



FEMEXER

HOW TO

CREATE

EFFECTIVE DIGITAL COMMUNICATIONS





¡HOLA!

I'm

Carlos David Peña
Aragón,

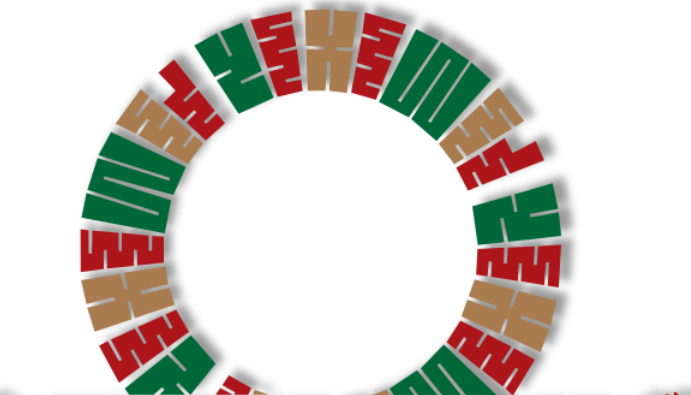
Spokesman of Gaucher
disease in México

...and Head of social
networks in FEMEXER

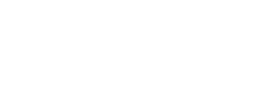
FEMEXER has been over 10 years...

1 Umbrella organization for more than 70 national ONGs for rare diseases.


2 Think-thank and operative arm for those who work and develop strategies to fulfill patient treatments.



FEMEXER



Social Networks


- In COVID-19 times we haven't stop our efforts for those waiting for their treatments.
 - Since 7 years ago we have developed daily infographics for many rare diseases in order to commemorate them.
 - This has been a wonderful strategy for patients, family, representatives, physicians and common people to acknowledge and embrace rare diseases.
 - Plus, we encourage patients and family to register on the first (and only!) national registry for rare diseases in México.
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Infographies and other posters...

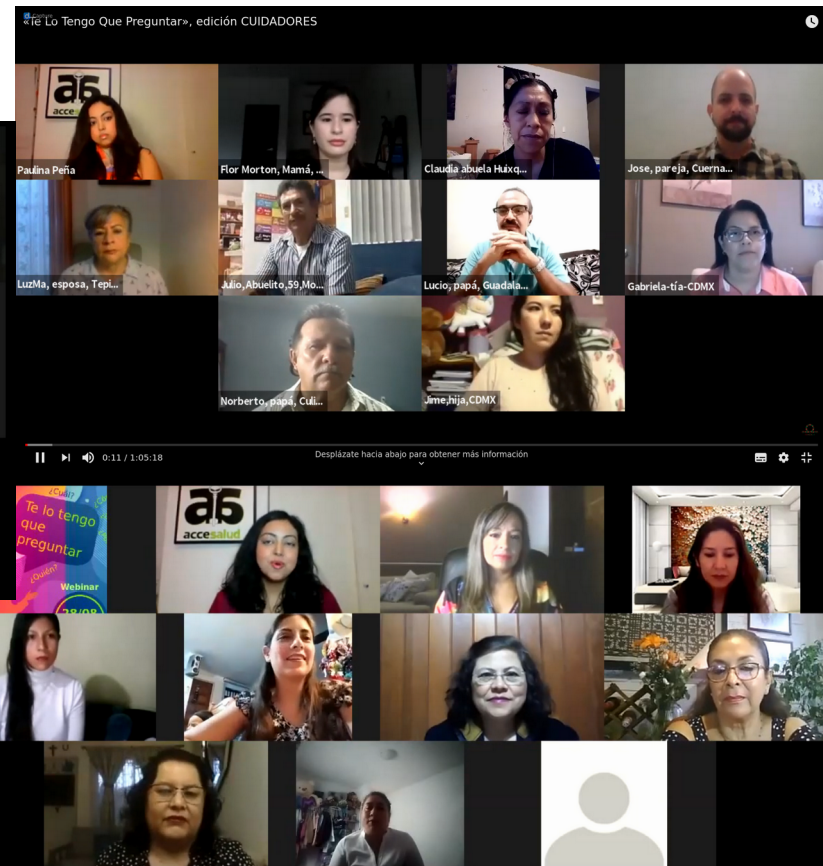
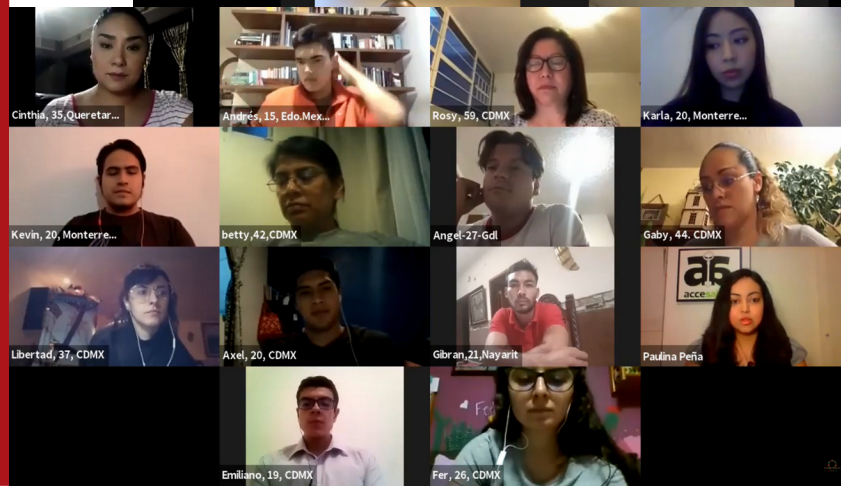


