



Italian Macroductily and PROS Association

About AIMP

When your child is diagnosed with a rare disease it can be very tough, especially if no informative resources are available.

Our patient-led organization was started in 2017 by parents of children with macroductily and now **provides support to persons with all the [PIK3CA related conditions](#)** and their families.

We have a **Scientific Committee** and co-operate with various clinicians, researchers and clinical centers with expertise in our conditions.

Our vision

Our vision is a world where...

- the **natural history** of macroductily and PIK3CA related conditions is well characterized
- shared **recommendations for diagnosis and management** exist
- persons with PIK3CA related conditions can have **equal access** to diagnosis, clinical, medical and social care and to opportunities for self-realization.

We are committed to...

- Mutual aid
- Support and information for families
- Support for research
- Collaboration with clinical centers and other patient groups

Some of our achievements

- Dec 2017 → 1st Italian meeting on macroductily (families and doctors)
- Nov 2018 → macroductily recognized as a rare disease and exemption from out-of-pocket costs for diagnosis and care
- Oct 2020 → Online webinar on PIK3CA related conditions (families and doctors)

Ongoing and mid-term projects

- ✳ Developing diagnosis and management recommendations specific for Italy
- ✳ Finalizing an agreement with a Telethon Biobank
- ✳ Expanding the PROS network in Italy
- ✳ Developing additional educational materials for persons with PIK3CA related conditions and their families
- ✳ Creating a disease registry

About macroductily

Macroductily is a condition where a baby's toes or fingers and/or the entire hand/or foot are enlarged due to overgrowth of bone, soft tissue and nerves. It can severely impact a child's ability to perform **normal activities**. Macroductily is not inherited and is often a [PIK3CA related condition](#).

Surgery is currently the only treatment option available and is aimed at restoring function.

Medical treatment and access to clinical trials is generally not available due to an unfavorable risk/benefit balance.

