THANK YOU

Cystinosis Research Network

ASOCIACIÓN MEXICANA DE CISTINOSIS A.C.
Unidos logramos más
The 2nd Cystinosis Training Course was successfully carried out, doctors from Zacatecas, Guadalajara, Toluca, and Mexico City attended punctually to the appointment previously established by our organization, Real de Minas Hotel in San Miguel de Allende was the venue for the course.

Alfonso Huante Anaya MD, nephrologist, and Erika Vargas Quevedo MD & PhD, specialist in Rare Diseases were the coordinators of the course.

Below, we share the relevant aspects of this training course:

**Gemma Ariceta MD, Pediatric Nephrologist, Hospital Va’Hebron Barcelona Spain**

She shared with us general data on cystinosis, including diagnosis, with focus on the renal damage that causes cystinosis, as well as the importance of cystine levels and clinical case including discussion among those present on some manifestations that present cases of Fanconi syndrome/renal tubulopathy.

Ariceta MD also shared important data on specific treatment including Cystagon/Procsb and Cystadrops/Cystaran, presented some tables demonstrating the effectiveness of the treatment and how it works in patient's bodies.

**Konreaad Veys, Pediatric Nephrologist, Researcher at the Pediatric Nephrology Laboratory of KU Leuven, attached to the University Hospital Leuven, Belgium.**

He shared with us the details of hematopoietic stem cell transplantation, presenting advances including a clinical case.

In his complementary talk, he told us about the report on the research study of chitriosidase as a biomarker that will work in the future to determine cystine monitoring in patients with cystinosis.

**Alfonso Huante Anaya MD, Pediatric Nephrologist graduated from the National Institute of Pediatrics and member of the IPNA.**

He talked about renal complications in cystinosis, sharing a whole scheme in tubulopathies, Fanconi syndrome and other complications, reporting a clinical case and putting it up for discussion.
Erika Vargas Quevedo Pediatrictian, Pediatric Internal Medicine, specialist in rare diseases attached to the Centro Medico Nacional 20 de noviembre ISSSTE.

She shared a typical clinical case of cystinosis A/B and discussed diagnosis, treatment, complications, and actions.

Hong Lian MD, Medical Ophthalmologist attached to Quinze-Vingts Hospital Paris France (Video recorded Previously)

She shared with us the generalities about cystine crystals in cornea, treatment with cystadrops and some statistics about the efficacy of the treatment, as well as recommendations during the use of the treatment.

He also told us about some important data on studies performed on patients with cystinosis during the use of cystadrops and alternatives in the use of drugs to alleviate some adverse effects.

This meeting turned out to be a great success and agreements were reached including:

- Mutual strengthening for the benefit of cystinosis patients in Mexico.
- Expanding support in raising awareness on cystinosis
- Teamwork to make possible the analysis of cystine levels.
- Teamwork for research projects

Our thanks to

Cystinosis Research Network

for their generous contribution that made possible this medical meeting