

## **AMDF calls for more research funding in the wake of baby Charlie's plight**

Our hearts go out to the family of UK baby Charlie Gard, whose quest to treat his severe mitochondrial disease has captured public attention.

Unfortunately for Charlie and more than one million others struggling with mitochondrial disease around the world, there are very few effective treatments and no cure for this debilitating and potentially fatal genetic disorder, which starves the body's cells of energy and can cause any symptom in any organ at any age.

While Charlie's specific type of mitochondrial disorder is rare, mitochondrial disease itself is not. There are more than 100 forms of this complex disease, which is now the second most commonly diagnosed serious genetic disorder after cystic fibrosis. At least one Australian child born every week will develop a severe or life-threatening form of mitochondrial disease (1 in 5000 births).

A further 30 Australian children born each week may develop a mild to moderately disabling form of mitochondrial disease during their lifetimes, or pass it on to their children – that's 1 in 200 people, or 120,000 Australians at risk.

Baby Charlie's plight reinforces the urgent need for more research into treatments and a cure for this insidious disease. And, given the role of mitochondria (our cells' powerhouses) in human health, disease and ageing, the expanding field of mitochondrial medicine has the potential to improve the way we tackle many common diseases, including dementia, Alzheimer's disease, diabetes, Parkinson's disease and some forms of cancer.

The Australian Mitochondrial Disease Foundation funds vital research into mitochondrial disorders, supporting affected people and their families, and educating the public and the medical profession.

We join our international counterparts in calling for greater awareness, support and funding. Treatments cannot come quickly enough to help the many adults and children across the globe struggling every day with mitochondrial disease.

Sean Murray

CEO

Australian Mitochondrial Disease Foundation

Sydney