

#### FAM-WEST. West Syndrom: building knowledge and singularity of the families experiences

Sophie Arborio, Emmanuelle Simon, Stéphane Auvin, Anne de Saint Martin

#### ► To cite this version:

Sophie Arborio, Emmanuelle Simon, Stéphane Auvin, Anne de Saint Martin. FAM-WEST. West Syndrom: building knowledge and singularity of the families experiences. 13th European Congress on Epileptology, Aug 2018, Vienne, Austria. , 2018. hal-01834303

#### HAL Id: hal-01834303 https://hal.univ-lorraine.fr/hal-01834303

Submitted on 10 Jul 2018

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers. L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

# FAM-WEST

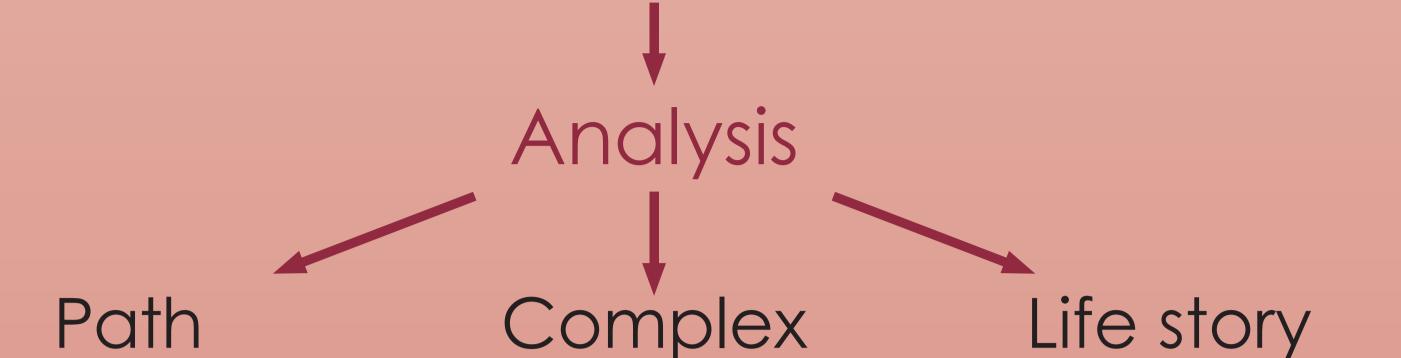
# West Syndrom: building knowledge and singularity of the families experiences

S. Arborio (MCU HDR, Université de Lorraine, Crem) – sophie.arborio@univ-lorraine.fr E. Simon (MCU, Université de Lorraine, Crem) – emmanuelle.simon@univ-lorraine.fr Pr. S. Auvin (PU-PH, Hôpital universitaire Robert-Debré, Inserm) – stephane.auvin@rdb.aphp.fr Pr. A. De Saint Martin (PH, Hôpital de Hautepierre) – anne.desaintmartin@chru-strasbourg.fr

> Associations Les Enfants de West, ASTB, Injeno

# Purpose

How knowledge and "know-how" are constructed by families in the case of West's syndrome (WS)?



# Methods

### A multidisciplinary research

- 30 families with children ages from 11 months to 15 years
- 60 semi-structured interviews with the mothers
- Participating observations at the hospitals and at the families homes (18 months) • Exchanges analysis through the discussion forum (Facebook Enfants de West)

