23 August 2009

More Support for Machado Joseph Disease Sufferers

Minister for Children and Families Malarndirri McCarthy today signed a Memorandum of Understanding with other partners to provide support to sufferers of Machado Joseph Disease.

“Machado Joseph Disease (MJD) is debilitating illness that affects individuals, their families and carers in communities across the Top End of the Territory,” Ms McCarthy said.

“Sufferers experience a reduced quality of life with symptoms including reduced mobility, impaired speech and reduced capacity for self-care.

“Research has helped health professionals and families better understand the genetic basis of the disease affecting families at the Angurugu, Yirrkala and Galiwin’ku communities.

“The MJD disease tragically has an ‘anticipation effect’ where children develop the disease around eight years earlier than their affected parent.”

The MOU was signed today at Groote Eylandt between the Anindilyakwa Land Council, the Machado Joseph Disease Foundation, the East Arnhem Shire Council, the Australian and NT Governments and is designed to ensure cohesive service delivery.

“It is imperative we have a collaborative approach to the delivery of MJD support services to enhance the well-being of individuals, families and carers,” Ms McCarthy said.

“It is also important we establish a process for sharing MJD information in relation to research, prevention and best practice treatment options.

“Program funding will see the supply and installation of appropriate adaptive equipment to individuals’ homes as well as community facilities.

“It will also work to increase respite trips for MJD clients and carers along with a greater number of specialists’ visits to Groote Eylandt.

“This is a unique program that will ensure service delivery is client centred and sensitive to local needs.”