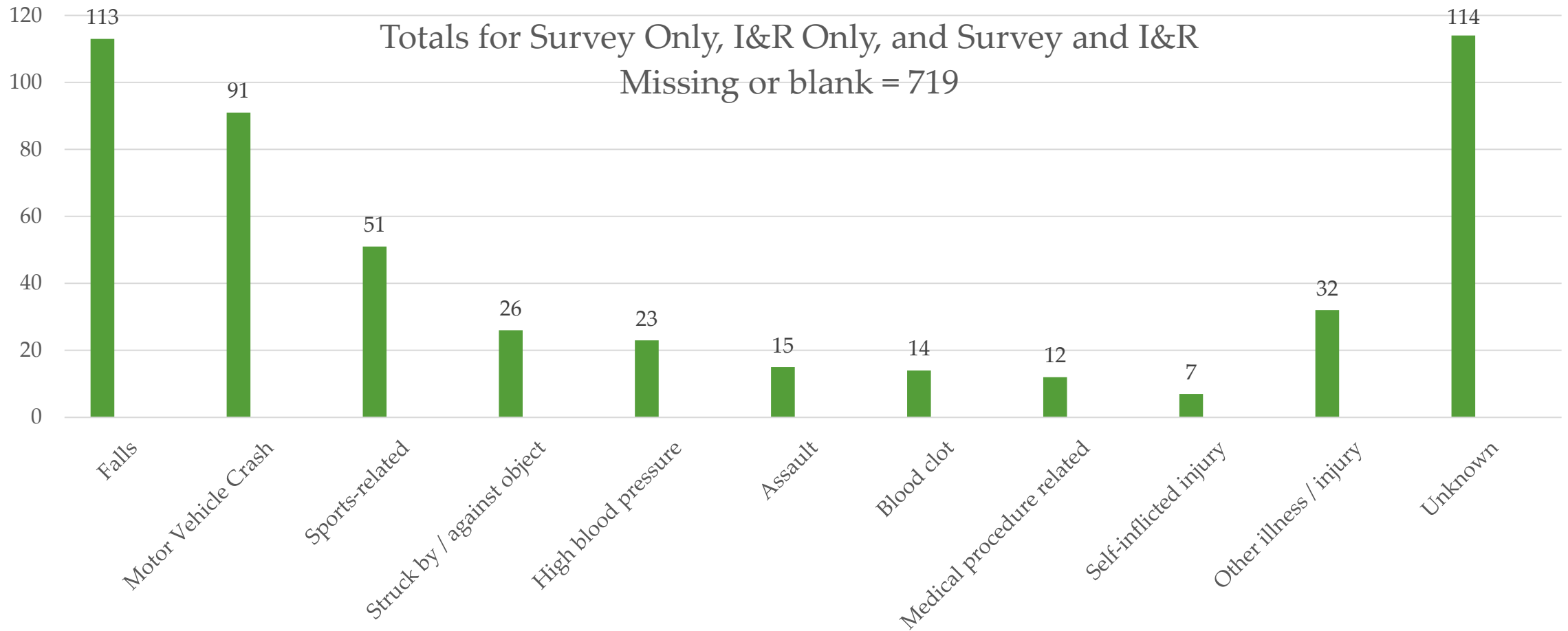
<b>Marital Status</b>	<b>Survey Only</b>	<b>I&amp;R Only</b>	<b>Survey and I&amp;R</b>	<b>Totals</b>
Married	132	72	70	<b>274</b>
Single	120	35	70	<b>225</b>
Widowed	39	17	29	<b>85</b>
Divorced	44	10	23	<b>77</b>
Separated	6	2	3	<b>11</b>
Missing or Not Applicable	21	539	5	<b>565</b>
<b>Totals</b>	<b>362</b>	<b>675</b>	<b>200</b>	<b>1,237</b>

