



## LUISA celebrates World Lupus Day addressing FAQs (frequently asked questions) in Lupus

*By: Rodeo V. Navarroza, MD*

On the 13<sup>th</sup> of May this year, the world celebrated Mother's Day in appreciation of the sacrifices our mothers made for us. But there was even more mark the day's importance, as we celebrated World Lupus Day. Thus, Lupus Inspired Advocacy (LUISA) of Rheumatology Educational Trust Foundation, Inc. (RETFI) organized the forum on "FAQs in Lupus", dedicated to our lupus patients and their caregivers, in order to increase awareness and empower them to take an active role in the management of their condition. The event was held at the Cathedral Heights Building, St. Luke's Medical Center, Quezon City, and was made possible with the combined efforts of rheumatology fellows, consultants and staff from University of Santo Tomas, St. Luke's Medical Center, and Jose Reyes Memorial Medical Center.



Participants and organizing staff of the recently held FAQs in Lupus gathered for a group picture.

The activity aimed to address questions that commonly lingered in patients' minds regarding various aspects of their condition. Participants were made to choose 2 out of 3 sessions beforehand, and an ice-breaker introduced each session for added fun.

One session focused on kidney disease in lupus. In this session, patients were encouraged to learn more about lupus nephritis, recognize the common signs and symptoms, indications and procedure of kidney biopsy, conduct of clinical trials for lupus nephritis and lupus in general, as well as how best to prevent the need for dialysis. This session was moderated by Dr. Francis Martin Cuenco, and facilitated by a panel of experts consisting of Dr. Leonid Zamora and Dr. Leonore Lague-Lizardo (rotation 1), and Dr. Marica Lazo, Dr. Eizelle Fernandez, and Dr. Joenavin Ngo (rotation 2).



Dr. Kaye Chua moderated the session on pregnancy in lupus. Beside her are expert panelists addressing the patients' queries. From left to right: Drs. Kathleen Geslani, Ma. Theresa Collante, and Dr. Sorrah Fiel Briones.

The second session tackled the topics of childhood, pregnancy, and genetic aspects of lupus, aimed to enlighten participants regarding the role of genetics in the development of disease, as well as counsel parents on child-rearing of pediatric patients. Equally relevant to the age of predilection of SLE, the

session addressed issues regarding pregnancy among patients with lupus. This session was moderated by Dr. Kaye Chua, and panelists included Dr. Kathleen Geslani, and Dr. Ma. Theresa Collante (rotation 1) and Dr. Lorieilyn Salvador and Dr. Maricar Bayo-ang, (rotation 2).

"Through this effort, much needed awareness will come about to give lupus the recognition and understanding it deserves and needs."

- Tanya Carlton, Volunteer VP, Lupus Canada

Another session focused on management of lupus, covering the effects and common side-effects of standard medications as well as strategies adopted by patients to improve their quality of life such as exercise, diet and nutrition; questions on alternative medicine were also raised and discussed. Moderated by Dr. Richelle Joy Bayson, the panelists included Dr. Evan Vista, Dr. Sorrah Fiel Briones, and Dr. Noreen Kintanar (rotation 1), taken over by Dr. Jonathan Paul Consignado, and Dr. Mary Flor Edar (rotation 2).



Ms. Boots Anson Roa-Rodrigo talks about the relevance of caregivers to the lives of patients suffering from chronic illnesses.

The closing remarks was delivered by no other than our very own Section Chief, Dr. Sandra Navarra, who inspired patients to soar like a butterfly despite their afflictions. Likewise, she reminded them to take an active role in the management of their condition – citing the important partnership between patients and physicians, and forums where doctors also continue to learn from their patients – a good reminder to treat the patient as a whole rather than focus on just the disease per se.

Excerpted from the book "Hope for the butterflies" authored by Drs. Laniyati Hamijoyo and Sandra Navarra, this letter from Melody - a lupus patient - to her doctor reflects the strength of the human spirit holding on to that hope...

"Words are drowned by the tide of gratitude that swells from my heart  
As I cross the finish line of an arduous race –  
A race against a terrible and treacherous enemy.  
You have been my noble captain, my enlightened guide  
A great sustainer of my failing strength.  
With you let me share the laurels of victory –  
For indeed they are your laurels as well.  
More races lie ahead,  
But with you behind me, in front of me, by my side,  
I shall face them undaunted.  
I shall fight in more battlefields, fight the common foe  
With you leading the charge, I shall fight to the end  
However we fight, my dear captain  
WE SHALL WIN!"



Dr. Marthony Basco gives a motivational speech to the audience, imparting the importance of a positive attitude in embracing their disease.

In between breakout sessions, Dr. Marthony Basco, a pediatrician and lively motivational speaker rallied the participants on embracing their condition with acceptance, at the same time encouraging them to always have a positive outlook in life by counting their blessings despite lupus.

Culminating the activity was a moving inspirational talk by no other than Ms. Boots Anson Roa-Rodrigo who shared her own life story and praised the caregivers for their untiring support and selfless service to their patients, ameliorating their suffering and improving their quality of life.