MYT1L

Les extra vaillants

Neurodevelopmental disorder linked to the MYT1L gene

ORPHAcode : 647799

- Rare genetic abnormality on chromosome 2p25.3, including the MYT1L gene
- As a deletion or mutation
- Usually inherited from asymptomatic parent or de novo

Involving

- Global developmental delay
- Heterogeneous profiles: from multiply handicapped to supported autonomy
- Severity and number of impacts vary from patient to patient
- Lifelong need for extra support at variable levels

Les Extra-Vaillants MYT1L

extravaillants@gmail.com

- Partnerships : Referential Center for developmental disorders at Rouen University Hospital, AnDDI-Rares health network
- Member of the Alliance des Maladies Rares
- Association of general interest

Site internet

Facebook

YouTube

Join us!

IMPACTS

- Predominantly language delay
- Intellectual disability or learning disability
- Almost 100% of individuals exhibit behavior disorders (alone or in combination), including ASD
- Psychomotor development and coordination disorders
- Weight disorders and/or eating behavior disorders
- Neurovisual disorders
- Sleep disorders
- Fatigability
- Epilepsy
- Non-specific dysmorphia
- Possible brain MRI abnormalities
- Possible EEG abormalities

TREATMENT

- **NO SPECIFIC TREATMENT TO DATE**
  Strict treatment or frameworks can be put in place for certain impacts

- **REQUIRES EARLIEST POSSIBLE MULTIDISCIPLINARY SUPPORT**
  medical, therapeutic, social-emotional and educational

FAMILIES

- As of November 2023, nearly **200 families worldwide*** and **48 families in France***.

(*families who have joined the association or primary family FB group)

MORE DETAILS and INFORMATION

- **on the association's website,**
- **YouTube channel**

Watch the replay of the MYT1L families, clinicians and researchers day held on 11/25/22 at Rouen University Hospital, a simplified video explaining the pathology and the role of the association Les Extra-Vaillants MYT1L

Site internet

YouTube

SCHOOL AND CAREERS (US)

A RANGE OF OPTIONS

MAINSTREAM SCHOOL (public or private)

- Mainstream class or special class with high teacher:student ratio
- Extra supports may include 1:1 aide, test accommodations, simplified curriculum/life skills focus, resource room, and/or in-school therapies like PT, OT, speech therapy, counselling.

DEDICATED SPECIAL NEEDS SCHOOL

HOME SCHOOLING with support from school district

INDIVIDUALS WITH DISABILITIES ACT GIVES EACH CHILD A RIGHT TO "FREE AND APPROPRIATE PUBLIC EDUCATION (FAPE) TO AGE 21 OR 22"

- If local schools cannot provide FAPE, school district must fund an appropriate alternative.

HEALTH INSURANCE MAY OFFER FUNDING FOR THERAPIES SUCH AS APPLIED BEHAVIOR ANALYSIS (ABA), OT, PT AND SPEECH

STATE MEDICAID WAIVER PROGRAM AND DEPARTMENT OF MENTAL HEALTH MAY OFFER FUNDING FOR SPECIAL EQUIPMENT, SPECIAL SUMMER CAMPS, AND RESPITE PROGRAMS.

ADULT CAREERS are less known; most people identified are under age 21. Some adults work part-time and live independently with supports, while others are unable to work or live independently. At the time of graduation, school districts must provide transition plan.

MYT1L PATIENT

- Name
- Phone number
- Mail

INFORMATIONS YOU WOULD LIKE TO SHARE ABOUT YOUR CONDITION