

a little book about



Illustrated by Dean Crawley & Martine Vanderspuy. Designed and written by Martine Vanderspuy.



**Especially dedicated to
Tom, who is so brave,
in his battle with
Mitochondrial Disease.**

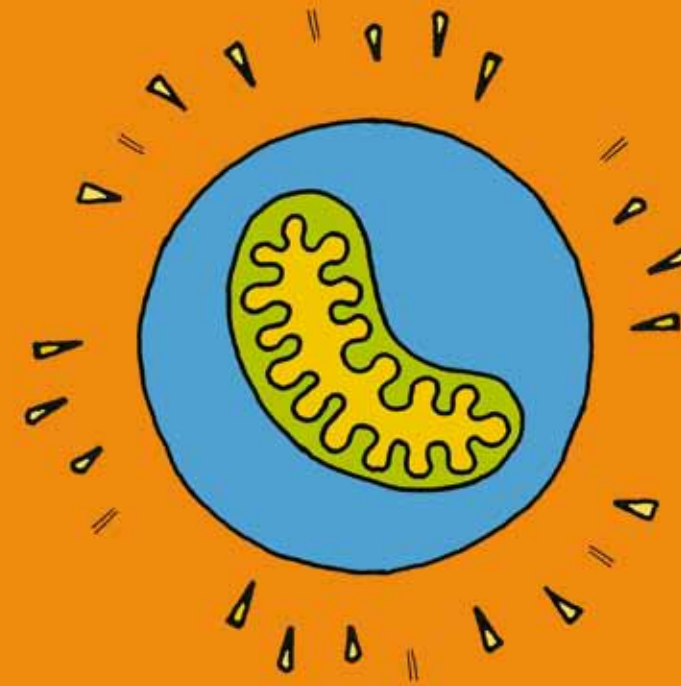
**Also dedicated to
all children and
adults who suffer from
Mitochondrial Disease.**

**Our hope is this book provides a tool to
create a clear understanding about
Mitochondrial Disease.**

A Special Thank You:

