

SDF held central event in World Lupus Day Observance

The Syamsi Dhuha Foundation (SDF), an NGO that gives special attention to Lupus and those suffering from it (Lupies), held an event observing World Lupus Day (WLD) 2011 at the West Hall at Bandung Institute of Technology, on May 7, 2011. This event, designed with the theme 'Never give up!' consisted of a free Lupus consultation, a talk show titled *'All about Lupus,'* an art performance called 'Beautiful Indonesia,' the launch of the 'Oops... The Luppy is naughty' book, which is a compilation of questions and answers concerning Lupus; an exhibition; a bazaar and the Care for Lupus SDF Awards 2011. "It isn't easy to live with the potentially fatal Lupus disease. This is even worse considering the geographical conditions of Indonesia which makes it difficult for those not living on the island of Java as it is more difficult to get access to treatment. In order to overcome this, SDF is attempting to develop an online support group system to provide encouragement despite the limitations of time and distance. This condition requires not only physical strength, but also financial and mental faculties to handle it. This is why we chose the theme 'Never give up!' to be highlighted in the World Lupus Day observance year," said Dian Syarief, a Lupy as well as the Chairperson of SDF.

Dr. Rachmat Gunadi, who specializes as an internist and is especially concerned with Lupus, adds, "Lupus, which is often referred to as the great imitator, obligates doctors to be extra thorough if they expect to diagnose this disease. It is for this reason that one of the objectives of World Lupus Day is to improve the skills of medical workers and outpatient services as well as hospitalization for those with Lupus. At every WLD event, we always try to provide free Lupus consultations with multi-disciplinary doctors as Lupus can attack a variety of systems/organs in the body, such as the blood, nerves, skin, joints, kidneys and lungs. Effective communication with doctors is also needed so Lupies can avoid choosing the wrong alternative therapies, which includes herbal treatments. They must be wise and critical when selecting which herbal therapy is suitable for those with Lupus and which ones are not. This is due to the nature of Lupus itself, which entails an overactive immune system, unlike most other people."

This event was officially commenced by the Binfar Alkes Director General of the Ministry of Health, Sri Indrawati, is the climax of WLD 2011, which was preceded by an education and socialization program called *Lupus Goes to Campus* and *Lupus Saves the Earth*. "We feel it is necessary to also be involved in the issue of global warming because pervasive sun exposure can add to the number of Lupus patients who are sensitive to ultraviolet light," commented dr. Shiane Hanako, SDF Manager.

We chose the theme *Beautiful Indonesia* for the art performance that was held on May 7th because it is related to the new SDF initiative, which aims to explore naturally available materials in Indonesia for supplementary Lupus therapies and find safe and effective therapies. These goals can be realized through the *Care for Lupus SDF Awards 2011i*. It is planned as an annual event to be held by SDF in an effort to enhance the quality of life for those with Lupus," Eko Pratomo, SDF founder, explained.

The *Care for Lupus SDF Awards 2011* consists of three categories:

- *Research Sponsorship*, which is awarded to the research or planned research concerning the use of natural materials available in Indonesia for supplementary therapies in the treatment or control of Lupus to enhance the quality of life for Lupies.
- *Writing Competition*, for the most popular writing on Lupus which has or will have a large impact in increasing public awareness of and concern for Lupus.
- *Lifetime Achievement*, an award intended for institutions, organizations, or individuals whose actions have served to boost concern for Lupus and those living with it.

Starting November 2010 until March 2011, candidates underwent a range of procedures and selection by the jury members, resulting in 5 finalists from the original 15 from different universities who were competing for Research Sponsorship. Of these 5 finalists, the three winners will be bestowed with a total of Rp. 90 million. Meanwhile, of the 14 Writing Competition participants, 3 winners were selected from 5 finalists to receive Rp. 11 million. In the Lifetime Achievement category, jury members have chosen 10 award recipient.

“It is hoped that the *Care for Lupus SDF Awards 2011*, which awards researchers, institutions, the media and volunteers who have been of service in increasing awareness, treatment and/or control of Lupus can further motivate Indonesian scientists to undertake original, innovative, and applicable research as well as add value in helping the therapies and/or management of this illness in order to enhance the quality of life for those with Lupus,” stated Prof. Dr. Elin Y. Sukandar, Head Jury for *Research Sponsorship*. It is also expected that this can advance the role of society, especially the media, to heighten socialization of Lupus to increase public awareness and concern for this disease through articles and other forms of writing.

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