

COMMON CHILDHOOD AILMENTS MAY NOT BE NORMAL.

There are early warning signals that often are dismissed as common childhood ailments, but as we teach our community, physicians and other professionals who work with children, what to look for and how these symptoms present, we can begin saving lives.

Many boys between 4 and 7 years of age are clumsy, have difficulty staying focused, wear eyeglasses, and are born with undescended or underdeveloped testicles. However, if a child has presented with even one of these indicators, further investigation by their physicians should be obligatory.

It is imperative that there is an open line of communication between the Pediatrician, Ophthalmologist, Urologist, parents and teachers. If headaches are involved, a Neurologist and an Endocrinologist should be consulted as well.

Of nearly 1600 boys diagnosed through Kennedy Krieger, ALD and AMN was traced to over 20,000 other family members.

A family history should be conducted to determine if there is evidence of any undetermined illnesses or deaths, MS, debilitating arthritis, or degenerative disc disease. This research should include all family members; boys, girls, men and women.

If there is even a remote possibility that ALD may be the cause, then a test kit to measure the VLCFA's can be ordered by contacting Kim Hollandsworth (hollandsworth@KKI.org) of the Kennedy Krieger Institute. The child's blood can be drawn at a local lab and shipped directly back to KKI for analysis. Everything is included in the kit and the cost is only \$160.

By the time a child presents with symptoms, the disease is too far advanced for treatment.

COMMON SYMPTOMS

- Visual disturbances, Strabismus
- ADD/ADHD, losing information
- Behavioral problems
- Seizures
- Eye pain/Migraines
- Recurring Viral Infections
- Lethargy, tires easily
- Clumsiness
- Undescended or underdeveloped testicles
- Tanning or bronzing of the skin

EMERGENCY SYMPTOMS

- Acute adrenal insufficiency; vomiting, headache, unconsciousness or coma
- Mimics Spinal Meningitis

Another common misdiagnosis is Addison's disease, an illness that affects the Adrenal gland. 50% of males with Addison's will also have ALD or AMN, however, most Endocrinologists do not automatically test for it up on diagnosing Addisons. AMN is considered to be the adult onset of ALD, short for Adrenomyeloneuropathy and is more prevalent among males than ALD.

In AMN, the myelin sheath in the brain is usually not affected, although it can be, but instead involves the myelin sheath in the spinal cord. Symptoms can be progressive with stiffness and weakness in the legs, abnormalities of sphincter control, sexual disfunction, incontinence, and depression. Many adults, men and women, are misdiagnosed with MS, debilitating arthritis and degenerative disc disease.

As with ALD, there is no known cure for AMN and treatment options are few. Most people learn to live with their disabilities and get some relief through pain medications.

Statistics now show that anyone who has the ALD gene will be affected at some point. Although a mere 2% show symptoms by age four, it goes up to 33% by age ten, 50% by age twenty and 98% by the age of fifty-two.

Mission Statement

Fighting Illness Through Education by bringing about awareness to our community and our medical professionals about ALD and AMN.

We aim to take away the mystery and replace it with knowledge and understanding of this devastating disease that is affecting thousands of families.

Sawyer's courage set an example for us all. One that will lead us forever forward in our own goals and desires to persevere. We will remember him fondly and continue our fight against Adrenoleukodystrophy in his honor.

NEW STUDY SHOWS USE OF LORENZO'S OIL PREVENTS ONSET OF DEBILITATING PEDIATRIC NEUROLOGICAL DISORDER

(Released from Kennedy Krieger Institute, July 11, 2005)

The study followed 89 boys, ages 7 and younger, who tested positive with X-ALD. All patients had a normal brain MRI and showed no neurological signs or symptoms of ALD prior to the study. Treated with Lorenzo's Oil and a moderately restricted diet, over a period of 7 years, 74% of the patients showed no signs of disease progression, demonstrating a significant preventive effect.

Let's Fight against the devastating affects of Adrenoleukodystrophy by understanding the importance of early detection and educating our community and medical professionals. Janis Sherwood/Founder

Tax Deductible donations (Tax ID #56-2467099) to help spread awareness can be mailed to:

Fight ALD
P.O. Box 3318
Vista, CA. 92085
or made on-line at:

www.FightALD.org

AdrenoLeukoDystrophy

This genetic disease is caused by a mutation on the X-Chromosome, which prevents the body from producing a much needed protein to break down the Very Long Chain Fatty Acids (VLCFA's) in the blood stream. These VLCFA's accumulate in the Adrenal Gland and eventually in the Myelin of the brain causing rapid neuro-degeneration. Mothers, who are carriers, often pass it to their sons who will have a 50% chance of presenting with symptoms. Their daughters will also often be carriers. Affected men will pass it on 100% to their daughters. In many cases, there is no previous family history of ALD.

Early Diagnosis is KEY in treating Adrenoleukodystrophy!

Symptoms are often misdiagnosed as Viral Infections, ADD/ADHD, and/or Migraine Headaches, and usually appear between four and seven years of age. Other symptoms can be vision problems including Strabismus, underdeveloped or undescended testicles, seizures, writing and learning difficulties or forgetting information that they previously had known.

These symptoms are often masked by the child's amazing ability to compensate.

Treatments

Steroids can support the Adrenal insufficiency, but the only known treatments once a child is symptomatic is a Bone Marrow or Umbilical Cord Blood transplant. But, all too often, the disease is too far advanced for a successful outcome.

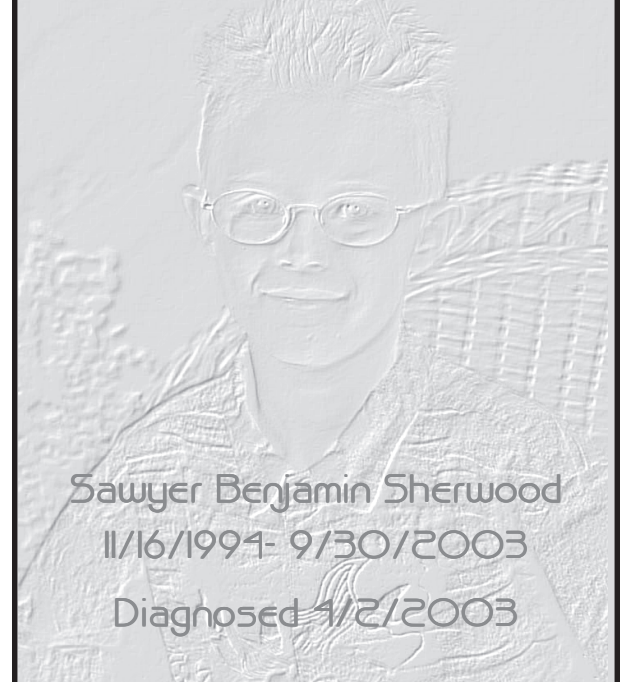
Another common misdiagnosis is Addison's disease, an illness that affects the Adrenal gland. Statistics have shown that 50% of males that had been previously diagnosed with Addison's will eventually be diagnosed with ALD or AMN.

ALD usually leads to a vegetative state within 6 months to 2 years after diagnosis, followed by death.

www.FightALD.org
Adrenoleukodystrophy
Fighting Illness Through Education
P.O. Box 3318, Vista, CA 92085

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In honor of



Sawyer Benjamin Sherwood

11/16/1994- 9/30/2003

Diagnosed 1/2/2003

X-Linked Adrenoleukodystrophy,
a genetic disease that affects

1 in 17,000 boys,

is usually misdiagnosed or goes undetected by medical professionals, until the disease is so advanced that their chances for treatment or survival are minimal.

www.fightald.org