Swiss Angiodysplasia Association

Angiodysplasias: understanding, connecting, supporting

Angiodysplasias are rare, congenital vascular malformations that alter the structure and function of blood and lymphatic vessels. They can occur in all regions of the body – most commonly in the arms and legs – and may present in very different ways.

Typical symptoms include chronic pain, swelling, blood loss, skin changes, and lymphatic congestion.

Additional characteristics may be, for example, naevus flammeus (port-wine stain), growth disturbances (over- or underdevelopment of affected body areas), as well as functional impairments resulting from secondary conditions.

Angiodysplasias occur in different forms, including:

- Arteriovenous malformations (AVM)
- Venous malformations
- Lymphatic malformations

Some individuals are also affected by more complex syndromes, such as:

- Sturge–Weber syndrome
- Klippel–Trénaunay syndrome
- Parkes–Weber syndrome
- PIK3CA-Related Overgrowth Spectrum (PROS)
- PTEN Hamartoma Tumor Syndrome (PHTS)

These conditions are medically complex and often poorly understood – for those affected, this can be distressing and isolating.

The Angiodysplasia Switzerland Association is a self-help group for people with congenital vascular malformations and their relatives. Founded in 2025, we are committed to connecting those affected, sharing experiences, and finding solutions together.

Personal exchange is at the heart of our work. Through regular online meetings, our communication channels, and occasional in-person gatherings, supportive connections are formed – along with the feeling of being understood. In the context of rare diseases, this is far from self-evident.

An interdisciplinary medical advisory board supports our work and provides expert guidance. This helps ensure that our activities remain professionally sound and assists affected individuals in navigating everyday medical care.

Our goal is to contribute to improving the healthcare situation in Switzerland in the long term, to raise awareness of these conditions, and to promote dialogue with the medical community. Everyone who wishes to get involved is welcome – whether as an affected person, a family member, or a healthcare professional.

Rare, but
not alone

Together we are stronger, can learn from one another, and achieve much more.

Would you like to be part of it too?

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