- of illness / disability
- diagnostic and therapeutic

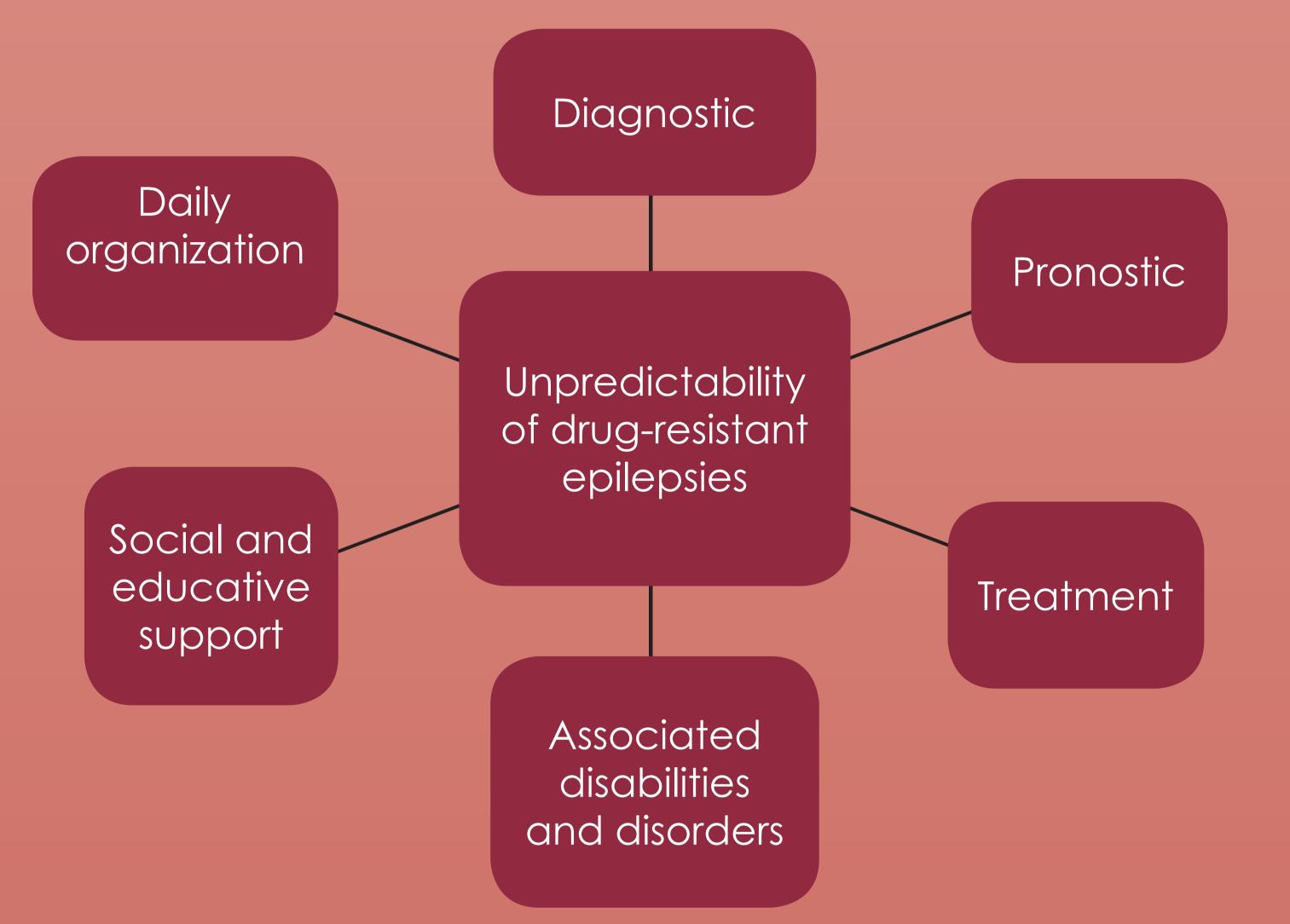
routes

of families

# Preliminary Results

Emphasize the importance of experience in building mothers' knowledge of care.

