

# Doctor calls for screening center

By CINDA ARNOLD  
Of the Emerald

Lee Neidengard, a physician and medical researcher, called for a screening and counseling program for victims of Tay-Sachs Disease, a little-known disorder affecting mostly Jewish persons, when he spoke Wednesday in the EMU.

Tay-Sachs Disease causes progressive degeneration of the nervous system, blindness, mental retardation, paralysis and

death, usually within five years of birth. The genetic disease affects Ashkenazi Jews (whose ancestors came from Central Europe or western Russia) 100 times more often than it affects non-Jews.

Neidengard, graduate of Johns screening center in Oregon to identify and counsel carriers of the recessive gene responsible for Tay-Sachs.

According to Neidengard, the steps to setting up a screening and counseling center are:

—Find leadership and support within a community.

—Devise publicity for the program.

—Enlist a dedicated corps of volunteers.

—Employ a medical center which can do the bio-chemistry research required for the testing.

—Have a place to confidentially keep records and,

—Provide counseling for known Tay-Sachs carriers.

The City of Portland tried to set

up such a program two years ago but didn't provide counseling and the program failed, Neidengard says.

Testing for the disease is done through blood sample. If a person is found to be a carrier, white blood cells are tested to verify the results.

The blood test costs \$17.50 per person at the University lab. Under an organized program the cost would decrease to \$10 to

\$12, says Neidengard.

Approximately one in 30 Ashkenazi Jews carries the Tay-Sachs gene. When both parents are carriers, their children face a 25 percent chance of suffering from Tay-Sachs.

Neidengard, a graduate of Johns Hopkins School of Medicine, is currently a pediatrics and genetics specialist at the University Health Sciences Center in Portland.

## Disability funds slim in Oregon

The Social Security disability program proved to be an obstacle to a large number of people seeking assistance from U.S. Rep. Jim Weaver this past year, says Weaver's staff.

More than 5,000 people turned to Weaver for aid in their struggles with the federal bureaucracy, according to staff members.

The largest problem, they say, is that the Oregon disability program isn't getting a fair share of federal Social Security funds.

Because of the lack of funds, Oregon is stiffening program requirements, causing extreme difficulty for disabled Oregonians to receive benefits says the staff. Program funds are allegedly being drained by New York, New Jersey, Pennsylvania and California.

"Many Oregonians with legitimate claims are being turned down on the initial stages of the program," says Peter Defazio, a Weaver staff member.

A typical Social Security denial, according to Defazio, concerned a 60-year-old construction worker with an arthritic condition and who had had two recent heart attacks. He was denied disability and was told to find different employment with his seventh-grade education and physical handicaps.

After reapplying for disability, his reconsideration was lost by the department. He was also denied his union pension since it was contingent upon receipt of the disability payment.

Defazio says the man has been battling with the Salem Social Security Office for six months.

Initial application for the program may take two to three months. If the claim is not favorable, it may be reconsidered, a process that may take six weeks, says Defazio.

Most claims do not reach this stage, he says, but those that do have a better chance of approval. Persons who find it necessary to appeal may have to wait another six months before their cases are heard in court.

Last year 54 percent of the cases turned down during the initial determination stage were later granted after they were heard in the courtroom, Defazio says.

According to him, "We are not getting fair treatment like many other states; we must have uniform national Social Security standards. House Bill 8076 coordinated by James Burk, plans a similar review on the national scale to balance the program."

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