

European Narcolepsy Alliance for Patients
eNAP
Egmontstraat 11, 1000 Brussel
RLE Brussels
<https://narcolepsy.eu/>
enap@narcolepsy.eu

MEMORANDUM OF INCORPORATION

Contents of the memorandum of incorporation:

- 1. Articles of association, including founders and registered office**
- 2. Certificate of appointment of the board members and certificate of appointment of the authorised representatives**

ARTICLES OF ASSOCIATION

The undersigned:

- Massimo Zenti, with place of residence at Via Spinetti 250 37050 Oppeano (VR), Italy
- Leontien Sickenga, with place of residence at Frans Halslaan 3, 3741 PC Baarn, the Netherlands
- Connie Benedicte Landstedt, with place of residence at Vorkvej 21, 6040 Egtved, Denmark

hereby declare to create a non-profit organisation in accordance with the Belgian Code of Companies and Associations (CCA), the articles of association of which read as follows:

TITLE I: NAME – REGISTERED OFFICE – PURPOSE - TERM

ARTICLE 1

The non-profit organisation (hereinafter referred to as the organisation) has the name: European Narcolepsy Alliance for Patients.

The abbreviated name is: eNAP.

ARTICLE 2

The organisation's registered office is located in the Brussels Capital Region.

The registered office of eNAP is situated at Egmontstraat 11, 1000 Brussel.

The board is authorised to move the registered office provided that this move does not result in a change in the language of the articles of association. The board is also authorised to incorporate the move of the registered office into the articles of association.

ARTICLE 3

eNAP serves an altruistic purpose and will not, under penalty of nullity, grant the founders, members, board members or any other private individuals any direct or indirect material benefit unless, in the case of private individuals, within the context of the altruistic purpose determined in the articles of association.

In these articles of association, the term "narcolepsy" will refer to "narcolepsy and other central disorders of hypersomnolence".

eNAP's altruistic purpose is the following:

- offer a better quality of life to people in Europe suffering from narcolepsy and other central disorders of hypersomnolence.
- be a voice for patients suffering from narcolepsy all over Europe.
- raise awareness with respect to the prevalence and impact of narcolepsy; leading to reduced stigma, isolation and discrimination for people suffering from narcolepsy.
- ensure that policymakers, decision-makers and major opinion leaders in Europe acknowledge the socio-economic burden as well as the health burden of narcolepsy and allocate means for treatments, services and support accordingly.

eNAP pursues the altruistic purpose within the context of one or several specific activities, which constitute the organisation's goals. These activities include:

- the co-ordination of awareness campaigns and initiatives.
- cooperation with our members and partner organisations for projects and activities of mutual interest.
- representation of the community of narcolepsy patients on relevant forums.
- communication and cooperation with members to bring about positive change and ensure that the actions of eNAP create added value for their concerns and activities.
- creation of strong partnerships and alliances with relevant stakeholders in the scientific, clinical, political and commercial fields to help us achieve our strategic goals.

These activities are listed purely as examples and the list is not exhaustive.

The organisation is authorised to undertake all actions to achieve the goals and promote the altruistic purpose, provided that the proceeds are used for the altruistic purpose and in accordance with the goals.

The organisation does not operate a business and is not involved in profitable operations within the meaning of article 2, 5° of the Belgian Income Tax Code of 1992. The organisation is involved in operations consisting of activities that are only incidental to industrial, commercial or agricultural operations or that are not performed in accordance with industrial or commercial methods within the meaning of article 182 of the Belgian Income Tax Code of 1992.

ARTICLE 4

eNAP is created for an indefinite period of time, but can be dissolved at any time.

The working language of eNAP is English.

TITLE II: MEMBERS

ARTICLE 5

The number of members is unlimited, but must be at least three. The legal provisions are only applicable to the members.

ARTICLE 6 AFFILIATED MEMBERS

6.1 The following organisations can become affiliated members of eNAP: national patient organisations within Europe, representing patients suffering from narcolepsy and other central disorders of hypersomnolence.

6.2 All national patient organisations (representing patients suffering from narcolepsy and other central disorders of hypersomnolence) of a European country can apply for affiliated membership and become an affiliated member of eNAP.

6.3 If eNAP becomes aware of a patient organisation in a European country that has not yet applied for affiliated membership, eNAP will contact this patient organisation and encourage this organisation to submit a request for affiliated membership.

