10th International Erdheim-Chester Disease Patient & Family Gathering

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Emotional Support Project for Families and Patients with Histiocytosis-ECD

Laia Ferrer Botella
Psycologist-Psycomotricist
Col.Num. 15.278
laia_psicomotri@gmail.com
orasociacion@gmail.com

Why This Program?

- Rare diseases like histiocytosis-ECD deeply affect psychological and emotional health.
- Patients and families face isolation, fear, uncertainty, lack of information, and emotional overload.
- The healthcare system often lacks specialized and continuous psychological support.
- We believe it is vitally important to complement medical treatment processes with patient empowerment through emotional management and support.

“In the beginning…We didn’t know if it was serious, if it could be cured, or if it could happen again. We felt alone."

ASOCIACIÓN DE AYUDA A LA HISTIOCITOSIS

Who We Are

OR Asociación: Patients affected by all types of Histiocytosis and ECD.
Founded in 2013 by the father of a child diagnosed with Multisystemic Histiocytosis.
Patient advocacy group based in Barcelona with international reach.
We promote research, visibility, and emotional support.

How We work

- Team of 3 specialized psychologists: Childhood, Adolescence, Families, Adults.
- Comprehensive Approach: systemic therapy, narrative, cognitive-constructivist, and grief therapy.
- 90% of sessions conducted online (reaching 7 countries).
- International collaboration with the Histiocytosis Association and ECDGA (simultaneous translation, expansion).

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What We offer

- Free, professional, and personalized program.
- Child and Adolescences psychotherapy and psychomotricity.
- Individual, family and couple's therapy.
- Parenting guidance.
- Monthly online **support groups:**
  - Adults with a diagnosis.
  - Parents of pediatric patients.

Provide a space for emotional sharing, psychological care, and specific information about the disease.

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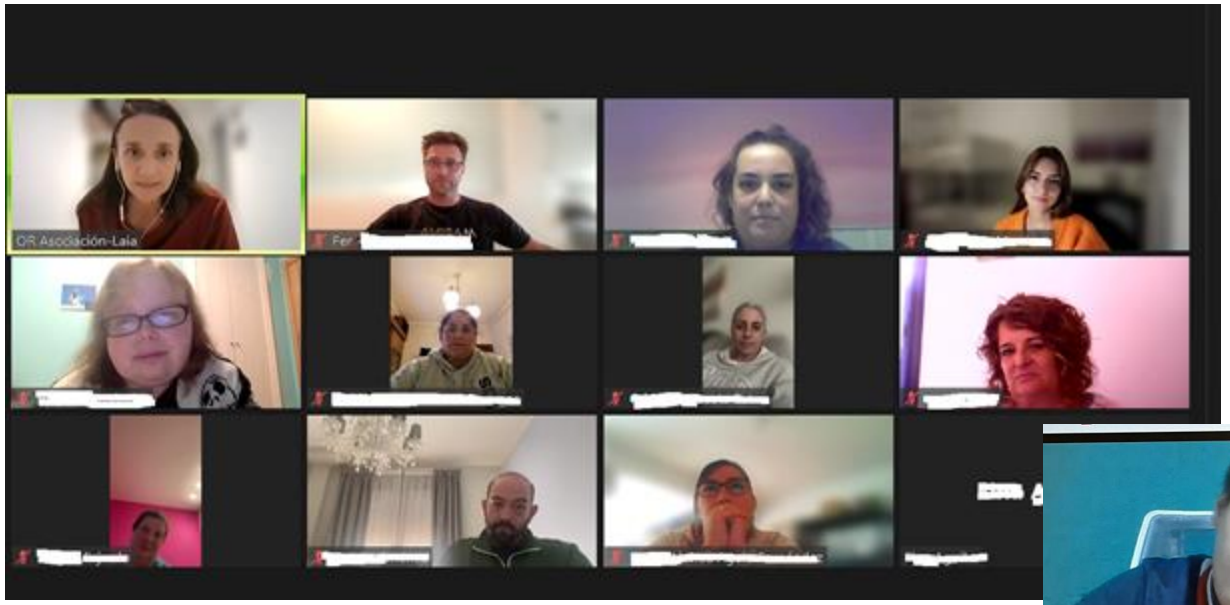
Emotional Impact



Feeling heard, understood, and supported.

Building community and empowerment.

Transforming pain into shared action.

It's not so much about the disease itself, but about how they live with it.

Closing

Emotional support matters.

We don’t just treat symptoms; we accompany stories.

We create a space to be vulnerable, connect, and heal.

Thank you for your attention.

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