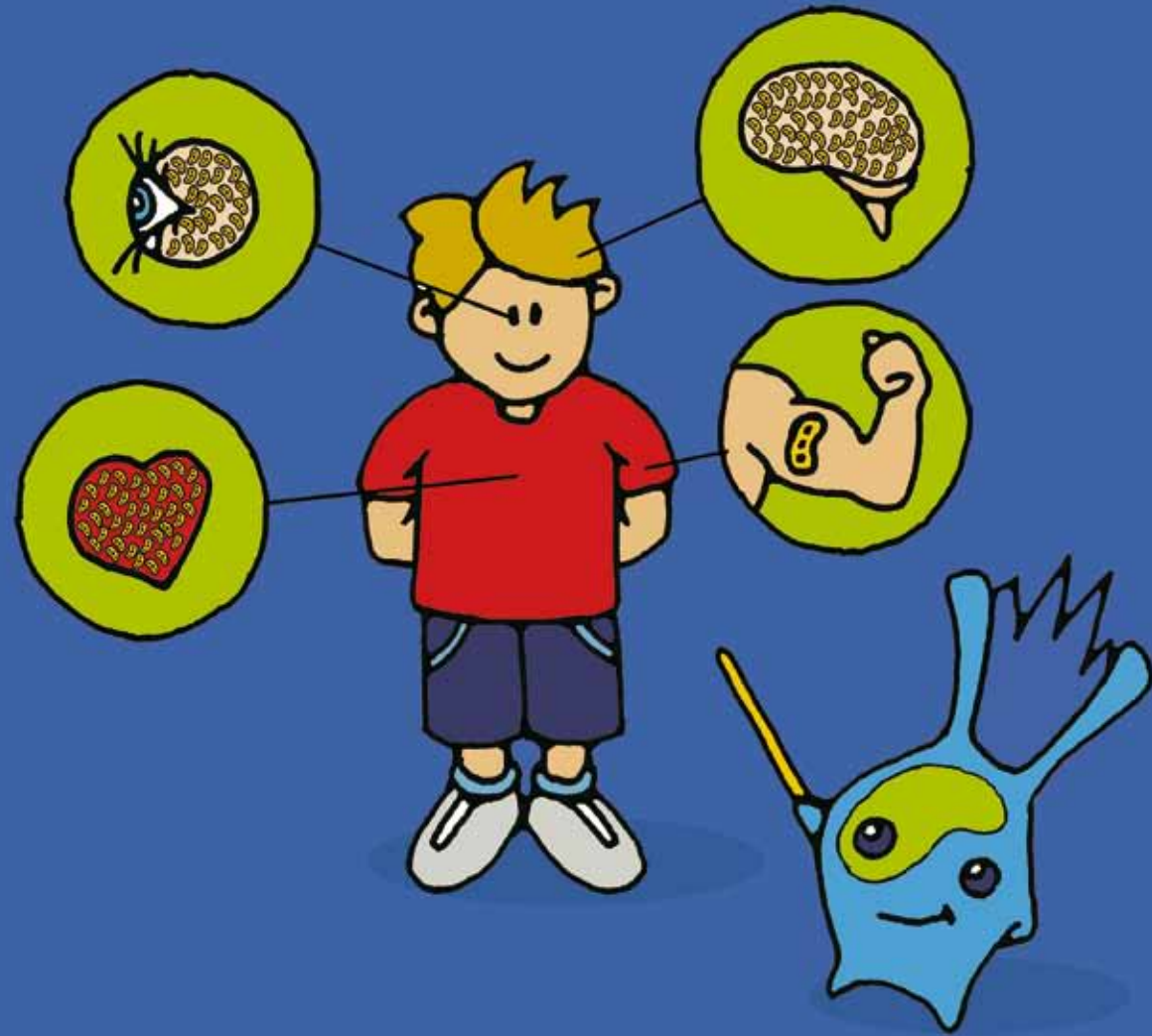
**To Dean Crawley for his help in developing the illustrations.
To Kim and Shara Sundell and Surfing World for their
very generous donation of the printing of this booklet.**

**This is a Mitochondria,
let's call it MiTO for short,
they are tiny but mighty...**



**They are in your cells
and make your body work.**

Mitochondria are everywhere in your body.
They act like the batteries in the cells.
The eyes, brain and heart need a lot
more energy to run
than the skin and teeth...



...just like you
need a small
battery to run a small toy
and a large battery
to run a truck.





