

What is Progena doing?

Supporting research

If research against rare genetic diseases is making progress each day, it is important to know that it doesn't benefit from state subsidies of any kind, and moreover, it is not profitable enough for the large pharmaceutical companies. Research hence depends entirely on private funding from foundations, associations or individuals.

This is one of Progena's reasons to exist: being able to perform **fundraising actions** in order to finance research against rare genetic diseases.

Supporting families

The diagnosis is devastating for the parents, for whom life will never be the same again. The family is destabilised at times when children need to feel safe and comforted. It is therefore crucial to set up multiple care plans in order to slow down the progression of the disease. Parents who are not in the position to suddenly face all these complex changes need help to draw the best out of the existing infrastructures.

Progena's mission is to help the parents by providing **detailed information** on the website www.progena.ch and by organising **parent meetings** on a regular basis.

Progena is committed to

- respecting your wish and allocating your donation to the projects you feel most concerned about
- managing the funds carefully and providing regular updates on the website www.progena.ch
- respecting your anonymity.



Action for children affected
by rare genetic diseases

Who can donate?

The act of giving is universal.

Each and everyone of you can contribute to help
Progena: individuals, associations, companies...

Maybe you?

Online:

www.progena.ch

By postal account transfer:

CCP 17-587864-8

In favour of Progena Foundation

By bank account transfer:

IBAN: CH30 0900 0000 1758 7864 8

BIC: POFICHBEXXX

Progena is a non profit, public utility foundation benefiting from tax exemption status. Thus, donations and bequests are deductible from tax, accordingly to local regulations.

Progena is a Swiss foundation, which purpose is to finance the research against rare genetic diseases of the child and to support the concerned families.

www.progena.ch
contact@progena.ch



Action for children affected
by rare genetic diseases





Where does the money go?

Targeted actions

Clinical trials for rare genetic diseases are currently being set up both in Europe and in the US. Through national registries, each country needs to ensure the participation of patients who could potentially benefit.

In 2008, the **Swiss Registry of Patients** suffering from SMA and DMD/BMD was established under the supervision of Doctor Pierre-Yves Jeannot, Neurological Pediatrician at the CHUV in Lausanne, and Doctor Andrea Klein, Neurological Pediatrician at the Children's Hospital in Zurich.

From the outset, Progena has contributed financially to the Swiss Patient Registry project, ensuring that Swiss patients participate in these crucial clinical trials in Europe and elsewhere.

Progena not only finances this type of project but also raises awareness in order to access public funds.

New projects are constantly under evaluation.

The Progena Foundation attaches great importance to the allowance of the funds entrusted by donors. In order to maintain a high efficiency level, the funds are assigned to specific projects, which have been thoroughly analysed and controlled by our committee.

Locally...

Parents of children who suffer from rare genetic diseases undergo huge changes in their everyday lives. They often need help with challenges such as integration at school, logopedics, ergotherapy, physiotherapy, auxiliary means, nutrition, and adapting the household.

To help parents find answers, support and especially understanding about all these issues, Progena started **meeting evenings** in 2008 for parents who have children who suffer from neuromuscular diseases.

These evenings serve as a forum where parents can meet and talk with other parents. Occasionally, specialist speakers (scientists, doctors, social workers...) are invited to share views with the parents. 3 to 4 meetings are organised each year and are considered very successful. The evenings programme can be consulted on: www.progena.ch.

Anyone who feels concerned by rare genetic diseases and wishes to meet other families, can contact Progena by e-mail at: contact@progena.ch

...and internationally

Due to the character and rare incidence of these diseases, it is absolutely essential to join forces and act across borders to find a common solution to fight and eventually treat these diseases. Progena represents Switzerland within larger associations and organizations in Europe as well as in the rest of the world.

Progena is hence a member of **UPPMD**, United Parents Projects Muscular Dystrophy, which brings together national organisations of parents with children suffering from DMD.

Progena is also member of **Treat-NMD**, a network created and financed by the European Commission in 2007. Its main objective is to establish therapeutic treatments and to accelerate the availability of treatments for patients suffering from neuromuscular diseases.



United Parent Projects
Muscular Dystrophy

