12.04.2026

Minutes of the Annual General Meeting

on April 12th 2026 - start 10:30 a.m.
in the large event hall of the Hohenwart Forum
Schönbornstraße 25 - 75181 Pforzheim-Hohenwart

Agenda

1) Welcome and election of the secretary
   Bas Albers was appointed as the minute taker.

2) Formalities for Opening the Meeting
   a) Determination of the proper invitation
      The invitation was sent on March 15, 2026, thus 4 weeks prior to the general meeting. There were no objections regarding the proper invitation. The proper convening of the meeting is hereby confirmed.

   b) Approval of the Agenda
      The agenda was approved unanimously.

   c) Determination of Represented Votes and Quorum
      According to the attendance list, 14 votes are represented. The meeting is therefore quorate in accordance with the association's statutes.

   d) Approval of the Minutes of the General Meeting of April 7, 2024
      There were no objections to the minutes of April 7, 2024. The minutes were approved unanimously.

3) Report of the board
   There are six topics the board wants to work in the period 2026-2028:
   - Update official documentation and leaflets (network input, doctor's input)
   - Translate emergency protocols
   - Create an emergency card
   - Website
     - Extend website (add photos, etc)
   - Administration of members
     - Update contact forms for existing families
     - Offer the possibilities to become a member online (full process)
     - Offering more connections between members
   - Research / medical
     - Connection with researchers and doctors

In the last two years the board worked on the following items:

- The website was built from scratch and all text were rewritten in four languages. The new website was launched in the spring of 2025 and attracted much more attention than the old website.
- There was a significant effort by the board to finance this years conference. As a consequence there were large financial donations by AktionMensch, EKFS and the Deutsche Krankenkasse. The communication with these institutions took a lot of time, because for application a lot of documents are required. As always the network is not financed by any pharmaceutical companies.
  We were able to invite Nutricia and Prente Romich Deutschland (PRD) to give presentations on artificial nutrition and speech generating devices. We did not focus on these companies, but on the products they supply, even though they are so widespread in their field that there are few alternatives.
- After the conference we will further finalize the applications for the donations we were granted. We will have to submit further documentation to show that the money was well spent.

4) Cash report of the treasurer

a) Report of the treasurer on the annual financial statements 2024 – 2025
Gero Bressel has presented the cash reports.

The figures presented are highly summarized; therefore, a number of explanatory comments are provided below.

2024
In 2024, we welcomed new members. Membership fee income has stabilized; however, it does not fully reflect the actual number of members. We are very pleased that many members voluntarily contribute higher-than-minimum membership fees, and we would like to express our sincere appreciation to them. Some members choose to pay on a monthly basis, resulting in a total contribution above the minimum annual fee. Members are always welcome to contact us if they wish to increase their contribution.

The Treasurer noted that it occurs relatively often that members forget to pay their fees and, after a reminder, settle payments for multiple years at once. Setting up automatic transfers could help streamline this process.

Donations amounted to approximately twice the value of the membership fees.

Subsidies represent by far the largest share of income. Without these substantial contributions, it would not be possible to organize the conference in its current form.

The next major income category consists of participation fees for the conference.

Expenses are broadly comparable to previous periods. Membership fees were paid to AKSE and EURORDIS. In the past, EURORDIS provided financial compensation for work carried out by the Board. Unfortunately, due to its current financial situation, EURORDIS is no longer able to offer such support. Nevertheless, EURORDIS remains important to us because of its international scope beyond Germany. AKSE plays a key role within Germany, particularly in the areas of training and prevention. Gesa has participated in several relevant webinars.

Board meeting costs remained very low, partly because some travel expenses were not reimbursed and certain restaurant expenses were not charged to the association.

The last conference incurred total costs of approximately €54,000, of which only €14,000 was covered by member contributions. The remainder was largely financed through subsidies.

For the last conference, we also introduced a financial leaflet outlining how the event was funded.

One aspect not directly visible in the figures is liquidity—specifically, when funds are available. Subsidy payments are often received later than needed. During the last conference, liquidity was tight. Although we knew at the outset that all costs would ultimately be covered, approximately €54,000 needed to be available at the start of the event. The hotel and technical service providers were understanding and agreed to delayed payments.

2025

2025 is a year without a conference. Membership fee income remains largely unchanged compared to the previous year.