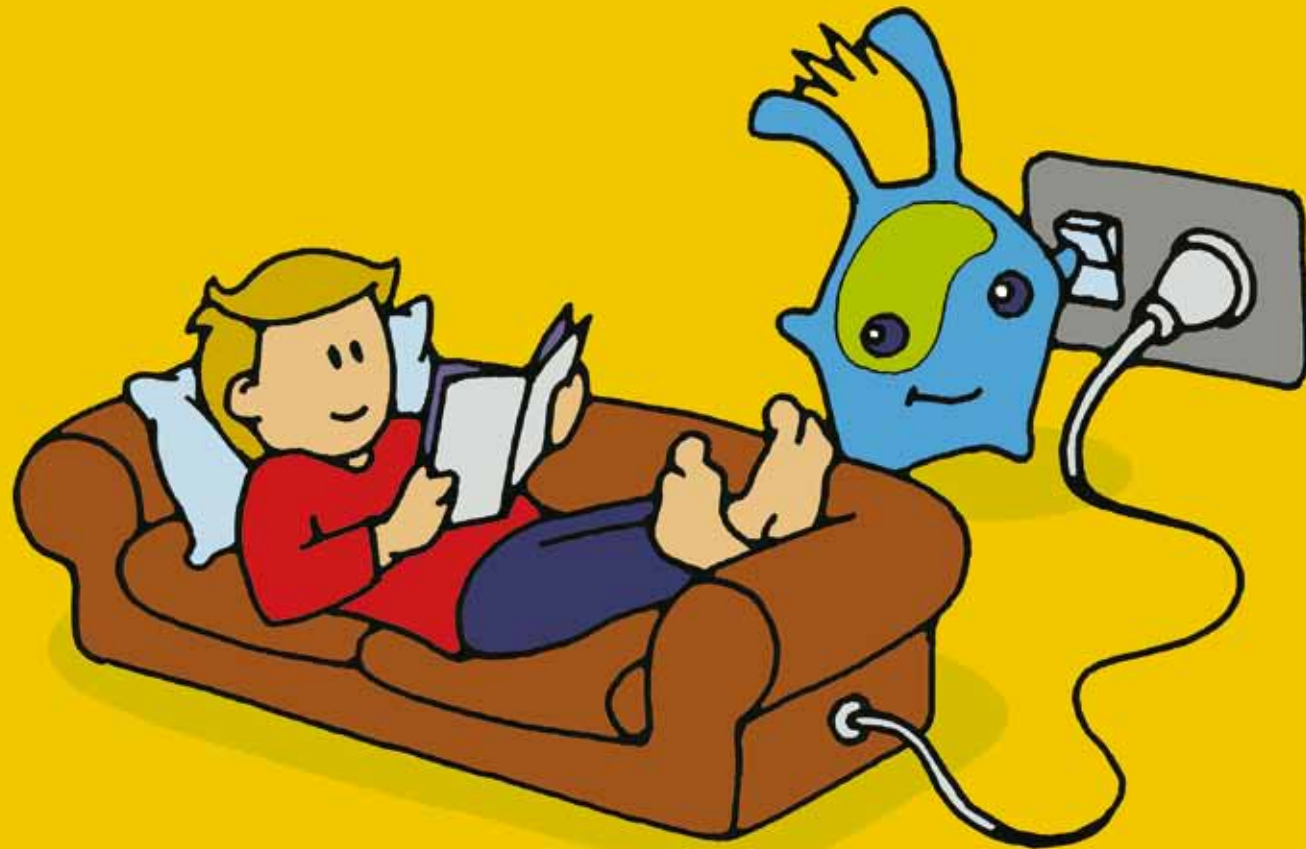
If you have MiTO disease
your body does not make enough energy
to make your organs work.



