

ORAL PRESENTATION

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Medical education: the role of patients

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Health care professionals cannot be taught or know about 6 000 to 8 000 rare diseases. Though research, care and treatments progress every year, rare diseases are chronic, severe, complex and disabling conditions affecting patients and their families 24 hours a day. The national plans in France organise a 2 hours course for medical students to raise awareness and provide tools. 2 mothers of children living with rare diseases participated in a 20 hour pilot course in a medical school in Paris. During this course, they present the outcomes of the EurordisCare studies (12 000 questionnaires to patients and families throughout Europe), discuss their daily experiences with students and present the complexity of a very necessary comprehensive approach for rare diseases: medical, educative, social, from childhood to adulthood, extended to parents and siblings.

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