6.4 Affiliated members of eNAP have to meet the following conditions:

- Be a legally registered non-profit entity.
- Be active as a national non-profit patient organisation
- Have a goal and/or purpose that is similar to that of eNAP, specifically representing patients suffering from narcolepsy and other central disorders of hypersomnolence.

6.5 Prospective affiliated members have to submit their application in writing to the board, accompanied by a copy of their articles of association or a similar document under foreign law, e.g. a certificate of registration.

6.6 The board will verify the conditions listed in article 6.4. If the board is of the opinion that the conditions are met, the organisation will automatically become an affiliated member of eNAP.

6.7 An affiliated member is deemed to resign from the organisation if the affiliated member no longer meets the conditions listed in article 6.4.

6.8 An affiliated member can also be excluded following a decision by the general assembly. The exclusion of an affiliated member is subject to the same rules as those described for an amendment to the articles of association.

6.9 An affiliated member does not have the right to vote in the general meeting.

6.10 An affiliated member can resign from the organisation by means of a written notice addressed to the board of eNAP.

ARTICLE 7 MEMBERS: START

7.1 Each country is represented by 1 member (private individual). This proposed member will automatically and with immediate effect become a member of eNAP.

7.2 The affiliated members established in the same country are entitled to jointly propose one member. This proposed member will automatically and with immediate effect become a member of eNAP.

7.3 Full membership, including the right to vote at the general meeting, is exclusively granted to the members. The members are those individuals whose name is mentioned in the register of members kept at the registered office of eNAP.

ARTICLE 8 MEMBERS: END

8.1 The affiliated members can decide at any time to replace the proposed member by another member. This new proposed member will automatically and with immediate effect become a member of eNAP.

8.2 A member can at any time be excluded following a decision of the general assembly of eNAP. The exclusion of a member is subject to the same rules as those described for an amendment to the articles of association. An intended exclusion of a member must be mentioned in the notice convening the general meeting and the member must be heard.

The decision to exclude a member results in the immediate termination of membership.

The affiliated members of the country whose proposed member is excluded are entitled to immediately propose a substitute member. This proposed member will automatically and with immediate effect become a member of eNAP.

The member who is replaced is deemed to resign on the day of his/her replacement.

ARTICLE 9

The members do not pay a membership fee.

TITLE III: GENERAL ASSEMBLY

ARTICLE 10

10.1 The general assembly is the highest authority of the organisation.

10.2 The general assembly consists of the members, who are entitled to participate in the consultations and to vote at the general meeting.

10.3 The board can allow extra guests to attend the general meeting in the capacity of observers.

10.4 The general meeting is chaired by the Chair of the Board or, in his/her absence, by the Vice-Chair.

ARTICLE 11 POWERS OF THE GENERAL ASSEMBLY

The general assembly has exclusive powers for:

- amendments to the articles of association, except in the cases where the Board has the required powers, as determined in the Belgian Code of Companies and Associations (see article 13.9 paragraphs 1 and 2)
- the appointment and dismissal of the Board members (1/3 present or represented + simple majority of votes)
- the determination of the Board members' remuneration if a remuneration is granted (1/3 present or represented + simple majority of votes)
- the appointment and dismissal of the auditors and the determination of their remuneration (1/3 present or represented + simple majority of votes)
- discharge to the Board members and the auditors and the institution of the organisation's claim against the Board members and the auditors (1/3 present or represented + simple majority of votes)
- the approval of the budget and of the financial statements (1/3 present or represented + simple majority of votes)
- the voluntary dissolution of the organisation (see article 13.9 paragraph 3)
- the exclusion of a member or affiliated member of the organisation (see article 13.9 paragraph 4)
- the conversion of the non-profit organisation into an international non-profit organisation, a cooperative company recognised as a social enterprise or an accredited cooperative company – social enterprise (2/3rds present or represented + 4/5 majority of votes)
- making or accepting a gratuitous incorporation of all assets and liabilities (2/3rds present or represented + 2/3 majority of votes)
- all matters as required by these articles of association or by law.

ARTICLE 12 – CONVENING THE MEETING

12.1 The annual general meeting is convened by the Board at the latest 6 months following the end of the financial year for the approval of the financial statements, the budget and the discharge of the Board members.