# First or Only Neurotrauma Injury





# Cause of First or Only NT Injury

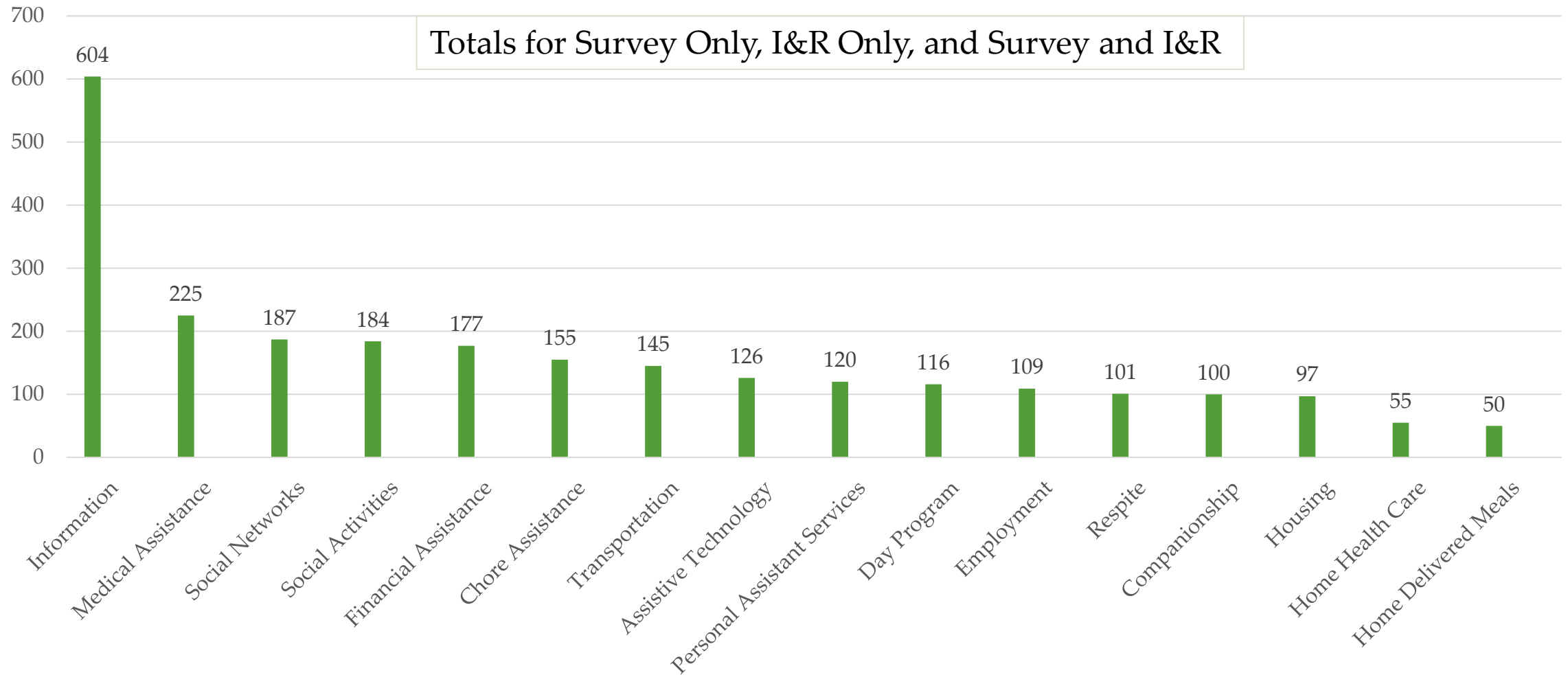


# Survivor and Caregiver Needs

- The #1 need by far:

# INFORMATION

# Needs by Category



# Qualitative Analyses Categories

1. Problems experienced
2. Needs and wants
3. Issues with medical care and services
4. Issues with other kinds of care and services
5. Overcoming adversity / doing alright
6. Desire to help
7. Military related
8. Issues with insurance coverage
9. Mahalo to HNTR

# Additional HNTR Activities

- Best Practices of Neurotrauma Registries Research
- Extensive Media / Social Media Campaign
- YouTube Channel
- Researched definitions of Cognitive Rehabilitation as related to legislation
- HNTR Advisory Board
- Resource Manuals
- Volunteer Program
- Workforce Development
- Upcoming Events Calendar
- Networking
- Brain Injury Awareness Month 2018 Activity



# Community Activities



Aiea High School  
Honolulu, Oahu



Senior Fair  
Honolulu, Oahu



Lanai City Middle &  
High School  
Lanai City, Lanai



KTA Superstore  
Waimea, Hawaii

KTA Superstore  
Hilo, Hawaii



Wilcox Hospital Keiki Bike  
and Skateboard Safety Fair  
Lihue, Kauai



Perry & Price  
Show  
Honolulu,  
Oahu