

# STATUTES OF RETT SYNDROME EUROPE

## NON-PROFIT ORGANISATION RETT SYNDROME EUROPE A.S.B.L.

Registered office: Cabinet D'Avocats Turpel & Schank  
59, Bd de Verdun L-2670 Luxembourg

**1. Ms. Irmgard WENZEL**

**Profession:** Secretary  
**Living in:** A-2120 WOLKERSDORF,3, Kaiser-Josef-Strasse  
**Nationality:** Austrian

**2. Mr. Dietmar DÖRR**

**Profession:** Functionnaire  
**Living in:** D-54441 WELLEN, 38, In den Hässeln  
**Nationality:** German

**3. Mr. Johan DELAERE**

**Profession:** Licentiate in Philosophy  
**Living in:** B-8380 DUDZELE, 57, Watergang  
**Nationality:** Belgian

**4. Ms. Yvonne MILNE**

**Profession:** Charity Worker  
**Living in:** UK-WR136AA MALVERN-WORCS, Hartspool, Golden Valley Castlemorton  
**Nationality:** British

**5. Mr. Ulf HÄNELL**

**Profession:** Consultant  
**Living in:** S-82075 HARMÄNGER, 12, Ronnebergsvägen,  
**Nationality:** Swedish

Hereby form a non-profit organization, which will be governed by the following articles of association and the provisions of the law of April 21st, 1928 relating to non-profit organisations and foundations.

### **Article I. Name - Registered Office**

The name of the association is Rett Syndrome Europe, using the international abbreviation RSE. It is a non-profit making organisation.

The association has its registered office in Luxembourg City.  
The registered office may be transferred to any other place within the Grand Duchy of Luxembourg by a decision of the board of administration.

## **Article II. Place of Registration**

The RSE is registered in Luxembourg. Other offices may be established either in Luxembourg or abroad by resolution of the board of administration.

The RSE can only be registered in a State, which is represented in the European Parliament.

## **Article III. Neutrality**

RSE is a non-political and non-sectarian organisation.

## **Article IV. Aims**

The aim of RSE is to represent the interest of people with Rett syndrome and their families, especially in the following areas:

1.

To make Rett syndrome better known to the public, professionals, carers and those who are directly concerned in all European countries.

2.

To improve the communication within the European Rett community.

3.

To promote, as a representative European organisation, the interests of people with Rett syndrome and their families.

4.

To expand the RSE to all European countries and to assist, if necessary, in the creation of national associations.

5.

To promote research into Rett syndrome.

These aims are to be especially attained by:

1.

Co-operation with Rett syndrome associations within Europe and Worldwide.

2.

Co-operation with other relevant international and national institutions.

3.

Co-operation with other social groups.

4.

Exerting influence on decisions concerning legislation in relation to medical, health, and education in professional and social fields.

## **Article V. Membership**

1.

Membership shall be open to Rett syndrome associations from European States.

Membership shall also be open to Rett syndrome subgroups of umbrella organizations.

If a European State has no formal association, Membership is open to up to two representatives of that State provided they have a direct interest in Rett syndrome.

2.

Membership is acquired by written application to the Secretary. The Executive Board decides upon admission and date of commencement of Membership. It is possible to appeal to the General Assembly against a decision by the Executive Board to refuse

Membership. The General Assembly shall have complete discretion whether to refuse or allow any such appeal.

**3.**

Members must, subject to article IX (5), pay the annual membership fee.

## **Article VI. Resignation and Exclusion**

**1.**

Member associations can leave RSE by declaration of this intention by its executive body. The Secretary of RSE is to be informed in writing of this resignation. When there is no association, individual member representatives can leave by writing to the Secretary.

**2.**

A member association, or member representative(s), may be excluded from RSE by resolution of the General Assembly deciding by a two thirds majority of the votes if:

**(a)**

Despite two written reminders from the treasurer, the Membership fees due for the business year have not been paid, or

**(b)**

They act against the aims of RSE.

**3.**

Should reasons for exclusion exist, the Executive Board is empowered to suspend a member association and a member representative(s) with immediate effect until a resolution can be placed before the General Assembly.

**4.**

A member, who has left or has been excluded from RSE, has no right whatsoever to the property of RSE and is not entitled to claim the reimbursement of paid memberships fees .

## **Article VII. Resources**

**1.**

The resources of RSE consist of any Membership fees, public subsidies and private donations.

**2.**

The Membership fee is fixed by the General Assembly.

**3.**

The liability of RSE and its Members is limited exclusively to the property of RSE.

**4.**

RSE shall not take loans.

## **Article VIII. General Assembly**

**1.**

The General Assembly shall be the supreme governing body of RSE.

**2.**

The Executive Board shall call an ordinary meeting of the General Assembly every year. After consultation with the Members, the Executive Board may, at its discretion, decide the date of the ordinary meeting. The announcement and request for motions must be sent to all the Members at least 4 weeks before the fixed date. The agenda, motions and the business and the financial report are to be sent to all the participants by the Executive Board at least 4 weeks in advance.

**3.**

An extraordinary meeting of the General Assembly may convene at the request of at least one fifth of the Members or at the request of the Executive Board upon not less than 4 weeks notice to all the Members of the General Assembly of the date, agenda and the matters to be discussed.

**4.**

The General assembly shall consist of not more than two delegates from each European State. There shall be a quorum of the General Assembly when five Member States are represented or half of the Member States are represented, whichever is the lesser.