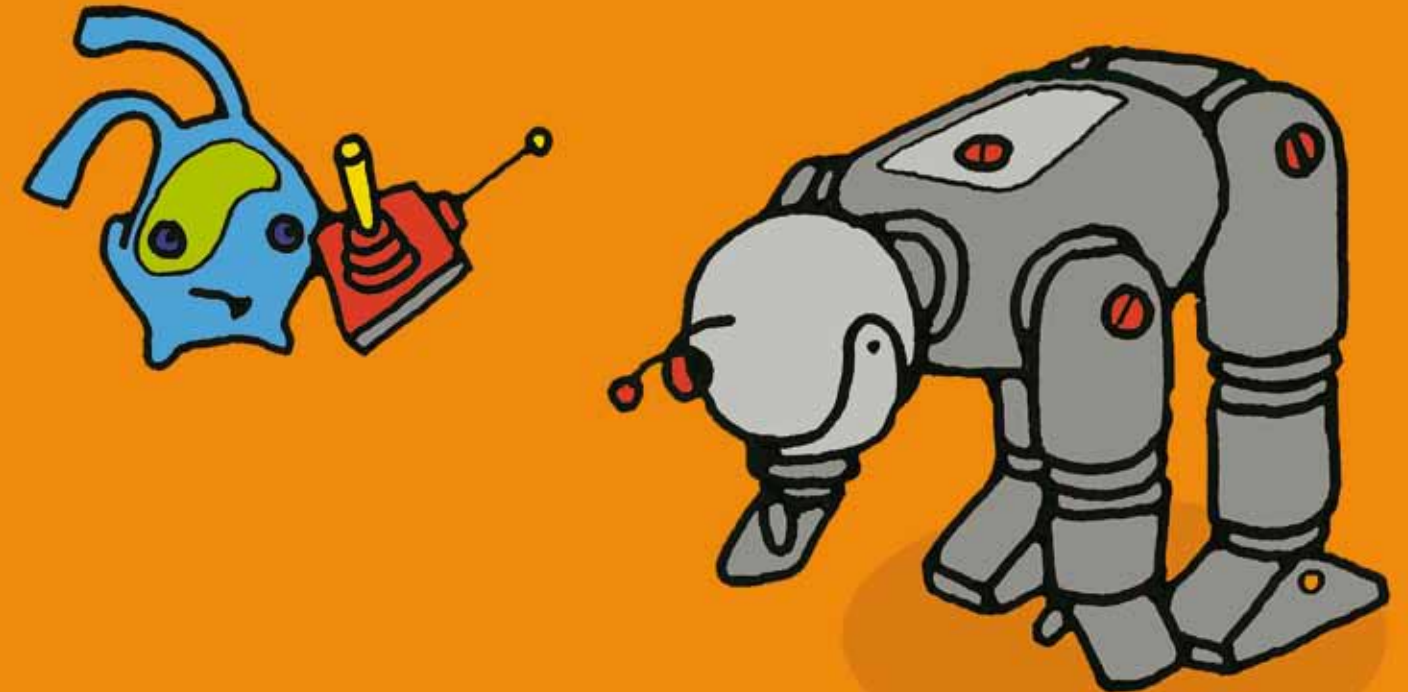
MiTO children look very
different from one another.
One MiTO child may not be able
to walk or talk...while another can
play and learn.



To keep a MiTO child looking great
their MiTO batteries need recharging.
They need to rest sometimes to
save their energy to run their bodies...



