Campaign to shed light on lysosomal storage diseases

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The Malaysia Lysosomal Diseases Association (MLDA) recently launched the Every Life Counts campaign to garner support and raise awareness of lysosomal storage diseases (LSD) throughout the country.

The campaign, set to run un-

til June, aims to attract more than 10,000 people to become 'Friends of MLDA.' These advocates will spread MLDA's story to their families, at their workplaces, schools and in their communities.

By educating the public about LSD, MLDA hopes to make known the plight of its patients, as well as to highlight the importance of early

diagnosis and early treatment.

"We need more hands, more minds and hearts, and, most importantly, we need more voices," said Lee Yee Seng, president of the MLDA, who urged Malaysians from all walks of life to sign up as 'Friends of MLDA.'

MLDA is a patient advocacy group committed to defending



Launch of the Every Life Counts campaign by MLDA.

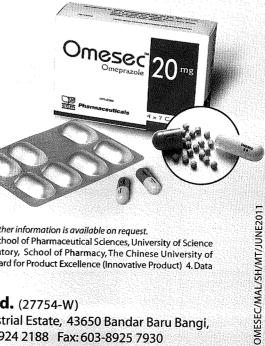
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the rights of LSD patients. Its mission includes championing for a sustainable healthcare system that guarantees fair and equal access to treatment for all LSD patients.

"We formed 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 kickstart these efforts," said Lee.

This campaign focuses on bringing the disease out of obscurity and into the consciousness of the public to ensure patients are correctly diagnosed and appropriately treated. Lack of awareness about LSD often leads to the disease not being identified or misdiagnosed.

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"We aim to put all our support 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. And we firmly believe that through dedicated effort we can ensure that LSD patients lead full and happy lives," explained Lee.

The Every Life Counts campaign launch was officiated by Dato' Dr. Azmi Shapie, director of Medical Development Divison, Ministry of Health (MOH), in February.

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to new treatments for both conditions... Heart failure should be treated as a stronger risk factor for fracture, just as the classic risk factors such as prior fracture and family history."

Part of screening for osteoporosis should involve looking at chest X-rays of patients with heart failure, said Sumit.

"Heart failure patients get a lot of X-rays and they often incidentally show many fractures of the spine that would automatically provide an indication of severe osteoporosis and need for treatment."