Donations increased, including a €5,000 contribution from EKFS.
Some participation fees for the 2026 conference were already received in 2025.

EURORDIS has changed its fee structure from a fixed membership fee to a revenue-based model. As a result, the fee increased from €25 to €150.

Banking costs have also risen. Previously, no banking fees were charged, but costs are now incurred, including for international transfers.

Board-related expenses mainly consist of travel costs.

Overall, the balance in the bank account has increased.

This year, we succeeded in ensuring sufficient liquidity to cover all expenses at the start of the conference. In doing so, we aimed to strike an appropriate balance between supporting our members and maintaining the financial health of the organization.

b) Report of the cash committee
Erwin Heijselaar had to leave earlier this morning. He has documented the proper audit in writing. He recommends granting discharge to the Board.

5) Resolution on the annual financial statements 2024 – 2025
The annual financial statements for 2024 and 2025 were approved unanimously with 13 votes (family Bartke had to leave the meeting early accounting for one vote less than the number of votes under item 2c).

6) Resolution on the discharge of the Board
   a) The Board was unanimously discharged, with the Board members abstaining from voting themselves.

7) Election of the new board
The current Board stood for re-election. The Board was unanimously re-elected, with its members abstaining from voting, and consists of:
Bas Albers, Caroline Albers, Gero Bressel, Gesa Bressel, Camille Henny-Raguin, and Olivier Raguin.

8) Election of the cash committee
Rutmer van Weringh was elected unanimously as first member of the cash committee, while Hanny Albers-Brok was elected unanimously as back-up.

9) Questions from the Plenum

Cindy de Klerk raised three questions, which were addressed as follows:

Question 1: In previous years, donations were listed per individual in the financial report. This has not been done in recent years. Was this a deliberate decision?
Answer: The Board explained that it was a deliberate decision to present donations in a more summarized manner. Additionally, it is not always clear

whether donors wish to be named publicly, and there may be data protection considerations (GDPR) that need to be respected. Both internal and external donations are included in the figures. If there is interest, more detailed information can be provided. The Board also noted that personal thank-you messages are sent to donors to express appreciation.

Question 2: A number of members left the meeting early. Is it possible to transfer voting rights by proxy, or is physical presence required?
Answer: The Board explained that proxy voting is currently not regulated in the association's procedures. While it may be technically possible, there are legal considerations, such as whether non-members may represent members and how many votes one person may hold. At present, the preference is to maintain the requirement of (physical or online) presence for voting.

Question 3: Question regarding online voting.
Answer: It was reiterated that, following a decision at the previous meeting, online participation and online voting are permitted.

After Cindy her questions there was a question from Muriel Böller

Question 4: New families in Switzerland who leave early may not fully see or understand the work of the Board. Could the member meeting be scheduled at a different time, also to allow other members to contribute?
Answer: The Board explained that the current scheduling is largely determined by practical and financial considerations. The conference program needs to consist of full content days in order to secure full funding, and the member meeting does not count as program content. For this reason, changing the timing of the member meeting is currently not preferred.

Two questions were raised by Peter Albers, which were addressed as follows:

Question 5: Should the medical protocols be translated into more languages, for example for use during travel to countries such as Italy or Spain?
Answer: The Board acknowledged this as a valuable suggestion. As a first step, efforts are focused on translating the protocol into the main languages within the network. It was noted that in some cases, such as in the United States, families arrange specific translations when traveling abroad. For the time being, the plan is to concentrate on the most important languages, while remaining available to support members in individual cases where additional translations are needed. Peter Albers offered to assist in expanding translations, which was welcomed by the Board.

Question 6: How difficult is it to obtain financial support from other countries?
Answer: The Board explained that, as a German-based organization with members across Europe, obtaining international funding remains challenging. Many funding bodies provide support only for their own national beneficiaries. This was also reflected in the current conference, where some donations were restricted to German participants. Previous attempts to secure funding from countries such as the Netherlands and France have not yet been successful. Peter Albers offered to explore funding opportunities in the Netherlands. Additionally, the concept of "transnational giving" was discussed; however, this requires country-specific arrangements to be set up annually and involves administrative effort and fees.

7) Miscellaneous

The general meeting was adjourned at 11.59 am.

Hohenwart, 12.04.2026

Bas Albers	Gesa Bressel
Minute taker	Chairman