**5.**

Each European State is entitled to one vote irrespective of how many Rett syndrome associations exist in that State. Written proxy votes are not accepted. Decisions are taken on the basis of a simple majority. In the case of equality of votes the chairman shall have a second or casting vote.

**6.**

The General Assembly shall:

**(a)**

At a meeting of the General Assembly elect from among the Members of the General Assembly an Executive Board consisting of a President, Secretary, Treasurer and two others, which shall be effective from the end of that meeting.

**(b)**

Decide on the directive principles of RSE.

**7.**

The General Assembly may exercise the following powers:

**(a)**

Power to discharge any member of the Executive Board. Members of the Executive Board are not allowed to vote on their own discharge.

**(b)**

Power to do all such other lawful things as are necessary for the achievement of the aims.

**8.**

The President shall act as chairman of the General Assembly. If the President is absent, the Members of the Executive Board present shall choose one of their numbers to be chairman of the meeting before any other business is transacted.

**9.**

The General Assembly shall keep minutes of the proceedings at their meetings.

## **Article IX. Executive Board**

**1.**

The Executive Board (Board of administration) is elected from the Members of the General Assembly and consists of a President, Secretary, Treasurer and two ordinary Members. At least two Members of the Executive Board must be family or carers of a person with Rett syndrome. A minimum of three States must be represented on the board.

**2.**

The term for each Executive Board member shall be two years. They may be elected for a further two terms.

**3.**

The Executive Board convenes when required, but at least once a year. Written notice is sent to the Members of the Executive Board at least 14 days prior to the date of each ordinary meeting. Any three Members of the Executive Board may call a special meeting of the Executive Board at any time, upon not less than 4 days' notice being given to the other Executive Board Members of the matters to be discussed.

**4.**

The Executive Board has to execute the business of RSE according to the law and statutes. Employed workers can be used in the execution of the work. The Executive Board is entitled to decide on the Membership of RSE to other organisations.

**5.**

The Executive Board may waive all or part of the membership fee of any member in their complete discretion.

**6.**

The President shall act as chairman of the Executive Board. If the President is absent from any meeting, the Members of the Executive Board present shall choose one of their numbers to be chairman of the meeting before any other business is transacted.

**7.**

There shall be a quorum when at least three Members of the Executive Board are taking part. Decisions are taken on the basis of a simple majority. In the case of equality of votes the chairman shall have a second or casting vote.

**8.**

The Executive Board shall convene the General Assembly. It may also be convoked by request of a fifth of the members.

**9.**

The Executive Board shall keep minutes of the proceedings of their meetings.

**10.**

The Executive Board shall present accounts of RSE every year.

**11.**

The Executive Board is vested with the broadest powers to perform all acts of administration and disposition in the association's interests.

**12.**

In the execution of their mandate, the members of the Board of Administration are not held personally responsible. As statutory agents of the Association, they are only responsible for the correct performance of their duties.

## **Article X. Auditors**

**1.**

The General Assembly appoints at least one internal auditor.

**2.**

Audits take place once a year. A written report on their results is submitted to the Executive Board.

**3.**

Every year, the Executive Board shall submit the accounts of the past business year and the budget forecast for the coming business year to the approval of the General Assembly gathered in an ordinary meeting.

## **Article XI. Sub-committees**

**1.**

The General Assembly or the Executive Board can use sub-committees for certain tasks. When their work is finished, the subcommittees are considered dissolved.

**2.**

Towards third parties the association will be validly committed by the joint signatures of the President and one other member of the Board of administration.

**3.**

Any litigation involving the Association either as plaintiff or as defendant will be handled on behalf of the Association by the Executive Board.

**4.**

The Executive Board may delegate its powers to conduct the daily management of the Association to one of its members or to a third party.

### **Article XII. Observers**

**1.**

All Members can send one observer to meetings of the General Assembly.

**2.**

Organisations dealing with questions concerning the aims of RSE may also send observers to the General Assembly.

**3.**

Costs are to be borne by the organisations or authorities sending observers.

### **Article XIII. Honorary positions**

The Members of the General Assembly and Executive Board carry out their work on an honorary basis. Reasonable expenses may be paid if possible, and by agreement of the Executive Board.

### **Article XIV. Business year**

The business year of RSE corresponds to the calendar year.

### **Article XV. Duration**

The duration of RSE is unlimited. It can be dissolved at any time.

### **Article XVI. Alteration of statutes**

These articles of association may be amended from time to time by decision of the General Assembly, subject to the quorum and voting requirements provided by the law of April 21st, 1928.

### **Article XVII. Dissolution and Final Regulation**

**1.**

The dissolution of RSE can be decided upon only in a General Assembly. If the Executive Board or any 10 Members acting together decide that it is necessary or advisable to dissolve the RSE, the Executive Board or the Secretary at the request in writing of those Members acting together shall call a meeting of the General Assembly. Not less than 28 days' notice (stating the terms of the resolution to be proposed) shall be given.

**2.**

If the proposal is confirmed by a two-thirds majority of the Members present and voting, the members of the Executive Board, acting as liquidators, shall have power to realise any assets held by or on behalf of RSE. Voting by proxy is not permitted. Any assets remaining shall be given or transferred equally to any Rett syndrome association, which is at the time of the vote a fully paid up member of RSE.

### **Article XVIII. Validity**

These statutes were adopted at the meeting of the General Assembly in Budapest on 26.05.2001.

Austria	Belgium	Denmark	Finland
France	Germany	Hungary	Italy
Malta	Norway	Poland	Serbia
Slovakia	Sweden	Spain	Turkey
United Kingdom			