

EVERY LIFE COUNTS

The Malaysia Lysosomal Disease Association is determined to ensure that no patient suffering from this life-threatening disease is deprived of medical care and support.

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Resource



Every second counts for children who suffer from lysosomal storage diseases (LSD). The sooner they are diagnosed and begin treatment, the greater their chances of living as normal a life as possible.

Unfortunately, because these diseases are so rare, many cases go unspotted and untreated. The outward symptoms of many LSDs are similar to those of common illnesses. By the time the patients are diagnosed, the damage done is irreversible. If they are not treated, the disability worsens progressively, leading ultimately to death.

In May 2011, eight families with children suffering from these diseases decided to kick-start efforts to establish a sustainable healthcare and support system.

"We believe all Malaysians should have an equal right to medical treatment, whatever their condition," says Ir Lee Yee Seng, the President of MLDA. He has two girls with Pompe's disease.

Lysosomal storage diseases are caused by an inherited genetic problem that causes a malfunction of the enzymes which rid our cells of waste. This waste builds up over time, damaging the cells and causing serious health problems.

The rarity of the disease is one of the biggest problems LSD patients and their families face. When they are diagnosed they often find themselves on a lonely and scary road. Information is scarce and confusing. And the lack of a cure is extremely frustrating.

"But a hard road travelled with a good support system can become easier to navigate. So we aim to provide an extensive support system to all patients – be it moral or logistical support or by connecting them to medical experts and providing the latest information on treatments and developments.

"Last but not least we aim to put all our strength behind any efforts to develop treatments and to find a cure. In my own family and in several other families we have already seen the effectiveness of some of the treatments available.



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And we firmly believe that through dedicated effort – we can ensure that LSD patients lead full and happy lives,” Lee explains.

MLDA has its work cut out. The challenges are immense. It is critical that the disorders are diagnosed early, before the disease has time to delay a child’s development, or cause movement disorders, seizures, dementia, deafness, blindness, enlarged livers and spleens, problems with heart and lungs or bone abnormalities.

How can we ensure that all newborns across Malaysia are checked for LSDs at birth? How do you “educate” parents, particularly those from underprivileged communities, to look out for the early symptoms of LSDs?

The cost of treatment is enormous – far beyond the pockets of most families. It can cost between RM300,000 to RM1,000,000 annually for each child for the rest of his or her life. At the moment, treatment for some LSD patients is funded by the Ministry of Health. Many children go untreated.



“We need more minds and hearts, and most importantly, we need more voices,” says Lee. With that in mind, MLDA has launched the “Every Life Counts Campaign to gain the support of at least 10,000 people as “Friends of MLDA.”

“What do we require of our 10 000 ‘Friends’? It is quite simple – we hope our ‘Friends’ will tell our story. We hope they will take our story to their families; we hope they will tell it at their workplaces and in their schools and we hope they will share it with their communities.

“Through them we will be able to educate people about Lysosomal Storage Diseases; through them we will be able to tell people the stories of patients waiting for treatments while a debilitating disease causes their bodies irreversible harm; and through them we will explain that there are a fortunate few who, with timely treatment, are leading happy and promising lives. They will be part of a crucial support system that will help us achieve our goals,” Lee adds.



To sign up as a Friend of MLDA, please visit the Association’s website at www.myllda.com.my.

