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JUNE 2010 AWARENESS

- LUGARIC'S DISEASE
- CANCER SURVIVAL
- STROKE AWARENESS
- NATIONAL HIV TESTING
- CLEAN AIR
- BRAIN INJURY
- SPINA BIFIDA

AMYOTROPHIC LATERAL SCLEROSIS

By: Lia Pelenato

This June, American Samoa joins in the National efforts to support the Amyotrophic lateral sclerosis (ALS) awareness. There are a few of our local people diagnosed with ALS and this month we will join in support through activities and advertisements to raise awareness about this disease. It is a fatal progressive neurodegenerative disease caused by the degeneration of motor neurons, and affects nerve cells and the spinal cord. This disease is often called the Lou Gehrig's disease after the famous New York Yankees baseball player who was first diagnosed with ALS in 1939. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, patients in the later stages of the disease may become totally paralyzed. A-myotrophic comes from the Greek language.

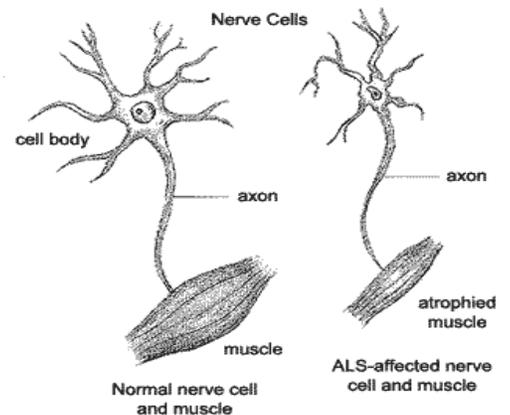
"A" means no or negative.

"Myo" refers to muscle,

"Trophic" means nourishment—"No muscle nourishment."

When a muscle has no nourishment, it "atrophies" or wastes away. "Lateral" identifies the areas in a person's spinal cord where portions of the nerve cells that signal and control the muscles are located. As this area degenerates, it leads to scarring or hardening ("sclerosis") in the region. As motor neurons degenerate, they can no longer send impulses to the muscle fibers that normally result in muscle movement. Early symptoms of ALS often include increasing muscle weakness, especially involving the arms and legs, and difficulty with speech, swallowing or breathing. When muscles no longer receive the messages from the motor neurons that they require to function, the muscles begin to atrophy (become smaller). Limbs begin to look "thinner"

as muscle tissue atrophies. It is known that ALS can strike anyone at any time. However; it is extremely rare in children. At first, symptoms of



Here is a picture of Nerve Cells. You can actually see the difference between a healthy muscle and a muscle with ALS

ALS may be barely noticed. However; over time the disease worsens as nerve cells die and the muscles they control stop acting and reacting correctly. Here are symptoms for ALS or Luga-ric's disease:

- Muscles in the arms, shoulders and tongue may cramp or twitch
- One or more limbs may lose strength
- You may become fatigued
- Feet and ankles may become weak, so walking may become clumsy & feet drags
- Swallowing, speaking or breathing is difficult

Symptoms of ALS

- Twitching
- Cramping
- Stiffness of muscles
- Muscle Weakness
- Slurred and nasal speech
- Difficulty chewing or swallowing

A WALK FOR PELE LANGKILDE

The morning began with gray skies and rain, but that did not deter over 200 members of the community from coming out early Saturday, June 26th, 2010 to show their love and support for Pele Langkilde, who has been stricken in the prime of life with the mysterious and yet incurable disease called Amyotrophic Lateral Sclerosis (ALS). Once again, ALS is a disorder in which there is progressive degeneration of motor nerves in the brain and spinal cord leading to paralysis and death, typically within three to five years.

Organizers of this event were Dr. Lina Scanlan, Tony Langkilde, Pastor Vickie Haleck, and Juliette

Parker. It has been a long journey for Pele and her family; for 14 years they have lived with a disease that most do not survive after just one or two years.

The main reason for the walk was to raise funds to help with Pele's medical costs. Pele is experiencing problems with covering her medical costs as she is only receiving social security.

The fundraising event was not only a walk, but the participants also helped clean up the environment. Pele Langkilde has three girls and one son, Tautai, who is currently serving his country in the U.S. He has pledged a portion of his pay to the ALS Foundation, in hope of them finding a cure.

The walk will consistently take place every year to assist the family with their finances, as well as to donate a portion of the proceeds to ALS research on behalf of Pele and American Samoa.

The event concluded with refreshments, music, and entertainment by the family and friends of Pele.