12.2 In order to be valid, the notices convening the general meeting must be signed or sent by a person designated by the Board. All members, Board members and auditors, if any, must be convened for the meeting by email or by ordinary or registered letter at the latest thirty days before the date of the meeting.

The convening notice mentions the place, date and time of the meeting and contains the agenda and the relevant documents, as determined by the Board.

12.3 Any general meeting that is not the annual general meeting can be convened by the Board whenever such a meeting is requested by the Board or by at least one fifth of the members.

In this case, the Board convened the general meeting at the latest twenty-one days following the request thereto. The general meeting is held at the latest on the fortieth day following this request.

The members will be informed in writing of the date, time and place of any meeting that is not an annual general meeting.

ARTICLE 13 AGENDA, QUORUM AND MAJORITIES

13.1 If a member submits a written request to the Board at the latest 15 days before the date of the annual general meeting, an additional item can be added to the agenda. The Board will inform the members of the change in the agenda at the latest 7 days before the date of the general meeting.

13.2 A quorum of 1/3 of the members is required for the adoption of ordinary resolutions (for which no compulsory requirements are imposed by law). A member may give another member or a third party an authorisation to represent them at a meeting. A member or third party cannot represent more than one other member.

13.3 Each of the members has one vote at the general meeting.

13.4 Resolutions are adopted by a simple majority of the members present or represented.

13.5 Votes are cast by show of hands, by roll call or, if requested by at least one of the members present or represented, by secret ballot.

13.6 In case of a tie, the Chair has the casting vote.

13.7 Meeting minutes are drawn up and signed by the Chair and a Board member. The meeting minutes are sent to the members at the latest one month following the general meeting. Members and any interested third parties can consult the minutes at the organisation's registered office.

13.8 A general meeting can be held online or by any other means of communication enabling all participants to identify each other remotely at any time during the meeting. Participation of members via such means of communication is equivalent to their presence in person.

13.9 Resolutions relating to amendments to the articles of association can only be adopted by the general meeting, except in the cases where the Board has the required powers, as determined in the CCA. The general meeting can only adopt the resolution if the amendment is specified in the convening notice and if at least 2/3 of the members are present or represented. If this quorum is not reached, a second meeting can be convened in the manner determined by these articles of association. This meeting can then validly adopt the resolution irrespective of the number of members present. This second meeting cannot be held earlier than 15 days after the first meeting.

In addition, a majority of 2/3 of the members present or represented is required for any amendment to the articles of association, also at the second general meeting. A change of the purpose or goal of eNAP requires a 4/5 majority. Abstentions and invalid votes are not taken into account.

A voluntary dissolution of eNAP is subject to the same rules as those described for a change in the purpose or goal of eNAP.

The exclusion of a member is subject to the same rules as those described for an amendment to the articles of association.

An intended exclusion of a member must be mentioned in the notice convening the general meeting and the member must be heard.

TITLE IV: THE BOARD

ARTICLE 14 COMPOSITION, APPOINTMENTS AND ALLOCATION

14.1 eNAP is managed by a Board acting as a body and preferably consisting of 5 Board members.

There must be at least 3 Board members at all times.

14.2 The Board members are natural persons appointed by the general assembly of eNAP.

14.3 Only members of eNAP are eligible for appointment as Board members.

14.4 The Board members are appointed by the general assembly for a period of 3 years with a simple majority of votes. Board members are eligible for reappointment.

14.5 Board members appointed to fill an interim vacancy complete the term of office of their predecessor. If the office of a Board member becomes vacant before the end of the term of office, the remaining Board members are entitled to co-opt a new Board member, who will complete the current term of office. The appointment of the co-opted Board member must be confirmed at the next general meeting. If the appointment is confirmed, the co-opted Board member will complete the term of office of their predecessor. In the absence of confirmation, the term of office of the co-opted Board member will end after the general meeting without affecting the validity of the composition of the Board until that time.

At the first Board meeting following the election, the Board members allocate the positions of Chair, Vice-Chair, treasurer, secretary and general Board member(s).

14.6 The Board members resign every 3 years upon completion of their term of office of 3 years.

14.7 If there is more than one candidate for one position, the votes must be cast by secret ballot.

14.8 A Board member who is deemed unfit to hold the position of Board member can at all times be dismissed by the general assembly with a simple majority of votes. A substitute for the dismissed Board member must be found within a reasonable period of time, which must not exceed three months.

