

## INSIDE THIS ISSUE:

FEMA MASS 2  
Care Team  
meeting

Special Needs 2  
Population Coa-  
lition (SNPC)  
meeting

Stop the Silent 3  
Suffering

PADD Meeting 3

UCEDD Acro- 4  
nyms, Mission &  
Staff Directory

## SYMPTOMS OF SPINAL MUS- CULAR ATRO- PHY:

- Muscle weakness
- Weak cry & cough
- Limpness to flop
- Clinched fists with sweaty hands
- Flickering/vibrating of the tongue
- Legs weak
- Head tilted to one side
- Bowel/Bladder weakness

## CATARACT AWARENESS

By: Lia Pelenato



August is  
Cataract  
aware-  
ness  
month  
around

the world. As cataract is one of the leading causes of vision loss in the U.S and other parts of the world. Cataract is a clouding of the eye's naturally clear lens. The cloudiness and pattern of a cataract can vary and sometimes people are not aware that they have a cataract. The most common cause of cataract is related to aging. Statistics have shown that most people age 70 and up are prone to having a cataract.

In an age-related cataract, the center of the lens gradually hardens and becomes cloudy, so your vision is not clear and you may not notice certain details of the object/person you are seeing. Here are common symptoms of cataract:

- A painless blurring vision
- Glare or light sensitivity
- Poor night vision
- Double vision in one eye
- Needing a brighter light to read
- Colors looking faded or yellow

By performing a thorough

eye examination, your ophthalmologist can detect the presence of a cataract. This will also allow the physician to eliminate any concerns or questions you may have pertaining to vision loss. The only cataract treatment is through surgery, but if it is not bothering you, then surgery may not be needed. It is also important to wear glasses or sunglasses that screen out ultraviolet (UV) light to slow the progression of a cataract. If you feel that you have these symptoms and are experiencing poor vision, you might want to schedule a visit to see your doctor today.

## SPINAL MUSCULAR ATROPHY AWARENESS

By: Lia Pelenato



Spinal Muscular Atrophy (SMA) is a neuromuscular disease characterized by degeneration of motor neurons, resulting in progressive muscular atrophy

(wasting away) and weakness. SMA effects can range from early infant death to normal

adult life with only mild weakness. The primary feature of SMA is muscle weakness, which is the loss of signals transmitted from the spinal cord. Many adults with SMA survive even into old age, depending on the severity of the disease. Although the muscles all over the body are weak, sensation and the ability to feel are not affected. It is also important that people understand how having SMA does not affect

the intellectual level and activity of a person. There are three types of SMA, and the most common form is Type 1, which affects about 70% of patients and it is the most severe. This is SMA Awareness Month, and we ask that if you are experiencing any symptoms (far left, box), please schedule an appointment with your doctor.



# FEMA MASS CARE TEAM By: Ernie Seiuli



**Members of the Special Needs community & FEMA team.**

A group of officials from the Federal Emergency Management Agency (FEMA) head office in Honolulu and Washington DC met with all private and government

agencies at the American Samoa Community College Faculty Lounge on August 4, 2010. Government and non-profit agencies met with FEMA officials in regards to improving services for the community, especially during pre and post evacuation plans. The officials' main agenda was to demonstrate how accessibility should be part of planning assumptions, and to emphasize that

discrimination against people with disabilities is prohibited in all aspects of emergency mitigation, planning, response, and recovery. The FEMA officials also highlighted how each agency is responsible for notification protocols, evacuation and emergency operation plans, shelter identification and operations, emergency medical care facilities and operations, human services, and other emergency response and recovery programs.

Agencies in attendance included the Faith based associations Catholic Social Services and Hope House, the American Samoa Volunteer Association (ASVOAD), Children & Families for Individuals with Developmental Disabilities

(CFIDD), government agencies such as the Office of the Governor Vocational Rehabilitation (OVR), and our own University Center for Excellence on Developmental Disabilities (UCEDD). The main UCEDD goal within the discussion was to familiarize agencies with the different communication and transportation needs, accommodations, support systems, equipments, and supplies that residents and individuals with disabilities need during an emergency or disaster. The meeting ended with local agencies (both government and non-profit) agreeing to meet in the coming weeks to formulate a coalition for the special needs community here in American Samoa.



# SPECIAL NEEDS COALITION By: Lia Pelenato



**Members of the SNP Coalition during the meeting at Homeland Security office**

As a result of the FEMA MASS care team meeting, members of various agencies within our government and non-profit organizations came together to collaborate on services that need to be provided for individuals with developmental disabilities in American Samoa.

The meeting took place on August 19, 2010 at the Home-

land Security conference room in Tafuna. The discussion focused on each agency providing a list of Durable Medical Equipment (DME) that is currently available/utilized by their clients, in the hopes of submitting a DME list to FEMA for stocked materials needed during a time of disaster. As a result, the Special Needs Population Coalition was formed and scheduled to meet on an annual basis each month to

discuss and update on any matters concerning policy, assistance and awareness and how to provide the necessary help to our people with special needs during a natural and/or man-made disaster in American Samoa.



