

Media Release

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National Stay in Bed this Sunday 22 August to Help Beat Serious Genetic Disease

It's National Stay in Bed Day this Sunday 22 August, when people around Australia will lie back and relax to help beat mitochondrial disease, a debilitating and potentially fatal genetic disorder that robs the body's cells of energy and can damage the muscles, brain, heart, liver, ears and eyes.

There are few effective treatments and no cure for mitochondrial disease, which affects children and adults. Sufferers often experience muscle weakness and fatigue, and need to rest and "recharge their batteries" in bed or in a wheelchair.

To help sufferers get out of bed, Australians are being sponsored to stay in bed on 22 August or sponsoring others via stayinbedday.org.au, hosting a pyjama party or 'bed-down', or donating to the Australian Mitochondrial Disease Foundation at amdf.org.au.

Sydneysiders also have the option of snuggling up with hundreds of others at *The Big Bed-Down at Bondi Beach* from 10-11am (BYO pillow, towel and teddy bear) in a world record attempt overseen by event ambassador and actor John Howard (now in 'Packed to the Rafters').

Fellow ambassador, comedian Julia Morris, will bed-down Hollywood style in Los Angeles in support of close friends whose two young boys suffer from mitochondrial disease.

Research shows stay-in-bedders are most likely to catch up on beauty sleep this Sunday, with 46.6 per cent of respondents to the Bedroom Secrets Survey for the Australian Mitochondrial Disease Foundation (AMDF) nominating sleeping in as their favourite bedtime activity on weekends.

About one in four (26.7%) stay-in-bedders are expected to indulge in "love and cuddles", 16.3 per cent will read books, magazines or newspapers, and 11.1 per cent will watch TV or DVDs. An enterprising 1.5 per cent of people plan to direct the household chores from bed.

AMDF chairman Doug Lingard, whose daughter Rose has mitochondrial disease, said funds raised from Stay in Bed Day would go towards much-needed research into better diagnosis, effective treatments and eventually a cure for the disorder.

"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 and we urge people to give what they can while they enjoy their day of rest," he said.

The AMDF also plans to set up a national patient registry to enable better patient care, help diagnose family members and aid genetic counselling for prospective parents.

Assumed to be rare, mitochondrial disease is now known to affect up to 90,000 Australians, with 1 in 250 people 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 our bodies need to function. Depending on which body parts are affected, sufferers can lose their sight or hearing, be unable to walk, eat, or talk normally, have strokes or seizures, or develop heart problems, liver disease, diabetes or respiratory or digestive problems.

Australian Mitochondrial Disease Foundation: 02 9488 8058, Helpline 0404 845 401
amdf.org.au, stayinbedday.org.au, [facebook.com](https://www.facebook.com) (search for AMDF)

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