14.9 The Board members hold their office without receiving any remuneration. Any expenses made within the context of their position can be reimbursed.

14.10 Board members who wish to resign must inform the Board in writing (by email or by ordinary or registered letter). The resignation takes effect immediately unless it causes the number of Board members to decrease below the minimum specified in these articles of association. In that case the Board must meet to:
- either co-opt a Board member within a reasonable period of time (in that case the co-optation must be confirmed at the next general meeting),

- or convene a general meeting, at which a substitute Board members will be elected, within a reasonable period of time.

The resignation of the Board member concerned will take effect, in the first case at the time of the co-optation and in the second case at the time the appointment of a substitute Board member is confirmed at the general meeting.

ARTICLE 15 POWERS AND REPRESENTATION OF THE BOARD

15.1 The Board manages the organisation and observes the applicable legislation, including the provisions of the Belgian Code of Companies and Associations (CCA) as well as the articles of association and the resolutions adopted by the general assembly.

15.2 The Board is authorised to undertake all actions and to adopt the resolutions that are necessary or useful to achieve the purpose of eNAP, with the exception of the resolutions that fall under the exclusive competence of the general assembly.

15.3 The Board represents the organisation for all the actions it undertakes, both in and out of court.

15.4 Without prejudice to the general power of representation of the Board as a body, the organisation is also represented in and out of court by two Board members, who have to act/sign jointly.

15.5 Without prejudice to the obligations of the Board as a body, the Board members can distribute the management duties among themselves.

15.6 The Board can delegate part of its powers to one or several third parties other than Board members. However, this delegation of powers cannot relate to the general policy of eNAP. This delegation of powers by the Board needs to take place by means of a specific authorisation.

15.7 The Board issues all bylaws they deem necessary and useful. The most recent approved version of these bylaws, if any, can be consulted at the organisation's registered office.

ARTICLE 16 – BOARD MEETINGS

16.1 Board meetings are convened by the Chair whenever requested by the Chair or another Board member, at the latest 14 days following such a request.

16.2 Resolutions are adopted by a simple majority of the votes cast by the Board members who are present or represented.

Each Board member has one vote. In case of a tie, the Chair has the casting vote.

16.3 The Board can deliberate and vote validly if the Chair or, in their absence, the Vice-Chair and two other Board members are present.

16.4 A Board member can be represented by another Board member at the Board meeting. Each Board member can represent one (1) other Board member at the most.

16.5 Board members who are unable to be present at a Board meeting, either in person or online, can have another Board member act as their authorised representative and cast their vote. The Board member concerned must send the Board a written authorisation before the Board meeting.

16.6 Board meetings can be held online or by any other means of communication enabling all participants to identify each other remotely at any time during the meeting.

Participation of Board members via such means of communication is equivalent to their presence in person.

16.7 The Board members meet at least twice a year to prepare for the annual general meeting, at which the financial statements and the budget are approved and discharge is granted to the Board members, and as often as a meeting is required in the interest of eNAP.

TITLE V: ACCOUNTS AND BUDGETS

ARTICLE 17

17.1 The financial year starts on 1 January and ends on 31 December.

17.2 The accounts are kept in accordance with the applicable legal provisions.

17.3 The accounts are kept on a continuous basis.

17.4 Every year the Board draws up financial statements for presentation and approval at the annual general meeting, which is to be held at the latest 6 months following the end of the financial year.

17.5 The financial statements are made available to the members prior to the annual general meeting.

17.6 At the latest one month following their approval at the annual general meeting, the Board sends the members a copy of the approved financial statements.

TITLE VI: DISSOLUTION AND LIQUIDATION

ARTICLE 18 DISSOLUTION OF THE ORGANISATION

With the exception of a dissolution ordered by court and a dissolution by operation of law, only the general assembly can decide to dissolve the organisation, provided that 2/3 of the members are present or represented at the general meeting and a majority of 4/5 of the members present or represented agree to a voluntary dissolution of the organisation. The proposal for voluntary dissolution of the organisation must be explicitly included in the agenda of the general meeting.

If less than 2/3 of the members are present or represented at the general meeting, a second general meeting must be convened, at which valid deliberations can take place irrespective of the number of members present or represented. However, a majority of 4/5 of the members present or represented is required for a voluntary dissolution of the organisation. Abstentions and invalid votes are not taken into account.