# STOP THE SILENT SUFFERING

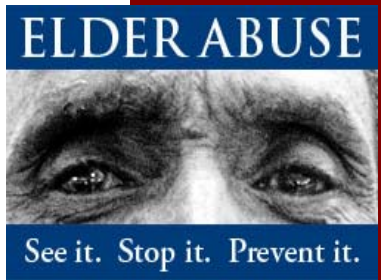
By: Lia Pelenato



Each year, many elderly fall victims to abuse, either physically, verbally or most often financially. There is a need to expose to the public the suffering that our elders are experiencing. June 15 of each year is the designated Prevent Elder Abuse Awareness Day, and purple is the awareness color. In the early morning of August 12, the UCEDD staff

joined with 400 other professionals around the world in a webinar conference about elderly abuse. During the webinar, we were introduced to various victims, all of whom have been suffering abuse at the hand of a caregiver or a family member. Since elderly care is the third fastest growing occupation in the nation, and requires only a minimal background check, most applicants are easily hired. There is a need to train paramedics, dispatchers and police officers on how to handle a 911

call for elders who need help/assistance. It is important to recognize abuse, since the abuser may be in the home or in proximity of the victim. Our Samoan culture and belief in the Lord has allowed us the privilege of treasuring our elders with love, respect and admiration. Samoans are known for their love of family and for accepting the wisdom of elders.



## PADD MEETING

By: Lia Pelenato

The office of Protection and Advocacy (P&A) held its annual Protection & Advocacy for Individuals with Developmental Disabilities (PADD) advisory council meeting on August 19, 2010 at 10:30a.m at their office in Tafuna. The meeting was conducted by Deputy Director Rev. Tinei Malepeai and various members of the council were present, including UCEDD Di-

rector Tafaimamao Tupuola and staff. The meeting also saw the introduction of the new manager for the PADD program, Mrs. Mi-Sook Save. The PADD program is under the office of P&A, which assures that persons with developmental disabilities (DD) receive care, treatment, and other necessary services that enable them to achieve their maximum potential. P&A also establishes and operates a system which coordinates, monitors, plans and evaluates services which ensure the protection of the legal, civil and human rights of persons with DD. During the meeting, the one issue on the agenda that brought about the most discussion was the acces-

sibility of services to children with DD at school. In the previous months, the office of P&A conducted a survey during their visits to our schools, and learned that most of our schools are not accessible and/or without access of services to children with DD. Plans are underway to request that the DOE Director address these issues and implement the necessary changes to accommodate students with DD who need access to proper education services and settings.



PADD program manager Mi-Sook, P&A Director Uta, and parent Lili'a Luavasa (right) during the meeting.



American Samoa Community College  
P.O. Box 2609  
Pago Pago, AS 96799

*If you would like to receive this newsletter in an alternative format, please call the American Samoa Community College UCEDD at: 699-9155 ext. 441 or 438*

**Please consider our environment before printing.**

## University Center of Excellence on Developmental Disabilities (UCEDD)

### OUR MISSION

*The University Center for Excellence on Developmental Disabilities (UCEDD) assures that individuals with developmental disabilities of all ages and their families participate fully in activities that will design and promote self determination, independence, integration and inclusion in all facets of life in American Samoa. The UCEDD will ensure the delivery and purpose of the Developmental Disabilities Act through culturally competent activities.*

[www.amsamoa.edu/academicssupport.htm](http://www.amsamoa.edu/academicssupport.htm)

### UCEDD STAFF DIRECTORY

#### **Ms. Tafa Tua-Tupuola**

UCEDD Director  
(684)699-9155 ext. 429  
t.tupuola@amsamoa.edu/tafaimamao@gmail.com

#### **Mr. Ernie Seiuli**

UCEDD Interdisciplinary Trainer  
(684) 699-9155 ext. 438  
e.seiuli@amsamoa.edu/ eseiuli@yahoo.com

#### **Mrs. Lia Pelenato**

UCEDD Trainer  
(684) 699-9155 ext 441  
p.pelenato@amsamoa.edu/ liapelenato@gmail.com

#### **Ms. Lesina Falaniko**

(684)699-9155 ext. 428

### ACRONYMS/MEANINGS

- ASVOAD:** American Samoa Voluntary Organization Active in Disaster
- DME:** Durable Medical Equipment
- CFIDD:** Center for Families of Individuals with Developmental Disabilities
- FEMA:** Federal Emergency Management Agency
- OVR:** Office of the Governor, Vocational Rehabilitation
- P&A:** Office of Protection & Advocacy
- PADD:** Protection & Advocacy for Individuals with DD
- SMA:** Spinal Muscular Atrophy
- SNPC:** Special Needs Population Coalition
- UCEDD:** University Center for Excellence on Developmental Disability
- UV:** Ultraviolet