



ASOCIACIÓN MEXICANA  
DE CISTINOSIS A.C.

*Unidos logramos más*

3 rd CNE international Cystinosis Conference  
Leuven, July 7 -10 2022

“Bringing good treatment for Cystinosis patients around the globe”



México City

Patients with cystinosis are mainly treated by a Pediatrician, Nephrologist, Transplant Specialist

These doctors are very supportive, regularly see patients every 3 months

Asking for labtest, and sending patients with specialists áreas when needed.

(or patients ask for special requests)

- We have available **Cystinosis treatment (Cystagon & Cystadrops)**

Access to treatment not affordable, its necessary to do a complete paperwork which takes time

- **We still have the need to continue training physicians, to reinforce**

**their knowledge on points such as the importance of treatment and research.**



**Cystinosis Organization Mexico has contributed to achieve the above mentioned, through the following actions:**

- Training physicians through small meetings with cystinosis experts from different parts of the world.
- Advising patients on the basic care they should receive.
- Establishing for 4 years a program of psychological care
- Family medical conferences
- We have established a financial support program to help patients in difficult financial situations to attend their medical appointments and receive their treatment
- And access to your cystine level analyses



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Thank you

[www.cistinosis.org](http://www.cistinosis.org)



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Asociación Mexicana  
de Cistinosis AC