Think of your favourite toy,
when the batteries run low
the toy slows down or stops
working altogether.



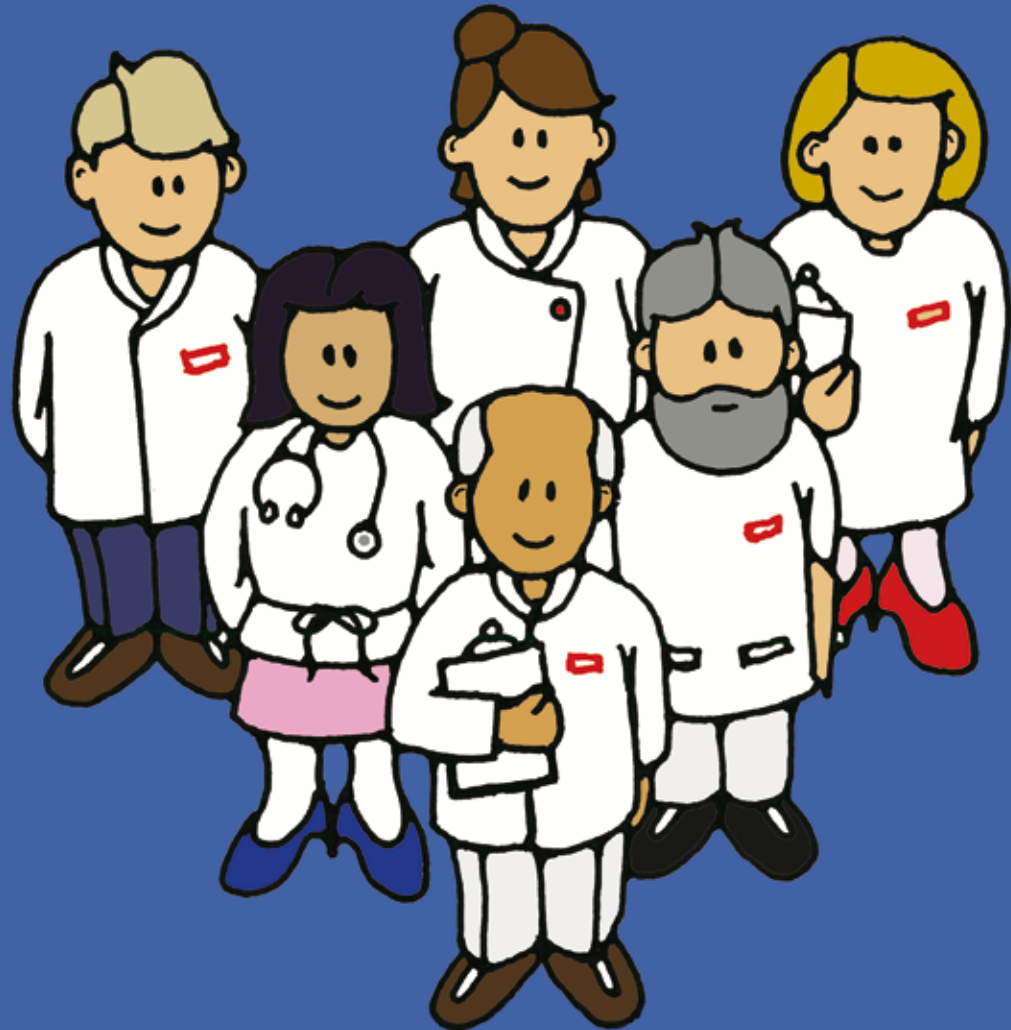
You can not see
if a child has MiTO.
Sometimes it is called
the INVISIBLE disease
as the child does
not look sick.
On a 'good day'
he or she looks great.



