

Doctors converge in Salem

A fibromyalgia conference draws experts from afar

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Imagine a disease that causes intense pain that can be felt from head to toe.

Imagine not being able to pinpoint the pain or symptoms for doctors.

Imagine being told the disease is psychological; it's all in your head.

Welcome to the debilitating world of fibromyalgia syndrome, or FMS.

"Fibromyalgia is complicated and frustrating," said Dr. Robert Bennett, the professor of medicine and nursing research at Oregon Health & Science University in Portland, after moderating the first part of a two-day discussion about FMS at the Salem Conference Center. The conference continues today.

Bennett was joined by doctors from around the world. All are at the forefront of research into a disease that 30 years ago was not even recognized as a condition.

Their goal: to tie together the many threads of research into a cohesive conversation that will lead to understanding of, better treatment of and a cure for FMS.

The importance of the discussion about research in Salem this weekend might not be realized for months or even years, some attendees said. But some FMS sufferers and patient advocates said that without scientists getting together to share their findings, good treatments and a cure remain decades off.

—About 75 people gathered in the Willamette River Room on the second floor of the Salem Conference Center. By all appearances, the quiet and dignified group of researchers, scientists, neurosurgeons and FMS patients did not seem like much. But the conference, sponsored by The National Fibromyalgia Research Association, was significant for the Salem Conference Center.

"I've lived here 30 years," said Rae Marie Gleason, the executive director of the National Fibromyalgia Research Association, which has its headquarters in Salem. "It's nice to have a conference center and hotel like this. It makes it nice for the doctors as well as patients who travel here."

Gleason said these conferences are held every two years, usually in Portland, where there is space for attendees to stay and hold meetings.

Gleason said the amenities, including nice hotel rooms, fine dining and other activities, make Salem a good place to hold conferences with out-of-town guests.

Sabrina Johnson, who came from Chicago to attend the conference, was a police officer when she found out she had fibromyalgia. The disease took away her ability to perform her job because of an intense medicine regimen.

"I get to hear the scientific findings before patients hear it," Johnson said of why she appreciates being in the company of some of the leading researchers of a disease she shares in common with 6 million Americans. "It's nice to hear fresh information."

After leaving her job as a police officer, Johnson started an organization called FACES, or Fibromyalgia Association Created for Education and Self-Help.

"As you can tell, I'm African-American," Johnson said. "So many minorities don't have access to good medical care."

Johnson advocates for minorities, especially those with cultural taboos that make it difficult to treat or even recognize FMS.

The National Fibromyalgia Research Association was begun 14 years ago by Jack Scott and Gleason as an effort by the Salem businessman to learn about the disease that afflicted his wife, Pam Scott.

Steve Johnson, president of VIP'S Industries of Wilsonville, the private company that administrates the Salem Conference Center, said that the conference is a great opportunity to draw in researchers and scientists from all over.

"We're happy to have them," Johnson said. "I'd like to commend Jack and Pam Scott for bringing all these people together."

The Salem Conference Center is in the midst of a busy conference month. Including the 100 or so registered attendees of the fibromyalgia conference, Johnson said, 4,485 people were projected to attend conferences and seminars in September alone.

Gleason said she plans to hold the next conference in Salem.

"We've put together scientists who may never have met," Gleason said about the conference. "Discussing fibromyalgia like this eventually will filter down to something that will help patients."

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