

II XUEC CONFERENCE ON SYSTEMIC AUTOIMMUNE MINORITY DISEASES

February 21st, 2024

SABADELL

Parc Taulí University Hospital

Organized by:

XUEC-AIS with the support of the Catalan Health Service

HOSPITALS THAT ARE PART OF XUEC-AIS (Network of Clinic Expertise Units – Systemic autoimmune diseases)

WHO ARE WE?

Coordinators XUEC-AIS 2023-24

HPTS: Dr. Jordi Gratacós

HCB: Dr. Ricard Cervera

Coordinators at each UEC (Clinic Expertise Unit)

Pediatric UEC:

Hospital Sant Joan de Déu: Dr. Jordi Antón

Hospital Universitari Vall d'Hebron: Dra. Estefanía Moreno

Hospital Universitari Parc Taulí: Dra. Judith Sánchez-Manubens

Adult UEC:

Hospital Universitari Vall d'Hebron: Dra. Sara Marsal

Hospital Universitari Bellvitge: Dr. Francisco Javier Narváez

Hospital de la Santa Creu i Sant Pau: Dr. Iván Castellví

Hospital Universitari Parc Taulí: Dr. Jordi Gratacós

Hospital del Mar: Dr. Tarek Carlos Salman

Hospital Clínic de Barcelona: Dr. Ricard Cervera

PRESENTATION

Systemic autoimmune diseases are caused by an abnormal response of the immune system against the affected individual. They are chronic, complex, and potentially serious diseases with a multifactorial etiology (genetic, hormonal, and environmental factors). They form a heterogeneous group of diseases with significant differences in their incidence, prognosis, treatment, and clinical manifestations, but all sharing the immune-mediated phenomena acting against the body's cells, tissues, and organs, leading to dysfunction of the affected structures.

In Catalonia, the care for rare diseases (RD) involves healthcare professionals from different fields, combining a high degree of specialization and clinical expertise with daily and close support for affected individuals and their families. This comprehensive, integrated, and quality care is patient-centered, focusing on the individual and their immediate environment through a network of centers and services working in coordination to address the healthcare, educational, and social needs of individuals with rare diseases and their families.

This care is provided through two levels of assistance:

1. The territorial or community-based team as the primary reference at home, which includes the primary care team, specialized hospital care, reference specialist centers in the region, social services, and educational services.
2. High-specialization teams in hospitals, organized into Networks of Clinical Expertise Units (XUEC). XUECs are clinical services comprised of a multidisciplinary team of professionals with a high level of knowledge and expertise.

These two levels of assistance work together, and their coordination is managed by hospital case managers, who also provide assistance to affected individuals and their families and offer support.

For more information, you can visit: <https://canalsalut.gencat.cat/ca/salut-a-z/m/malalties-minorities/atencio-tractament#bloc1>

ADDRESSED TO

Specialized physicians, primary care professionals, territorial reference hospitals, patients with Systemic Autoimmune Rare Diseases (SARD), family members, and patient associations.

OBJECTIVES

1. Raise awareness about Clinical Expertise Units in Systemic Autoimmune Rare Diseases (SARD) and how to access them.
2. Provide patients with SARD information about quality care and access to highly specialized health services.
3. Showcase the work carried out by a multidisciplinary team and the network collaboration among recognized clinical expertise units.
4. Facilitate collaboration and coordination among all professionals in the network (XUEC Territorial Reference Hospitals - Primary Care).
5. Collaborate with patient associations.
6. Share knowledge.

ACCREDITATION:

Activity accredited by the Catalan Council for Continuing Education of Healthcare Professionals - Continuing Education Commission of the National Health System. A certificate of attendance will be provided to all attendants in 100% of the sessions.

ENDORSEMENT:

The II Conference on Systemic Autoimmune Rare Diseases by XUEC-AIS has received the endorsement of the European Reference Network on Rare Connective Tissue and Musculoskeletal Diseases (ERN ReCONNET).