

Ann prays for breakthrough

By AMY HALLETT

CLAREMONT resident Ann Jones is forever hopeful of a cure for Huntington's disease and is remaining optimistic that a new clinical trial will bring this dream a step closer.

Mrs Jones, the Huntington's WA chair and International Huntington's Association president, lost her husband Llewelyn to the disease three years ago.

Her two daughters Tracey and Julie have also tested positive to the genetically inherited condition, which mostly affects adults aged 30 to 50.

Each child of an affected parent has a 50 per cent chance of inheriting the defective gene of the genetic brain disorder, which results in motor cognitive and behavioural signs and symptoms, and eventually leads to death.

Symptoms include jerking, difficulty swallowing, depression, memory loss, irritability, speech changes and personality changes.

Mrs Jones said she had noticed slight tremors and sudden movements along with strange reactions before her husband was diagnosed with HD.

"When we danced he was out of step. We had been married for more than 40 years. I only realised years later," Mrs Jones said.

"I am ever hopeful of new treatments and the ultimate cure and I believe we need to become more proactive to ensure these are provided.

"The day-to-day challenges of living with the disease are enormous, not only for the person with it, but also their families and their community.

"It's by far the most challenging thing I've been through.

"We do know what's around the corner but there is always the unexpected."

A study drug known as PBT2 has been shown to improve motor function and control, increase life span and reduce the amount of brain cell degeneration in mice, along with a small group of patients with Alzheimer's disease.

Researchers are investigating whether the drug will have similar effects with HD patients.

An international clinical trial assessing the effect of PBT2 on patients with early to mid-stage HD is underway in Perth and the Neurodegenerative Disorders Research needs participants.

Mrs Jones has encouraged participation in important trials, such as this one, so the outlook for Huntington's families and future generations was more optimistic.

To register call 6380 2255 or email enquiries@ndr.org.au.



Ann Jones... hoping for a breakthrough.
Picture: Andrew Ritchie d385378