

# Speaking Out

By ELAINE EVERHART

## For Quality Care



Elaine Everhart after speaking at the Governor's public hearing.

I cannot hold the newspaper in front of my eyes, as you are, to read a guest opinion. I can't raise my arms. I have a rare disease that is turning my soft tissue into bone. My joints are fusing together. Very little of me moves. Anything that I do, I must have help with. I can't step. My jaw is clenched, permanently fused since 1975. I have trouble breathing. My wheelchair is specially made so that I can "sit" in it standing up.

My disease, called fibrodysplasia ossification progressiva (FOP), sends deranged genetic instructions that slowly displace muscle, tendons and ligaments, locking me inside a rigid skeletal encasement. It afflicts one in two million births. About 300 cases are documented worldwide with about half of them in the United States. I am one of two persons in Oregon with this disease; a young woman of about 19 in Klamath Falls also has FOP.

I've had this disease all my life. Next week (February 13), I turn 55. But, I was active. I loved to ride horses. I could drive cars up until about 10 years ago. I've run my own business. I was married for 31 years; with my husband, I hunted and fished. I was an office coordinator at my church, putting in as many as 60 hours a week.

Now, activities that may take

you five minutes will take me 25. I need caregivers 24/7. Five of them work shifts to help to do the things a healthy person does almost without thinking. Whether it's bathing, using the toilet, getting in and out of bed, dressing or eating, I need someone to help me do it.

The lives of real people will be impacted by the decisions the Legislature makes — or doesn't make — over the course of the special session that begins on

February 8. The state budget is in deficit by \$850 million, a number beyond the comprehension of many of us. But, for me, and hundreds of thousands of others just like you, that number determines the level of our safety, our health, our education and our independence.

These programs enable elderly Oregonians to continue to live at home. Another one gives teenaged girls a safe place to reside as they turn their lives around. Some provide temporary assistance for needy families. Working Oregonians need care for illness, injury and catastrophe.

We hear talk about bringing government closer to the people. Well, it can't get any closer to me. The cuts proposed for the state budget will affect me where I live.

The cuts will not reduce fat. They will eliminate muscle, bone and brain. Our lawmakers need to see people — not just numbers — on the spreadsheets in front of them.

Legislators and the Governor have a big task. Now is not the time for them to ignore or abandon the people our government was put in place to serve.

**EDITOR'S NOTE:** To learn more about fibrodysplasia ossification progressiva (FOP), go to [www.ifopa.org](http://www.ifopa.org).

# Initiatives

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ment, pushing many of their costs — especially those of k-12 schools — onto the state government. This measure would make it difficult to meet the needs of Oregonians, including those it acquired from local government in the past 12 years.

Since Measure 5's passage, state government has assumed more and more of the cost of k-12 public education, after the property tax — which largely was used to pay for local schools — was capped. Additionally, ballot measures approved by the voters can take huge bites out of the state government budget. For example, Ballot Measure 11, approved by the voters in 1994, enacted high mandatory minimum sentences for a long list of felonies. As a consequence, with forecasts that predict the prison population will exceed 14,000 by 2008, the state has embarked on an ambitious — and expensive — prison construction program.

If the growth of the state budget is limited without regard to demand for services, costly voter-approved initiatives or imbalances between revenue and expenditure, rising costs in one part of the budget must come from another.

Building new prisons, for example, would have to be paid for with money now going for education, human services and employee pay and benefits.

Together with the Oregon AFL-CIO, SEIU Local 503, OPEU is also assessing several other potential pro-active measures. One would require the state government only to contract with vendors who agree to certain standards of employment, one that prohibits a public employer from using public funds to influence the decision of employees about union organizing, and another to increase the minimum wage to \$6.90 during 2003 and that it be increased annually to keep up with inflation.

At the same time, the Union is keeping an eye on some other harmful initiatives that could wind up on the ballot, including a measure contracting out the Oregon Liquor Control Commission and another of Lon Mabon's perennial measures attacking gay and lesbian rights. ●