

“Living Well With Lupus” Workshop

by Francis Martin T. Cuenco, MD

“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” – World Health Organization

On a beautiful Sunday, 11th of February 2018, the Lupus Inspired Advocacy (LUISA) in partnership with St. Luke’s Medical Center (SLMC) and University of Santo Tomas Hospital (USTH) conducted the “Living Well with Lupus Workshop” at St. Luke’s Medical Center Quezon City CHBC Auditoriums. The workshop is the culminating event for this year’s National Lupus Advocacy Week (Presidential Proclamation 1435) decreed beginning February of 2007. With the **#VoicesOfLupus** and **#VoicesForLupus** as recurring themes in all multimedia formats. This activity was fully supported and conducted under the auspices of the Rheumatology Educational Trust Foundation, Inc. (RETFI) headed by its founder, Dr Sandra Navarra. The RETFI is the umbrella organization for both LUISA and the People Empowerment for Arthritis and Lupus (PEARL).

The workshop aims to assist lupus patients in taking control of the situations affected by their illness, through experience-sharing and focused group discussions. The workshop was facilitated by rheumatologists from SLMC and USTH as well as rheumatology fellows from SLMC, USTH, and Jose Reyes Memorial Medical

Center. Medical residents, post-graduate interns, and medical clerks from USTH also served as scribes and helped in the workshop. Staffs from both SLMC and USTH Section of rheumatology also lend their helping hand during the event.

Dr. Evan Vista and Lupus patient and advocate Ms Robelle Tanangunan, both volunteers and co-convenor of PEARL opened the event by introducing the workshop volunteers and discussed the objectives. The participants were divided into two big groups. Each big group rotated into four stations namely physical, psycho-emotional, spiritual, and social. The physical aspect aimed to identify the changes that they experienced in terms of their functionality or mobility and the coping patterns in relation to these changes because of their SLE. The psycho-emotional aspect aimed to know the emotional or psychological state of the patient by asking common questions such as: *Kamusta ka* (How are you); *Ano ang nagbago sa iyo* (What are the changes that happen to you); *Paano na yan* (What comes next); *May maitutulong ba ako sa iyo* (How can I help you).

The social aspect looked into the changes in patients and caregivers’ interpersonal relationships and further examines which of these are founded on trust. The station has two parts: the first portion inquired on the persons they have put their trust on and the qualities that they possess; and the second part dealt on the qualities that participants need to be improved to make them trustworthy. The spiritual aspect dealt into the beliefs or spiritual outlook that has been transformed by the illness regardless of the patient’s religious affiliations. After the participants rotated into all four stations, there was a synthesis/summary by Dr. Marthony Basco,



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who developed the concept and mechanics of the “Living Well” workshop. Dr. Basco talked about 3As namely awareness, acceptance, and action. With these 3As, lupus patients can take better control of their disease and have a more positive outlook. After Dr. Basco, patients, caregivers, facilitators, and scribes/medical students shared their experience during the workshop.

For the patients and caregivers, the workshop was an opportunity to be their catharsis. It also gave them a chance to meet and hear other lupus patients and their stories and strategies to cope with their disease. One participant was quoted as saying the workshop was their opportunity to be heard and be listened to. It was a blessing for them. A post-graduate intern from USTH, Dr. James Satuito, shared his eye-opening experience during the workshop that it was his first time to see lupus patients not in medical consultation but in a setting where other just-as-important aspects of their lives are given due attention. He shared that being a doctor you are not just treating the disease but the patient as a whole. Dr. Jonathan Consignado represented the insights of the workshop facilitators, reiterating that as physicians we are not only there to treat the disease but to treat and manage the whole person encompassing the 4 stations of the workshop: physical, psycho-emotional, spiritual, and social.

The entire workshop lasted for half-day but the experience of the participants namely the lupus patients, caregivers, medical students/clerks, post-graduate interns, medical residents, rheumatology fellows and staff, and rheumatology consultants was a treasure to cherish for a lifetime. Everybody had a blessed and wonderful Sunday, LIVING & LOVING well...



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FACILITATORS:

- I. *Consultants*
 - a. Dr. Evan Vista
 - b. Dr. Sandra Navarra
 - c. Dr. Charles Villamin
 - d. Dr. Melissa Villamin
 - e. Dr. Sorrah Briones
 - f. Dr. Marian Velasco
 - g. Dr. Jonathan Consignado
 - h. Dr. Lenore Lizardo
 - i. Dr. Leonid Zamora
 - j. Dr. Liza Traboco
 - k. Dr. Sheila Reyes
 - l. Dr. Theresa Collante
 - m. Dr. Lorielyn Salvador
 - n. Dr. Mary Flor Joy Edar
 - o. Dr. Bryan Paras
 - p. Dr. Joenavin Ngo
- II. *Patient/Caregiver*
 - a. Cathy Zulueta
 - b. Lois Espinosa
- III. *Fellows*
 - a. Dr. Vivian Santos
 - b. Dr. Francis Cuenco
 - c. Dr. Noreen Kintanar
 - d. Dr. Ronald Ramirez
 - e. Dr. Richelle Bayson
 - f. Dr. Mardi Dañez
 - g. Dr. Maricar Bayo-Ang
 - h. Dr. Kaye Chua
 - i. Dr. Miguel Molina
 - j. Dr. Rodeo Navarroza
 - k. Dr. Mika Frio
 - l. Dr. Kathryn Yee
 - m. Dr. Michelle De Jesus
 - n. Dr. Mayce Italia

SCRIBES:

- I. Residents:
 - a. Dr. Shane Villamonte
 - b. Jason Yuhon
- II. Postgrad Interns
 - a. Dr. James Satuito
 - b. Dr. Patricia Sanota
 - c. Dr. Alicia Coscos
 - d. Dr. Jojo Manahan
- III. Clerks:
 - a. Rai Mortel
 - b. Macon Mendoza
 - c. Marione Nicer
 - d. Vito Nicanor
 - e. Marianne Navarette
 - f. Kristel Mendoza

SUPPORT STAFF

1. Robelle Tanangunan
2. Ramon Frio
3. Mary Grace Manansala
4. Romelie Dannug
5. Barry Dones
6. Carlo Tenepere
7. Irene Guna
8. Haydee Gabuay
9. Maricris Ocampo
10. Louie Morales
11. Grace Ongue
12. Kennedy Morales
13. Marlon Gabuay
14. Juliet Brecino

GUESTS

- a. Dr. Marthony Basco
- b. Leonore Basco
- c. Melody C. Milan
- d. Matthew Mila
- e. Guian M. Salgado
- f. Maria Antonio Gabriel
- g. Jedidiah Segui
- h. Mary Joy Irlanda
- i. Israel Vidal
- j. Dr. Juan Javier Lichauco
- k. Dr. Julie Li-Yu

