

# Every life counts

MAGINE taking care of a child who has a rare disorder, one that requires care provided by healthcare professionals from multiple disciplines and support from various agencies. To compound the problem, access to such medical care and services can be hard to come by, causing undue suffering and despair.

This is what is being faced on a daily basis by families who live with patients with lysosomal storage diseases (LSD).

There are about 50 different types of LSD diseases, which mostly affect children, who often die at a young and unpredictable age, many within a few months or years of birth.

LSD are caused by a lack of enzymes that normally eliminate unwanted substances in the cells of the body. The enzymes are found in sac-like structures in cells called lysosomes. Lysosomes act as the "recycling centre" of each cell, breaking down unwanted material into simple products for the cell to use to build new material. The lack of certain enzymes causes a build-up of the substance that the enzyme would normally eliminate, and deposits accumulate in many cells of the body.

Abnormal storage causes inefficient functioning and damage of the body's cells, which can lead to serious health problems. As this condition is so rare, it is often misdiagnosed or overlooked, which causes crucial treatment time to be lost.

The symptoms of lysosomal storage disease vary, depending on the particular disorder and other variables like the age of onset, and can be mild to severe. They can include developmental delay, regression, movement disorders, seizures, dementia, deafness and blindness. Some people with LSD have enlarged livers (hepatomegaly) and enlarged spleens (splenomegaly), pulmonary and cardiac problems, and bones that grow abnormally.

Today marks World Rare Disease Day and it's the perfect opportunity to highlight a campaign that is attempting to put the spotlight firmly on lysosomal storage disorders.

## Fact Box

The 'Every Life Counts Campaign' aims to garner the support of 10,000 (and hopefully many more) people to become 'Friends of MLDA'.

There are no cures for most of the LSD and treatment is mostly symptomatic. However, bone marrow transplantation and enzyme replacement therapy (ERT) have been tried with some success in some cases.

"We need more hands, more minds and hearts, and most importantly, we need more voices," says Malaysia Lysosomal Diseases Association (MLDA) president, Lee Yee Seng as he called on Malaysians around the country to sign up to become "Friends of MLDA" at the launching of the Every Life Counts Campaign recently.

MLDA is a non-profit organisation which advocates for patients' rights to a sustainable healthcare and support system. It also raises the awareness of the general public about the life-threatening LSD.

"We formed the MLDA last year in May. Eight families with children suffering from this disease decided that we were no longer willing to sit idly by and wait for someone else to help our children. We knew that we would have to be the ones to kick-start these efforts," Lee explains.

The association's main goals are to advocate for a sustainable healthcare system, where all patients have access to the best possible medical

care available and to raise awareness of this disease.

World Rare Disease Day 2012 presents an opportunity for MLDA to spotlight LSD with the "Every Life Counts Campaign". The campaign's aim is to garner the support of 10,000 (and hopefully many more) people to become "Friends of MLDA". The Association hopes these "advocates" will help them spread this story in their individual homes, workplaces and schools as well as in their communities.

Representing the Health Ministry as the director of Medical Development, Datuk Dr Azmi Shapie.

His presence underlined the ministry's commitment to creating a healthcare system that will facilitate and support the people and to ensure a high quality health system that is customer centric, equitable, affordable and innovative.

He also commended the spirit of the MLDA members and offered them the ministry's full support in their efforts to raise awareness of LSD and rare diseases.

The campaign has already secured a small but growing number of advocates as "Friends" for the MLDA. Singer and songwriter, Juwita Suwito wrote and composed *Every Little Smile* especially for the campaign. The song highlights how unpredictable life can be, and yet how precious it truly is – it was a touching tribute to the importance of doing everything we can to support each and every LSD patient.

Also taking to the stage during



(Top) Singer and songwriter Juwita Suwito wrote and composed *Every Little Smile* especially for the 'Every Life Counts Campaign'.



the launch was Joanna Bessey, who told *A Mother's Story* written by Jo Kukathas. The monologue portrayed the many trials that parents of LSD patients face, and shared that ultimately all parents have the same wish for their children – to live happy, healthy and fulfilling lives.

The "Every Life Counts Campaign" will run over the next three months. It hopes to successfully bring the diseases out of obscurity and into the consciousness of the Malaysian public.

For more information, please visit [www.mylsda.com](http://www.mylsda.com), <http://www.youtube.com/watch?v=yECd3H2DQY>, and <http://www.rarediseaseday.org>.

President of the Malaysia Lysosomal Diseases Association Lee Yee Seng: "We need more hands, more minds and hearts, and most importantly, we need more voices (to support the campaign)."

**Young fighters:** Kelly (left) and Aqilah are among those who have to face the trials and tribulations that come with lysosomal storage disorders.



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