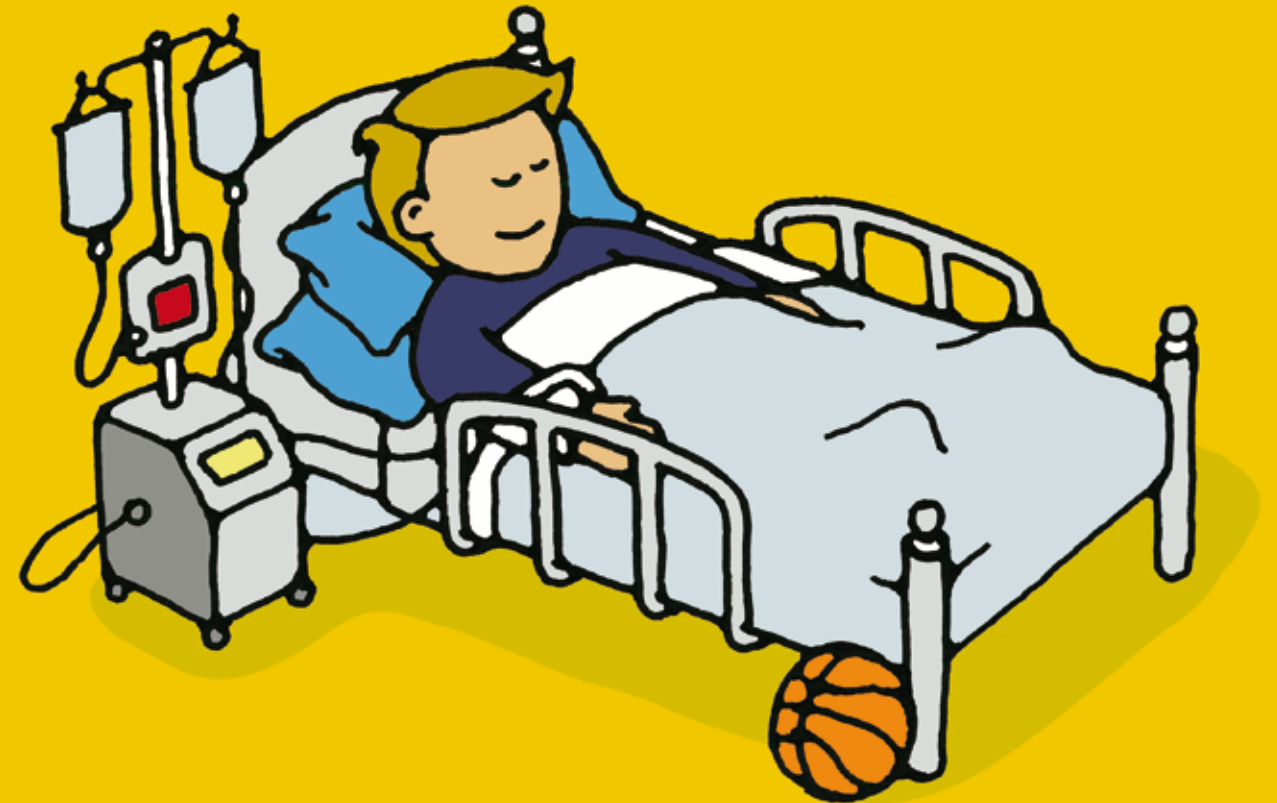
When a MiTO child can't
make energy,
they don't feel good,
they might get tired,
or parts of their
body don't work
properly and
they get run down and
sometimes sick.