## **Knowing how to do with uncertainties?**



# **Experiencing the knowledge**

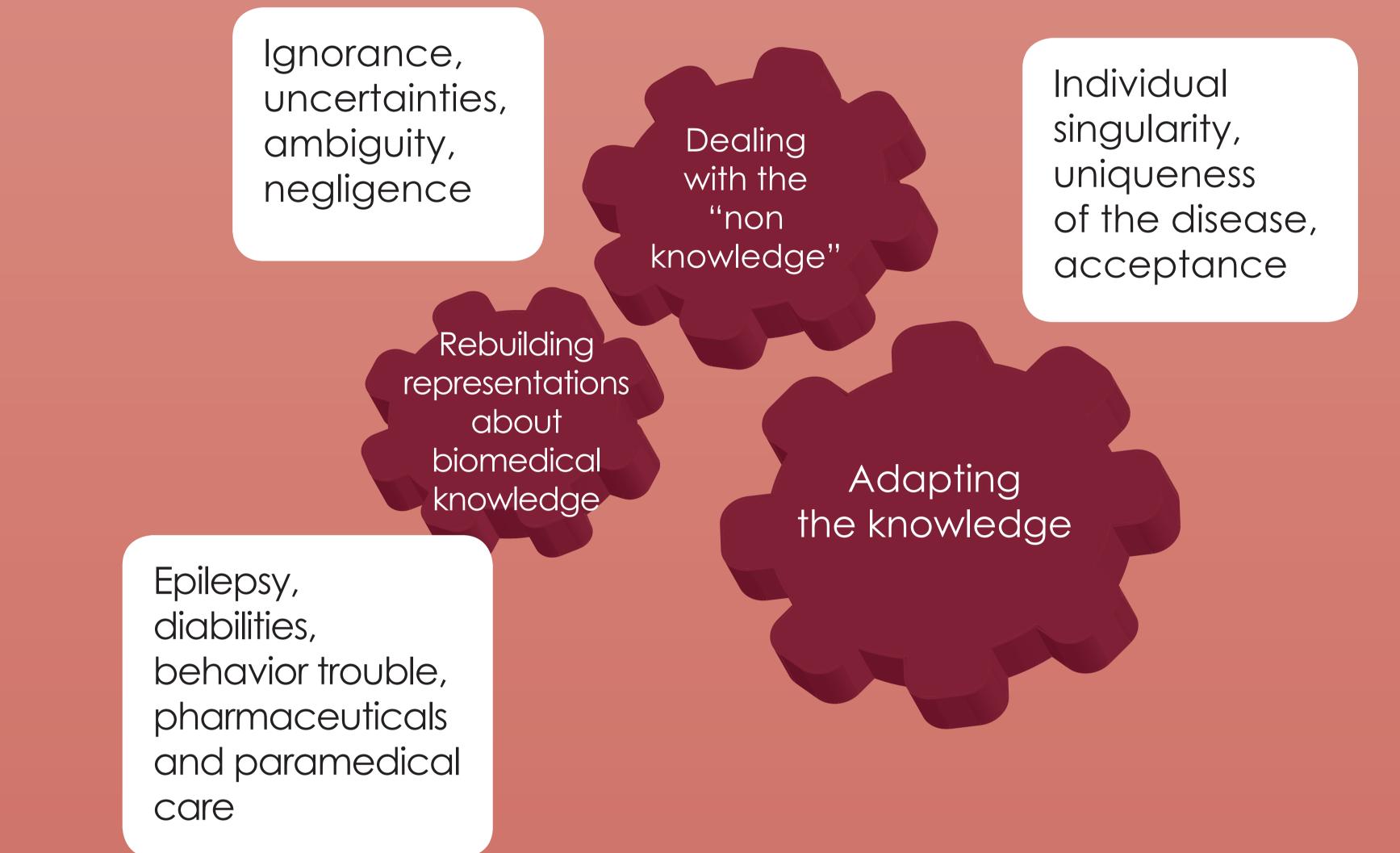
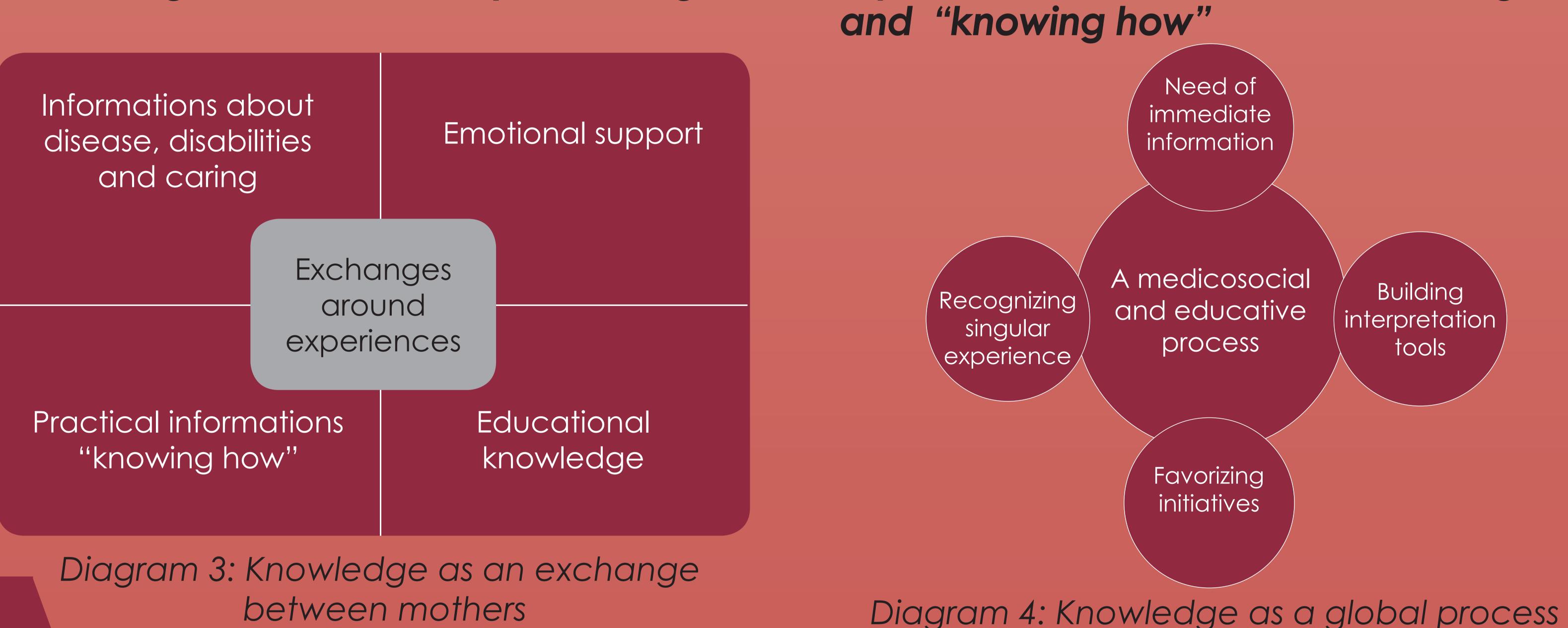


Diagram 1: The different levels of unpredictability

#### **Knowledge as a necessary exchange**

## Diagram 2: Knowledges as a building process

## A process as the interface of knowing



# Conclusion How to build patient educational programs?

Emphazing through a diachronic process the families experiences ("knowing how") instead of only the medical "knowing that" help to adapt educational programs to families daily care.

maladie

rares

Emphazing on a global approach rather than a medical one

Privileging experience as a possible answer to uncertainties

de parents d'enfants extraordinaires

Viewing educational program as a structured and social exchange

Offering time to rebuild parental identity

Les Hôpitaux

**Universitaires** 

de STRASBOURG

Hôpital universitair

Robert-Debré

ASSISTANCE DE PARIS

astd

Association française

sclérose tubéreuse de Bourneville

