

# The diseases are rare but the patients are numerous!

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In Switzerland, it is estimated that between 530,000 and 700,000 people are affected by a rare or orphan disease. On the European level, 30 million individuals are affected. In 80% of the cases, these diseases are of genetic origin.

AEMO, created in 2004, whose headquarters are located in Monthey, is a non-profit association, recognized as being of indispensable public value. It has the uniqueness of taking into account all the rare or orphan diseases listed by Orphanet<sup>\*</sup>.

A rare disease is a disease that has a low prevalence in the population. In Europe, a disease is said to be rare when it affects less than 1 in 2,000 people in the general population.

Orphan diseases are those for which there is no effective treatment, i.e. there is no cure for the disease. The treatments proposed for these diseases are limited to reducing the symptoms. This means that it is vital to assist the children and their families with targeted help.

Orphanet is a unique resource resulting from a European effort, gathering and improving knowledge on rare diseases, in order to facilitate and improve the diagnosis, care and treatment of patients with rare or orphan diseases.

# **OUR HELP/SERVICES**

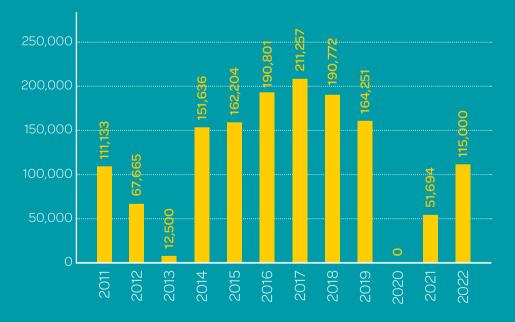
# **Helping families**

Each year, AEMO organizes a fundraising campaign to provide direct assistance to families living in Switzerland.

Currently, AEMO supports 130 families, 120 of which are in French-speaking Switzerland, covering costs and care not covered by insurance.

#### **Funding therapies**

Therapies such as First Step help families improve the daily life of their sick children. With the help of these therapies, these patients progress in their actions, their language, their behaviors, their autonomy... the family regains a little reassurance and hope.



#### First Step grants (in CHF)

The small amounts allocated to First Step in 2020 and 2021 are directly related to health crisis (inability to gather, cancelled therapies, etc.)

financial transparency ethical approach honesty in advertising professional guidance

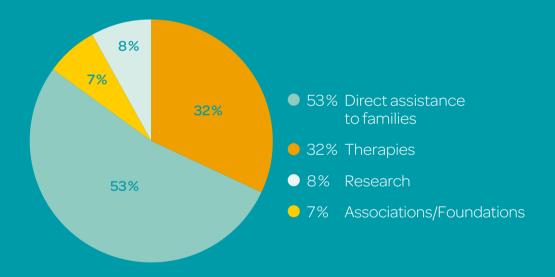
# Supporting hospitals, researchers, associations or dedicated foundations

AEMO financially supports specific parts of research programs that concern rare or orphan diseases as well as the activities of institutions such as Orphanet.

## Inform and educate

To provide the general public with information so they are aware of the difficulties encountered by families and the assistance options available to them. We contact nearly 30,000 people by phone each year and we distribute 15,000 copies of detailed brochures.

# Distribution of aid for 2022





**7,000** rare diseases listed.



more expensive, health care expenses among people with rare diseases.



**Over 6,5 millions** francs redistributed to the cause of orphan diseases by AEMO.



#### Our committee is composed of six members. It directs and represents AEMO. It takes all useful and strategic decisions of the association.

We also have an ethics committee that visits families, wherever they are in Switzerland, in order to clearly identify the specific needs of the child, to understand the reality of the family situation as closely as possible, on all moral, financial and therapeutic levels. This ensures that the financial resources of AEMO are used correctly.

#### **MANAGEMENT COMMITTEE**



Bhira Meyer President



**Olivier Meyer** Vice President



Francesca Seegy Member



Silvana Gonzalez Member



Jacques Guhl Member



**Dre Loredana D'Amato Sizonenko** Member, Orphanet Switzerland coordinator

#### THE ETHICS COMMITTEE



Manon Weibel Rosello



Sylviane Puhovic Moreillon

# ONE SUPPORT, MANY BENEFITS:

## Image

It is always good to support associations, children and families in difficulty. Your image is strengthened and your level of activities and occupations is increased tenfold.

# Visibility

Depending on the support provided, your logo will appear on our website, our detailed brochure, our roll-ups and other supports according to the deployment of our activities.

#### **Tax deduction**

Thanks to our certificate of support.



#### DONATE:

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