Most MiTO children
have many teams of doctors helping them.
Each team looks at how the
rundown MiTO cells
affect each part of the body.



**Sometimes MiTO children have
to stay in hospital for long periods.**

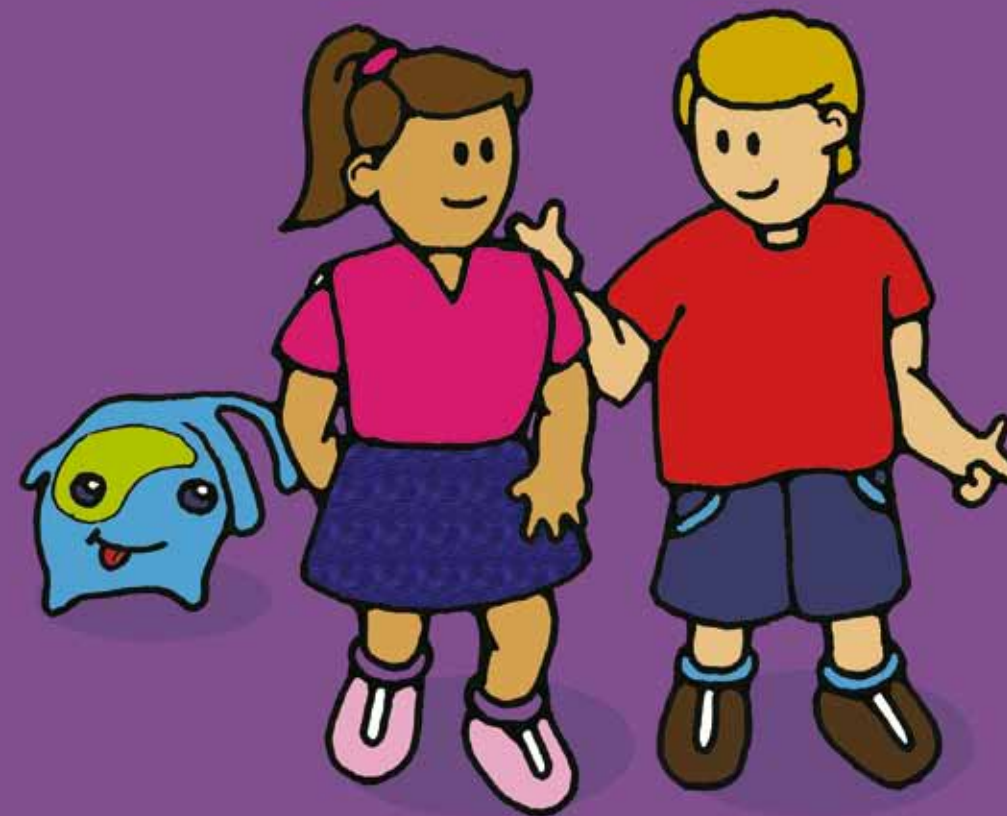




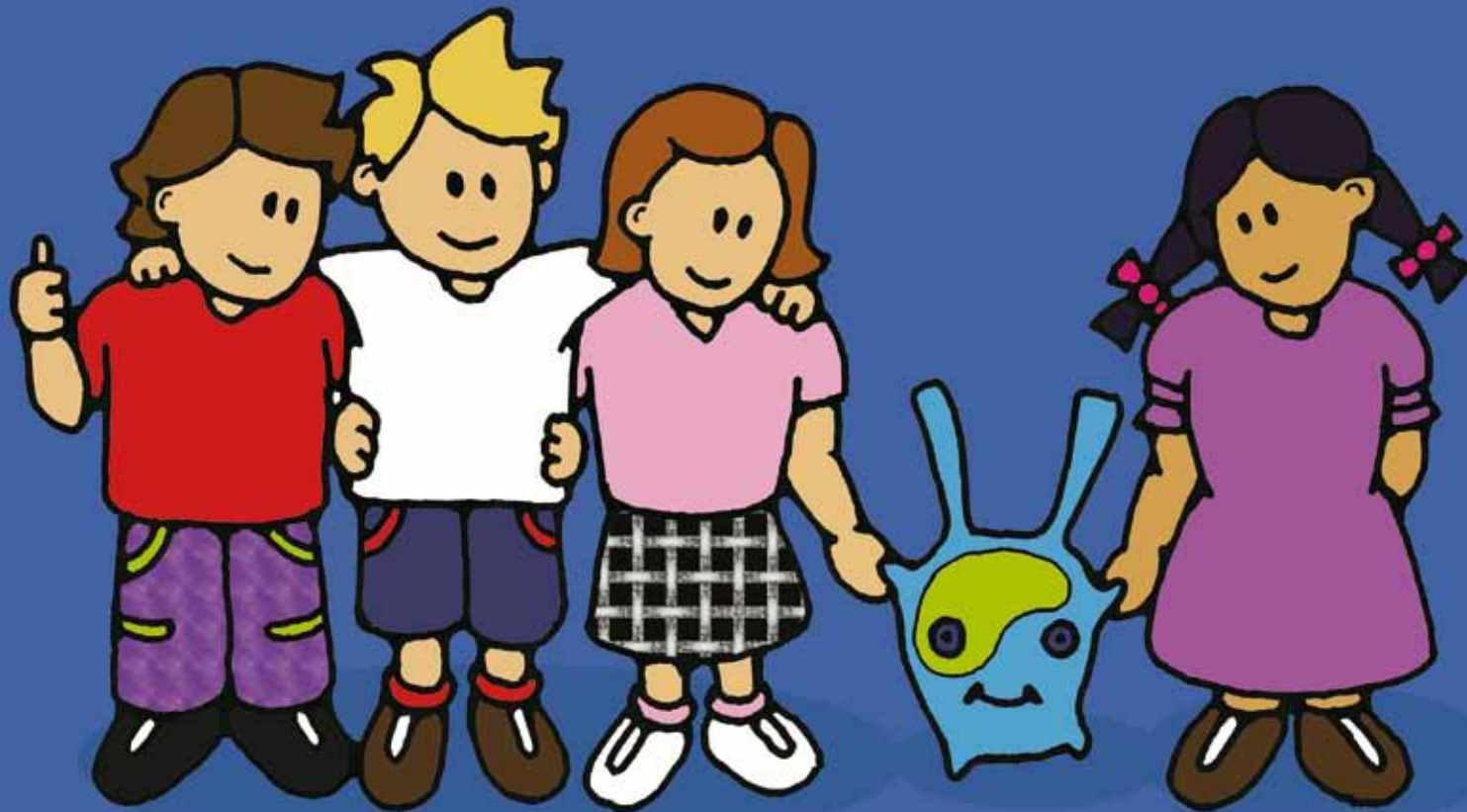
MiTO children like the same things as healthy children.



