

Media Release

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John Howard & Sydneysiders set world record at *The Big Bed-Down at Bondi Beach for National Stay in Bed Day*

Two hundred people set a world record for the most people in the world's biggest bed at The Big Bed-Down at Bondi Beach for National Stay in Bed Day on 22 August in aid of mitochondrial disease, a debilitating genetic disorder that robs the body's cells of energy.

Sydneysiders exhausted from the election snuggled up in the 50m-wide sand bed, enjoyed coffee, croissants and newspapers, and were entertained by singing and commentary from event ambassador, actor John Howard (*Packed to the Rafters*), who has three friends with mitochondrial disease.

People around the country were sponsored to lie back and relax on National Stay in Bed Day to raise funds for mitochondrial disease, which affects up to 90,000 people and is potentially fatal yet has few effective treatments and no cure.

Mito disease can damage the muscles, brain, heart, liver, ears and eyes. Sufferers often experience muscle weakness and fatigue, and need to rest and "recharge their batteries" in bed or in a wheelchair.

AMDF chairman Doug Lingard, whose daughter Rose has mitochondrial disease, said money raised from Stay in Bed Day would fund research into better diagnosis, effective treatments and a cure for the disorder.

There are also plans for a national patient registry to enable better care, help diagnose family members and aid genetic counselling for prospective parents.

"Patients are often misdiagnosed or endure a merry-go-round of tests over months or years before being diagnosed with mito disease; even then there are few targeted treatments and much uncertainty about the progression of the disease in individual patients," Dr Lingard said.

"We were delighted when last year's inaugural Stay in Bed Day raised sufficient money to fund three PhD research scholarships at leading Australian medical facilities. These and other initiatives give sufferers and their families hope for the future, but there's a long way to go," he said.

Mitochondrial disease was assumed to be rare but it is now known that 1 in 250 people are likely to carry the genetic changes that can cause the disease; multiple family members are often affected.

Mitochondrial disease impairs the "batteries" in our cells that produce 90 per cent of the energy needed to function. Depending on which organs are affected, sufferers can lose their sight or hearing, be unable to walk, eat, or talk normally, have strokes or seizures, or develop liver or heart disease, diabetes, or respiratory or digestive problems.

For information, photographs and interviews with John Howard, Stay in Bed Day/AMDF representatives and people affected by mitochondrial disease, contact:

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