

Woman tracks down cause of her paralysis

She hopes to help build new awareness of rare syndrome

By Jim Moore
of the Daily Courier

More than half a century later and after countless frightening episodes, Susan Hunter is now convinced she knows why she passed out twice when she was 11.

HUNTER It's the same reason the 62-year-old Grants Pass woman has had repeated experiences of strange and scary drastic muscle weakening or tightening and even episodes of complete paralysis.

After disappointing experiences with multiple care providers, Hunter took it upon herself to investigate her symptoms and came to a startling conclusion — that she suffers from Andersen-Tawil syndrome, a form of periodic paralysis that is a genetic disorder so rare that only about 100 cases of it have ever been reported.

Last month, after undergoing dangerous and grueling procedures, she said she finally convinced medical personnel of her malady.

Hunter is certain there are a lot more people in the world with Andersen-Tawil syndrome or other forms of periodic paralysis than the few who have been reported. She said, for example, that several people in her family may be afflicted.

Now she wants to educate the local medical community so it can recognize and understand the strange disorder that afflicts her.

There's no better way to do that than to recount a few of Hunter's tribulations over the



TIMOTHY BULLARD/Daily Courier

Susan Hunter, diagnosed with possible Andersen-Tawil syndrome, uses her laptop to do research. She is also writing a book about her disease.

formed to leave when she was 50 because of her ailments.

Over the years, Hunter endured the strange episodes and felt them increasing. In her 40s she was diagnosed with fibromyalgia and for several years she assumed that was what ailed her. But then her legs got weaker and her muscles experienced tightening so a physician sent her to a neurologist.

She underwent a battery of tests and was misdiagnosed with a plethora of scary diseases before it was determined she probably had multiple sclerosis.

"I went with that for 10 years," Hunter said. However, her condition continued to worsen and she started having heart problems. She had procedures. Was hospitalized. Made trips to emergency

rooms. And she had more and more tests that led to more frustrations because the tests kept coming back normal and it seemed to her that doctors thought she was being hysterical.

She and her husband Calvin moved from Utah to Grants Pass in 2005 and one of many local care providers she's seen locally referred her to Oregon Health and Science University in Portland where it was determined Hunter did not have multiple sclerosis.

In essence, that left her back at square one. So she took matters into her own hands. "One morning I searched the Internet under periodic paralysis," Hunter said. "Everything I read made me believe this is what I have."

She learned that potassium shifting into her muscles caused the paralysis and that virtually all over-the-counter medications exacerbate her condition. She and Calvin created a pH balanced diet for her and concluded she needed to be on oxygen at all times. Doing those things and avoiding the over-the-counter medicines have made a big difference in her life.

She believes that's the case most everywhere and is one reason why there have only been about 100 reported cases of Andersen-Tawil syndrome. She's hoping her story will create more awareness about Andersen-Tawil syndrome.

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Reach reporter Jim Moore at 541-474-3721 or jmoore@thedailycourier.com

And she tries to maintain an even keel. "I can't do anything that will get my adrenaline going," she said.

"I have not had an episode during the days since I started this," Hunter said.

Just as she was able to find ways to improve her condition once she knew what she was facing, Hunter was also able to look for a medical professional who understood periodic paralysis.

Her queries led her to some local specialists who conducted the proper tests that led to the astonishing and rare diagnosis.

Along the way Hunter learned that almost none of the nearly three dozen medical professionals who treated her were aware that such a malady even exists.

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Sewing Guild chapter has new co-leaders

Leslie Momyer and Susanne Harmony are the new co-leaders of the Grants Pass Neighborhood Group of the Medford chapter of the American Sewing Guild. They are working together to plan the group's future events.

These include a new members tea in Rogue River May 7, which is open to all members who have joined the American Sewing Guild within the last six months and to long-time members. Representatives from each of the 16 neighborhood groups in the Medford chapter will be on hand to introduce new members to the different sewing, crafting, quilting, embroidery, doll making, knitting and dressmaking programs available.

The local group also plans to celebrate national sewing month in September with a visit to a local retirement home, spending the day replacing buttons, repairing rips or hemming clothing of the residents.



Leslie Momyer, left, and Susanne Harmony are the new co-leaders of the Grants Pass Neighborhood Group of the American Sewing Guild.

Two Grange halls serving breakfast

Breakfast is being served Sunday at two Josephine County Grange halls.

The Rogue River Valley Grange, at the corner of G Street and Lincoln Road in Grants Pass, is serving breakfast from 9 a.m. until noon.

The menu includes plain and blueberry pancakes, eggs any style, bacon or sausage and beverages.

The cost is \$5 for adults, \$3 for children 12 and younger. Bring a canned food donation and get 50 cents off the cost of the meal.

The Illinois Valley Grange, 3763 Holland Loop

Road in Cave Junction, is serving an all-you-can-eat breakfast from 8 a.m. until noon.

Members of Boy Scout Troop 880 will be helping serve to raise money for their troop activities.

The menu includes butter-milk and blueberry pancakes, French toast, hash browns, biscuits and gravy, eggs any style, ham, sausage links, bacon and fruit served with a choice of beverage.

The cost is \$7 for adults, \$4.50 for children 4 to 11 and \$1.50 for toddlers 3 and younger.

Bring a nonperishable food donation and get 50 cents off the cost.

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Grants Pass Community Sewing is also part of the Grants Pass Neighborhood Group. This program, led by Carol Stocking, does sewing for various community agencies and for military troops.

The Grants Pass Neighborhood Group meets on the fourth Tuesday of the month from 1 to 3:30 p.m. at Oregon Health Management Services, 128 S.W. 1 St. Special programs are planned each month, including fashion sewing star Lyla Messinger in May, decorating diva Pam Damour in August and fiber artist Donna Greenwald in October.

For more information about the group, contact Momyer at 541-476-6888 or Harmony at 541-226-2194.

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