The Long Journey - Part I

When the American with Disabilities Act (ADA) was signed into law in 1990 by President George H.W. Bush, it promised to be a vital means of protecting the interests of people who were treated unfairly because of their disability or perception of a disability. In fact, it has been very successful in opening doors to people with a wide variety of disabilities. Employers cannot ask in advance of hiring whether you have a disability; the physical world is more accessible; and you cannot be excluded from participation in public activities and facilities because you have a disability. You may ask for an accommodation in the workplace if you believe you need it to do your job. Most importantly, people with disabilities like diabetes, cancer and other conditions recognize that they are entitled to equal protection of the law, and are

increasingly seeking to protect their rights. The general public believes in the principle that people should be hired based upon their ability to do the job at hand, not on the basis of preconceived notions about people with disabilities. But a major problem was also brewing over the first 15 years of ADA implementation. Federal courts were increasingly holding that people with conditions like diabetes and epilepsy, who might take medication, or who might be doing well enough to manage daily life in between seizures or insulin shots, were not covered by the law, even if they had faced discrimination because of their condition. A series of Supreme Court decisions severely narrowed who was covered by the law. Much to their surprise, most people with epilepsy who went to court to allege employment discrimination found they were not pro-

tected by the ADA.

On September 25, 2008, President George W. Bush signed into law the Americans with Disability Act Amendments Act of 2008 (ADAAA). This law restored the rights of persons with disability to be protected under the ADA and to be treated fairly by employers. Once again, people with any type of disability should no longer have to worry they will not be protected by law from discrimination in the workplace. The ADAAA makes it clear that Congress intends, as it did originally, for people with conditions such as epilepsy, diabetes, cancer and multiple sclerosis to be covered by the law and protected from discrimination on the basis of their disability.

“Disability is a matter of perception. If you can do just one thing well, you’re needed by someone”.

By: Martina Navratilova

FAIPULE CORNER

By: Lia Pelenato



Rep. A. Soliai, Tafa and M.J. participating during the DD Awareness Wave in March

In a time when many government officials are experiencing a crisis due to so many unemployed locals, a couple of government officials – Representatives to be exact—stay true to the meaning of service to our local community. The Developmental Disability (DD) Community has

been blessed to have the support of our local Representatives who have been adamant in pushing policies for equal opportunities for individuals with developmental disabilities as well as our children with DD. During the past six months, we have witnessed a tre-

mendous effort and outpouring of support by our local Representatives in participating in our local events and activities to promote the pursuit of self determination for our children and people with DD.

It is important for Individuals with DD to attest to the influence and countenance of District Representatives in the course of achieving quality services and pursuing individuality within our government and communities. 2010 began



Rep. Vaiausia during the Tri-Agency meeting

with a full schedule of activities every month in the first-half of the year, Representatives have been promoting valuable services for people

with DD. Not only are our Representatives attending events, a few of them (Rep. A. Soli'ai and Rep. H. Sesepasara) are active members of the advisory councils to DDPC and UCEDD programs. Within on our advisory councils, these Reps provide insights and recommendations on local and federal policies that affect or change the benefits of individuals and children with DD. Fa'afetai ma fa'amalo le lagolago!



Representatives Satele and Sani-toa during the Deaf Awareness Opening in May 2010



2010 DISABILITY & HEALTH MEETING

The 2010 Disability & Health Conference was held in Atlanta, Georgia in May. The aim was to timely provide health statistics, research findings, and health promotion information to individuals with disabilities and their families, as well as professionals and policymakers. The conference's main agenda was to highlight the gaps and disparities between people without disabilities and people with them.

People with disabilities have:

- Less health insurance coverage and use of the health-care system
- Higher rates of chronic conditions—diabetes, depression and

sadness, elevated blood pressure and block cholesterol

- Lower rates of social participation—regular education classrooms & high school completion, employment and social events
- Lower rates of recommended health behaviors.
- Less availability and accessibility of public and private facilities

The meeting also emphasized how to improve of the availability and accessibility of medical facilities, government offices, shelters, and transportation for people with disabilities, and the inclusion of modified equipments in those facilities. In American Samoa alone, more than 50% of govern-

ment and private offices, and public facilities are not compliance to ADA Act, and are very difficult for people with disabilities to use. The meeting's main goal was to make sure that all 50 States will place more emphasis on making facilities more accessible for people with disabilities. American Samoa should take into consideration improving our facilities to make them more accessible for people with disabilities.



“People with disabilities have abilities too and that is what this course is all about—making sure those abilities blossom and shine so that all the dreams you have can come true”.

By: Mary McAleese



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Please consider our environment before printing.

University Center of Excellence on Developmental Disabilities

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

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ACRONYMS/MEANINGS

- ADA:** Americans with Disabilities Act
- ADAAA:** Americans with Disabilities Act Amendments Act
- ALS:** Amyotrophic Lateral Sclerosis
- ASCC:** American Samoa Community College
- ASL:** American Sign Language
- DD:** Developmental Disabilities
- DDPC:** Developmental Disability Planning Council
- P&A:** Office of Protection & Advocacy
- UCEDD:** University Center of Excellence on Developmental Disabilities
- US:** United States