

# Jack needs your help

Two year old Jack Lenehan has an extremely rare condition known as Spinal Muscular Atrophy Type 2 (SMA).

SMA is a disease that attacks the Survival Motor Neurone Gene. This gene ensures the survival of the nerves that control gross motor function. This disease is progressive, which means that as Jack grows older his symptoms will become more severe and life threatening. Jack has the only known case of SMA type 2 on the Gold Coast.

Jack's disease prohibits him from developing the gross motor skills that other children develop normally. All Jack's major muscles that are involved in normal growth are weak due to the degeneration of the nerve which triggers the muscle.

Due to this degeneration Jack will never have the ability to be mobile and play like a normal child. This includes activities and development such as crawling, walking, and moving his head upwards.

SMA also affects Jack's breathing and ability to swallow, meaning he will often be subject to chest infections and will eventually need aids to help him breathe and swallow food.

Even though he is very intellectually capable, Jack will need 24 hour assistance including daily physiotherapy and frequent hospital visits.

Jack's parents, Cassy and Joe, need the support of the Gold Coast Community to help fund the expensive and necessary equipment that Jack will require in order to give him the best chance at optimal health and quality of life.

#### Jack needs:

- wheelchair accessible vehicle
- motorised wheelchair
- lifting hoist
- specially designed postural chairs
- bathing utilities



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**All donations are tax deductible** If you are able to help in any way, please contact Deb Smith on **0412 389 607** or donate online at Jack's Appeal at: **[www.dreamworkers.com.au](http://www.dreamworkers.com.au)**

*Together we can make a huge difference in Jack's life, so let's show what a great Community the Gold Coast is.*

# About SMA

## **Spinal Muscular Atrophy (SMA)**

is a rare, inherited disease that results in the loss of nerves in the spinal cord and weakness of the muscles connected with those nerves. The muscles most frequently affected are those of the neck and trunk that control posture, those of the leg and arm that control movement, and those of the area of the ribs that help breathing.

People with SMA generally appear normal at birth; the symptoms develop as early as three months in the most severely affected, around one to two years of age in the moderately affected, and more rarely in the late childhood or adult years in mildly affected individuals.

There is no known treatment for SMA; historically, nearly half of babies born with the most severe form of the disease have died before aged two. All people with SMA have a higher than normal risk for progressive disability. The most severely affected are at risk for breathing complications and premature death.

*No two cases will follow the same course, everyone is different!*

Yet very few people have ever heard of it, and 1 in 40 people carry the gene. Fortunately, there is much we can do in providing the required care along with the many possible treatments becoming available that may help alleviate some of the symptoms to improve the quality of life but not to necessarily extend it. No two cases will ever be the same, everyone is different. **There is no known cure.**



**SMA IS THE NUMBER  
1 GENETIC KILLER OF  
CHILDREN UNDER 2  
YEARS OF AGE!**

**THERE ARE APPROX  
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SMA AUSTRALIA WIDE  
SOME CASES GO  
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