Exclusive screening of the film *"Complicated"* on Ehlers-Danlos syndrome

Presented in partnership by

RQMO
REGROUPEMENT QUÉBÉCOIS DES MALADIES ORPHELINES

EDS Foundation

November 1, 2025 in Montreal

An "Open-Eye Pictures" production

Summary of the discussion with the audience after the screening of the film

Film « Complicated » on Ehlers-Danlos syndrome (EDS)

- Film produced by « Open Eye Pictures »
- Information on the film and film preview: https://openeyepix.org/complicated

« COMPLICATED tells the untold stories of children suffering from complex, invisible illness, marginalized by a medical system that fails to provide the care they desperately need. Shuffled between specialists, misdiagnosed, and often labeled with psychological disorders, these young patients fight for validation, respect and normalcy. The film exposes a dark side of pediatric medicine, where parents pushing for answers risk being accused of medically harming their children and even losing custody. » *(excerpt from Open Eye Pictures' website)*

- Although the participants found the film shocking, they believe it is necessary to show these extreme cases, because they exist in Quebec, to raise awareness and "wake up" the medical community. Some know people who have had similar experiences as the young women in the film.

- Gail Ouellette of the RQMO and Sandy Smeenk of the EDS Canada Foundation testified to the high number of people with Ehlers-Danlos syndrome (EDS) who contact their organizations and some people in situations as dramatic as those presented in the film.

- The participants expressed their satisfaction at meeting others today who have been diagnosed with EDS or who suspect they have it—people who understand them and do not judge them.

- People have recounted their long journeys before receiving a diagnosis, or still without an official diagnosis at this time: 22 years, 14 years, and so on.

- Many were not believed and were referred to psychiatry. They received diagnoses of psychosomatic illness, functional neurological disorder, etc. They are told, "It's all in your head"; they are accused of "shopping around" for doctors; they speak of "trauma inflicted by medical staff." They are traumatized by the reactions of doctors in the emergency room.

- The fact that these judgments are recorded in their medical file follows them and harms them even further.

- One mother says she hasn't been accused of child abuse like the mothers in the film, but she often felt that doctors suspected she was inventing her child's symptoms.

- Another mother, who sees symptoms beginning to appear in her children, is afraid to speak up in case she isn't believed.

- Communication with doctors is difficult. Especially since consultations are limited to 15 minutes and a single health issue (even though EDS is a multi-systemic disease!).

- One person reports experiencing frustration that leads to fatigue, which in turn impacts her condition.

- It's difficult to observe that elsewhere care and treatment are available for this disease, while in Quebec and in rest of Canada there are so few services. We rely on other affected individuals to learn and get help. It's difficult to have to be an expert on the disease yourself, instead of doctors who don't know much about it. It's stressful…

- Some people have suggested training medical students and using artificial intelligence for diagnosis, for example.

Summary written by Gail Ouellette, RQMO

15 ANS RQMO

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