In case of a voluntary dissolution, the general meeting or, if no general meeting is held, the court appoints one or several liquidators.

Their powers and the conditions for liquidation are also determined at the general meeting within the limits of and with observance of the relevant legal provisions.

If several liquidators are appointed, each of them individually is authorised to undertake all actions that are necessary or useful for the liquidation of the organisation. Each of them individually can represent the organisation within the context of their appointment.

After payment of all debts, the assets will be transferred to an organisation at European level with an altruistic purpose in the field of rare disorders.

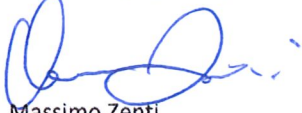
TITLE VII: OTHER PROVISIONS

ARTICLE 19

The Belgian Code of Companies and Associations applies to all matters not covered by or settled in these articles of association.

Thus drawn up and approved at the founders' meeting of 17/05/2022

At Brussels, signed by the founders



Massimo Zenti



Leontien Sickenga



Connie Benedicte Landstedt

European Narcolepsy Alliance for Patients
eNAP
Egmontstraat 11, 1000 Brussel
RLE Brussels
<https://narcolepsy.eu/>
enap@narcolepsy.eu

CERTIFICATE OF APPOINTMENT OF THE BOARD MEMBERS

The following Board members were appointed at the founders' meeting of 17/05/2022:

Massimo Zenti, with place of residence at Via Spinetti 250 37050 Oppeano (VR), Italy
Leontien Sickenga, with place of residence at Frans Halslaan 3, 3741 PC Baarn, the Netherlands
Connie Benedicte Landstedt, with place of residence at Vorkvej 21, 6040 Egtved, Denmark
Alan Hickey, with place of residence at Limerick City V94 A31X, Ireland
Maarit Rautio, with place of residence at Ulvilantie 19d b 52, 00350 Helsinki, Finland

The Board manages the organisation and observes the applicable legislation, including the provisions of the Belgian Code of Companies and Associations (CCA) as well as the articles of association and the resolutions adopted by the general assembly.

The Board is authorised to undertake all actions and to adopt the resolutions that are necessary or useful to achieve the purpose of the organisation, with the exception of the resolutions that fall under the exclusive competence of the general assembly.

The Board represents the organisation for all the actions it undertakes, both in and out of court.

Resolutions are adopted by a simple majority of the votes cast by the Board members who are present or represented. Each Board member has one vote. In case of a tie, the Chair has the casting vote.

The Board can deliberate and vote validly if the Chair or, in their absence, the Vice-Chair and two other Board members are present.

At Brussels, signed by the founders

Massimo Zenti

Leontien Sickenga

Connie Benedicte Landstedt

European Narcolepsy Alliance for Patients
eNAP
Egmontstraat 11, 1000 Brussel
RLE Brussels
<https://narcolepsy.eu/>
enap@narcolepsy.eu

**CERTIFICATE OF APPOINTMENT OF THE PERSONS AUTHORISED TO
REPRESENT THE ORGANISATION**


Extract from the articles of association:

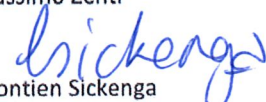
Without prejudice to the general power of representation of the Board as a body, the organisation is also represented in and out of court by two Board members, who have to act/sign jointly.

The Board members are

Massimo Zenti, with place of residence at Via Spinetti 250 37050 Oppeano (VR), Italy
Leontien Sickenga, with place of residence at Frans Halslaan 3, 3741 PC Baarn, the Netherlands
Connie Benedicte Landstedt, with place of residence at Vorkvej 21, 6040 Egtved, Denmark
Alan Hickey, with place of residence at Limerick City V94 A31X, Ireland
Maarit Rautio, with place of residence at Ulvilantie 19d b 52, 00350 Helsinki, Finland

At Brussels, signed by the founders


Massimo Zenti


Leontien Sickenga


Connie Benedicte Landstedt

Voor eensluidende vertaling ne varietur van het Nederlands naar het Engels

A certified true translation from Dutch into English

Gedaan te Oostende op 24/05/2022

Done at Oostende on 24/05/2022

Ik zweer dat ik mijn opdracht in eer en geweten, nauwgezet en eerlijk heb vervuld
I swear that I have performed my duty in good conscience, accurately and honestly



Ann Scharre
Beëdigd vertaler
Sworn translator



