MYT1L

Les extra vaillants

Neurodevelopmental disorder linked to the MYT1L gene

- Global developmental delay
- Heterogeneous profiles: from multiple disabilities to supported autonomy
- Severity and number of impacts vary from one patient to another
- Lifelong support and care

Les Extra-Vaillants MYT1L

extravaillants@gmail.com

- Collaborations: AnDDI-Rares Health care network, Rouen University Hospital's Reference center for developmental anomalies
- Member of the Alliance des Maladies Rares
- Association recognized as being of general interest

Site internet | Facebook | YouTube

Come and join us !

Les extra vaillants

IMPACTS

- Predominantly language delay
- Intellectual disability or learning disability
- Almost 100% behavior disorders (alone or in combination)
- Psychomotor development disorder
- Weight problems and/or eating disorders
- Epilepsy
- Brain MRI abnormalities
- Neurovisual disorders
- Sleep problems
- Fatigability
- Non-specific dysmorphia

TREATMENT

- NO SPECIFIC TREATMENT TO DATE FOR THIS SYNDROME
- Treatment or strict frameworks can be put in place for certain impacts
- MOST EARLY POSSIBLE multidisciplinary support is needed (medical and paramedical, medico-social, educational)

GUIDELINES for learning

- Encourage a 1:1 approach to learning
- Building self-confidence
- Reinforce commitment to the task
- Increase attention
- Help with positive emotional management
- Feedback on progress

! Individual help is not an obstacle to autonomy

- Use planning tools and markers.
- Support learning with visuals and manipulatives
- Compensate for the gesture with a tablet or a computer or mobile letters if necessary.
- Accept to give and take more time, it may be very tiring for the person.
- Have ambition and a project built in the proximal zone of development

FAMILIES

- By February 2023, more than 180 families identified internationally and nearly 40 families in France (families who have joined FB groups or the association)

MORE DETAILS and INFORMATION

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

with the conference replay of the MYT1L international physicians, clinicians and families day - 25/11/22 - CHU of Rouen

Site internet

YouTube