

family support project

respite weekend for ELA families

- Objectives**
- Bring together families affected by leukodystrophy
 - Get together, recharge their batteries, unwind, reconnect, and break out of isolation

Budget **Total cost of the project: €280,000 (accommodation / catering / activities, etc.)**
Average cost per family: €1,550

Durée 3 days in August

Description Living with a person affected by leukodystrophy on a daily basis means taking care of them 24 hours a day. Those close to the affected person are caregivers (parents, brothers, sisters, spouses, etc.). They provide daily physical and moral support, which tires them and can lead to a form of isolation.

During a weekend, families benefit from a pleasant setting, leisure facilities adapted for their children, and activities that allow them to share moments of well-being and conviviality.

Dedicated activities, workshops and entertainment are organised to help children and families relax. They also benefit from information meetings and discussion groups.

Impacts 180 ELA families, representing 900 people, are participating in the respite weekend. Children and parents are enjoying moments of happiness, escape, conversation, new encounters and mutual support.



**Video: "Give our champions
a moment of respite !"**

<https://youtu.be/9tONGNGGFIM>