**You can help MiTO children.
If you are playing and they get tired,
give them a break or
change over to a quiet activity.
Visit them in hospital when they are sick.
Don't tease them if they wear a medical
backpack or are in a wheel chair.
Be their friend and support them.**



You are lucky to know a
MiTO child.
They are special.



MiTO Facts.

- Mitochondrial disease is a debilitating and potentially fatal genetic disorder that robs the body's cells of energy causing organ systems to become damaged and fail.
- Mitochondrial disease was thought to be rare (one in 20,000 people), but recent research shows that up to 90,000 Australians (1 in 250 people) may carry the genetic changes that can cause mitochondrial disease. Many of these people are symptomatic but undiagnosed or misdiagnosed, or are at risk of developing the disease or passing it on to their children.
- Mitochondria are the energy source in every body cell. Often called the cells' powerhouses or batteries, mitochondria transform food to produce 90 per cent of the energy needed by the human body to function, sustain life and support growth.
- Energy has little to do with how active a person is. It is more about how the systems and organs are powered. Patients may not look ill, therefore it is sometimes called the 'Invisible Disease'. The patient's symptoms may vary from intermittent to constant, from mild to severe.
- Mitochondria are most plentiful in organs that require a lot of energy to function; the disease therefore causes most damage to the cells of the muscles, brain, heart, liver, ears and eyes.

Continued...



MiTO Facts.

- Depending on which parts of the body are affected, sufferers may experience muscle weakness and pain, loss of motor control, gastrointestinal disorders, swallowing difficulties, poor growth, cardiac disease, liver disease, diabetes, respiratory complications, strokes, seizures, visual or hearing problems, lactic acidosis, developmental delays, intellectual disability and susceptibility to infections.

- Every year at least 50 children born in Australia will develop mitochondrial disease during their lifetime (estimated 1 in every 5,000 births).

- The World Health Organisation (WHO) calculated that neurodegenerative diseases, also associated with Mitochondrial dysfunction, will become the world's second leading cause of death by the year 2040.

- There are very few effective treatments and no cure. There is much uncertainty regarding the progression of the disease/symptoms and patients' prognosis. Generally in children the prognosis is poor and the life span short.

- Mitochondrial disease is difficult to diagnose due to the widespread type and severity of symptoms and its varying onset and impact on patients' lives (from none to severe); there are more than 100 known subgroups of mitochondrial disease.



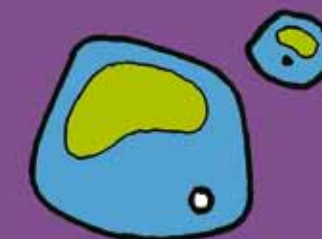
- Mitochondrial disease affects both children and adults and often multiple family members. Adult onset is becoming more commonly diagnosed, when the increasing load of repeated mitochondrial impairment (cell injury and cell death) over time starts causing organ systems to fail and symptoms become evident.

- Mitochondrial Disease robs the body of energy and life.

- Most patients have a genetic mutation in the mitochondrial or nuclear DNA. The condition can be inherited from the mother or from both parents, or can arise as a genetic mistake at the time of conception.

- The Australian Mitochondrial Disease Foundation - AMDF, was set up in 2009 by family members, friends and doctors of sufferers to fund essential research into the diagnosis, treatment and cure of mitochondrial disorders, and to support affected individuals and families. For more information about Mitochondrial disease please visit the AMDF's website: www.amdf.org.au

- Fundraising activities range from school pyjama parties, home pyjama parties, movie fund raisers, fairs and the AMDF's major national fund raising activity, Stay in Bed Day, held each August.



Please Help find a Cure for MiTO...

www.everydayhero.com.au/thomas_martin

www.stayinbedday.org.au

www.amdf.org.au

Funding is essential for research into the diagnosis,
treatment and cure of mitochondrial disorders.

