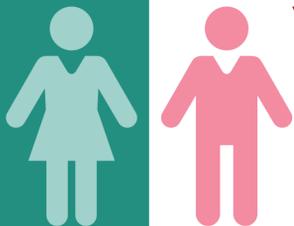




MEMBERS IN ABRANGHE

1.642 patients



216 youngsters age 12-26 patients/caregivers

INFORMATION ABOUT THE MEMBER ORGANISATION

1 major achievement of member organization for patient community



ABRANGHE (Brazilian Association of Hereditary Angioedema), helps us in difficult times with the exchange of information, giving guidance on treatment options available and giving space to share experiences, showing that there are more people who are going through the same as we are, showing us that we are not alone and creating strong bonds of friendship.

Current available treatment options

For Prophylaxis:
Danazol,
Tranexamic Acid,
Oxandrolone

For Crisis:
Icatibanto
C1 Inhibitor
Lanadelumab
(Judicial Request)

Barriers to accessing treatment

The treatment of Hereditary Angioedema is very difficult in our country. Most of us do not have access to specific medications, which is why we use Danazol, Tranexamic Acid and Oxandrolone as prophylaxis. In order to have access to treatment, we need to go to court and still have the risk of not getting it. In case of acute crises, our best option is to transfuse fresh plasma, even though it is not the ideal treatment, because it can cause adverse reactions, such as allergies. The high cost of medication is a problem for patients in Brazil.

YOUNGSTER'S EXPERIENCE

Common challenges that young patients experience

In Brazil, young people, beyond the difficulties we have to access specific medications, suffer from obstacles to deal with some stressing situations, destabilizing us emotionally. We have limitations to carry out some activities that can cause us crises, such as some sports and hobbies. It is also important to note that this can have consequences for academic life, because sometimes it is possible that we will have to miss classes and tests at school or colleges due to unexpected crises.



What does "Creating a path to better health" mean to you?

"In order to have better health, we must reduce the limitations that crises bring us to have a normal life, but for this to happen, we must have equal access to specific prophylactic medication for treatment."