Social Networks

Over this troubled times we've also held weekly Zoom meetings with parents, siblings, caretakers, nurses , physicians so they can share in their own personal way how rare diseases touch their lives.

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Many virtual meetings & interviews with different actors...



Many
virtual
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&
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actors...

YouTube ^{MX} en la Asociación

 46:36 Alejandra Camacho Molina + FEMEXER 30 vistas • hace 2 meses	 35:00 Mitocondriales + FEMEXER. Entrevista a L... 151 vistas • hace 2 meses	 25:09 Esclerosis tuberosa + FEMEXER. Entrevista a T... 10 vistas • hace 2 meses	 31:02 XLH y otros raquitismos + FEMEXER 69 vistas • hace 2 meses	 29:03 Wolf-Hirschhorn + FEMEXER. Entrevista a... 157 vistas • hace 2 meses
 34:57 Hidrocefalias y otras malformaciones del tub... 15 vistas • hace 2 meses	 32:20 Tamiz neonatal ampliado + FEMEXER. Entrevista ... 146 vistas • hace 2 meses	 29:31 Fabry + FEMEXER. Entrevista al líder de... 20 vistas • hace 2 meses	 32:10 Ictiosis + FEMEXER. Entrevista a Asociación ... 412 vistas • hace 2 meses	 35:23 Ehlers-Danlos + FEMEXER. Entrevista a... 225 vistas • hace 2 meses
 46:37 César Alberto Cruz Santiago + FEMEXER 61 vistas • hace 2 meses	 28:53 Angelman + FEMEXER. Entrevista a la Asociació... 90 vistas • hace 2 meses	 29:03 Atrofia muscular espinal + FEMEXER. Entrevista a... 30 vistas • hace 2 meses	 43:47 Juana Inés Navarrete Martínez + FEMEXER 59 vistas • hace 2 meses	 1:00:30 Gabriel Cortés Gallo + FEMEXER 10 vistas • hace 2 meses
 1:04:55 Ricardo Cortés Alcalá + FEMEXER. 27 vistas • hace 2 meses	 32:42 Mielofibrosis + FEMEXER. Entrevista a NeuroSER 26 vistas • hace 2 meses	 31:24 Morsier + FEMEXER. Entrevista al grupo de... 144 vistas • hace 2 meses	 33:08 Albinismo + FEMEXER. Entrevista a la Fundació... 28 vistas • hace 2 meses	 7:05 ¡Lo vamos a lograr! 23 vistas • hace 2 meses

2021

RDD

DE-STIGMATIZING «RARE»



Rare Disease Day 2021

We're working alongside with standup comedians and influencers from Mexico and Latin America to develop a video to de-stigmatize people with rare diseases in a friendly and fun way.

In this way, we hope people will embrace their diseases and we'll all be able to work side by side.

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THANK YOU
