

## Membership charter for ALAN Maladies Rares Luxembourg

This membership charter for the non-profit association (association sans but lucratif – a.s.b.l) ALAN – Maladies Rares Luxembourg (hereinafter referred to as "ALAN") is based on the association's by-laws and defines the rights, advantages, roles and responsibilities of its members more precisely. By becoming a member of ALAN, each individual or legal entity commits to respecting ALAN's by-laws and this charter.

The mission of ALAN is to help improve the quality of life of individuals and families affected by a rare disease in Luxembourg. Thus, ALAN defends the interests of all those affected by a rare disease, without favouring a particular disease or group of diseases. A disease is considered rare if it affects less than 5 in 10,000 people, as defined by "Orphanet" ([www.orpha.net](http://www.orpha.net)). Each rare disease is unique, but the problems and challenges to be addressed are similar (lack of information, delayed and incorrect diagnoses, complex administrative procedures, lack of medical expertise, etc.). There are hence many common interests.

The majority of ALAN's members are individuals. These are people affected by a rare disease and their relatives, volunteers, as well as people that wish to support the objectives of ALAN. Legal entities can also join ALAN, as long as they do not pursue a profit. Any individuals or legal entities that fill in the application form and pay the annual fee automatically become an "sympathising" affiliate member (*membre affilié « sympathisant »*), according to the terms of the by-laws.

### Rights and benefits of members

As the voice of patients, families and associations in the rare disease community, ALAN represents a key discussion partner to defend their interests in front of policy makers and the public.

Through the membership, each member gains access to the national and international rare disease networks and can stay informed about new developments in this field in Luxembourg, in Europe and beyond. ALAN acts as a relay and spokesperson for its members through its involvement in the National Plan for Rare Diseases and through its membership in EURORDIS, an international alliance of more than 900 rare disease patient associations. Since 2005, ALAN has been recognized as the Luxembourgish national alliance by EURORDIS and actively participates in the biannual meetings of the "Council of National Alliances" as well as in international projects and congresses.

ALAN members are regularly invited to participate in the association's activities. Individual members can participate in the recreational and physical activities organized by ALAN. Individuals can obtain either personal or family memberships. The latter allows members of the immediate family to participate in the sports and recreational activities of ALAN.

Individual and collective actions undertaken by ALAN members may be promoted by ALAN and thus gain more visibility, provided that these actions align with ALAN's objectives, missions and values. This support may include the dissemination of information through ALAN's communication channels (newsletter, website, social media, etc.) and/or the permission to use ALAN's logo. By supporting members who are legal entities, ALAN in no way replaces the missions and objectives pursued by these legal entities.

"Sympathising" affiliate members who wish to contribute more actively to the objectives of the association can apply to become an "active member" by following the procedures set out in the by-laws. Active members have the right to vote at the general assembly and are eligible for the Board of Directors of ALAN.

Legal entities whose main mission is to defend the interests of people with rare diseases can become an active member. These legal entities will be represented by an individual, who needs to be designated *in writing* by the legal entity.

According to the by-laws of ALAN, a legal entity which has the status of "active member" can be elected to the Board of Directors. In this case, the mandate as member of the Board of Directors will be fulfilled by an individual designated as the "permanent representative" of the legal entity. The permanent representative of a legal entity cannot hold a seat on the Board of Directors as an individual.

### Roles and responsibilities of members

Through the membership, each member supports and legitimizes ALAN's actions to defend the interests of those affected by a rare disease, as well as their families and their associations. Thus, each member adheres to the objectives of ALAN as defined in its by-laws and presented in its official communication. In addition, members commit to respecting the principles of political, ideological and religious neutrality, as well as respecting the vision and values of ALAN.

For the membership to be valid, each member must

1. submit or (if necessary) update his/her personal data required to manage the membership, and
2. pay the annual membership fee. Only valid memberships represent an effective form of support for ALAN.

In principle, a legal entity which is an "active member" is represented at ALAN, including at the general assembly of ALAN, by the individual designated by the legal entity to represent it in accordance with its governance and by-laws. In the event that a "permanent" representative is appointed, this representative is presumed to have a mandate in all respects for the purpose of representing the legal entity at ALAN.

Any member is free to resign from ALAN and can withdraw his/her membership at any time by following the procedures set out in the by-laws. In accordance with these by-laws, any member who seriously violates ALAN's by-laws, values or interests or who refuses to cooperate in good faith with the other members may be excluded from ALAN upon proposal by the Board of Directors.