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# FINANCIAL REPORT 2024

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May 2025



# EURORDIS

Association governed by the French law of July 1, 1901

96, Rue Didot

75014 PARIS

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## Statutory auditor's report on the financial statements

For the year ended December 31, 2024

*This is a translation into English of the statutory auditors' report on the financial statements of the association issued in French and it is provided solely for the convenience of English-speaking users.*

*This statutory auditors' report includes information required by French law, such as information about the appointment of the statutory auditors or verification of the management report and other documents provided to stakeholders.*

*This report should be read in conjunction with, and construed in accordance with, French law and professional auditing standards applicable in France.*

## EURORDIS

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### Statutory auditor's report on the financial statements

For the year ended December 31, 2024

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To the annual general meeting of Eurordis,

#### Opinion

In compliance with the engagement entrusted to us by your annual general meeting, we have audited the accompanying financial statements of EURORDIS for the year ended December 31, 2024.

In our opinion, the financial statements give a true and fair view of the assets and liabilities and of the financial position of the Association as of December 31, 2024 and of the results of its operations for the year then ended in accordance with French accounting principles.



## **Basis for Opinion**

### **Audit Framework**

We conducted our audit in accordance with professional standards applicable in France. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Our responsibilities under those standards are further described in the “*Statutory Auditor’s Responsibilities for the Audit of the Financial Statements*” section of our report.

### **Independence**

We conducted our audit engagement in compliance with independence requirements of the French Commercial Code (code de commerce) and the French Code of Ethics (code de déontologie) for statutory auditors, for the period from January 1, 2024 to the date of our report.

### **Emphasis of Matter**

We draw attention to the change in accounting method concerning the first application of the ANC accounting regulations 2022-06 and 2023-03 described in the section change in accounting policy (“Changement de méthode”) of the notes to the financial statements.

### **Justification of Assessments**

In accordance with the requirements of Articles L. 821-53 and R. 821-180 of the French Commercial Code (code de commerce) relating to the justification of our assessments, we inform you that the assessments made by us focused on the appropriateness of the accounting principles used, the reasonableness of accounting estimates and the overall financial statements’ presentation.

These matters were addressed in the context of our audit of the financial statements as a whole, and in forming our opinion thereon, and we do not provide a separate opinion on specific items of the financial statements.

### **Specific verifications**

We have also performed, in accordance with professional standards applicable in France, the specific verifications required by French law.

We have no matters to report as to the fair presentation and the consistency with the financial statements of the information given in the management report of the Board of Directors and in the other documents with respect to the financial position and the financial statements provided to the members.

### **Responsibilities of Management and Those Charged with Governance for the Financial Statements**

Management is responsible for the preparation and fair presentation of the financial statements in accordance with French accounting principles, and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, management is responsible for assessing the Association’s ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless it is expected to liquidate the Association or to cease operations.



The financial statements were approved by the board of directors.

### **Statutory Auditor's Responsibilities for the Audit of the Financial Statements**

Our role is to issue a report on the financial statements. Our objective is to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with professional standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

As specified in Article L. 821-55 of the French Commercial Code (*code de commerce*), our statutory audit does not include assurance on the viability of the Association or the quality of management of the affairs of the Association.

As part of an audit conducted in accordance with professional standards applicable in France, the statutory auditor exercises professional judgment throughout the audit and furthermore:

- Identifies and assesses the risks of material misstatement of the financial statements, whether due to fraud or error, designs and performs audit procedures responsive to those risks, and obtains audit evidence considered to be sufficient and appropriate to provide a basis for his opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control;
- Obtains an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the internal control;
- Evaluates the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management in the financial statements;
- Assesses the appropriateness of management's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Association's ability to continue as a going concern. This assessment is based on the audit evidence obtained up to the date of his audit report. However, future events or conditions may cause the Association to cease to continue as a going concern. If the statutory auditor concludes that a material uncertainty exists, there is a requirement to draw attention in the audit report to the related disclosures in the financial statements or, if such disclosures are not provided or inadequate, to modify the opinion expressed therein;
- Evaluates the overall presentation of the financial statements and assesses whether these statements represent the underlying transactions and events in a manner that achieves fair presentation.

Paris-La Défense, May 15, 2025

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY



**EURORDIS 2024 Financial Status**  
(Assets and Liabilities)

Assets	2023	2024	Δ in euros	Δ in %
<b>FIXED ASSETS</b>				
Intangible assets	985	27	-958	-97%
Tangible assets	58 431	41 772	-16 659	-29%
Financial assets	8 860	8 860	0	0%
<b>TOTAL</b>	<b>68 276</b>	<b>50 659</b>	<b>-17 617</b>	<b>-26%</b>
<b>CURRENT ASSETS</b>				
Account receivable due within one year	2 017 972	2 386 773	368 801	18%
Account receivable due after one year	1 048 613	1 521 085	472 472	45%
Other receivables	62 830	72 482	9 652	15%
Liquid assets	2 068 074	1 760 319	-307 755	-15%
Prepaid expenses	41 656	32 049	-9 607	-23%
<b>TOTAL</b>	<b>5 239 145</b>	<b>5 772 708</b>	<b>533 563</b>	<b>10%</b>
<b>Conversion adjustment</b>	<b>0</b>	<b>0</b>	<b>0</b>	
<b>TOTAL ASSETS</b>	<b>5 307 421</b>	<b>5 823 367</b>	<b>515 946</b>	<b>10%</b>

Liabilities	2023	2024	Δ in euros	Δ in %
<b>ASSOCIATION FUNDS</b>				
Reserve	1 912 369	1 994 247	81 879	4%
Profit & loss for the year	81 879	-345 601	-427 480	-522%
Subsidies of investment	0	0	0	
<b>TOTAL</b>	<b>1 994 247</b>	<b>1 648 646</b>	<b>-345 601</b>	<b>-17%</b>
Provisions for risk and charges	142 894	298 071	155 177	109%
Dedicated funds on grants	0	0	0	
<b>DEBTS</b>				
Bank loans and overdraft	0	0	0	
Trade creditors	143 110	126 230	-16 880	-12%
Tax payable and social liabilities	498 360	549 920	51 560	10%
Other debts	0	142 309	142 309	
Deferred income within one year	999 371	1 317 919	318 547	32%
Deferred income after one year	1 529 438	1 740 273	210 835	14%
<b>TOTAL</b>	<b>3 313 173</b>	<b>4 174 721</b>	<b>861 547</b>	<b>26%</b>
<b>Conversion adjustment</b>	<b>0</b>	<b>0</b>	<b>0</b>	
<b>TOTAL LIABILITIES</b>	<b>5 307 421</b>	<b>5 823 367</b>	<b>515 946</b>	<b>10%</b>



## Financial Status 2024

(Profit and Loss including in kind contributions)

Revenue	Fin. Status 2023	Fin. Status 2024	Ratio	Δ in euros	Δ in %
<b>Patient Organisations</b>	<b>1 028 212</b>	<b>1 051 075</b>	<b>16%</b>	<b>22 863</b>	<b>2%</b>
Financial contributions	670 000	670 000	10%		
AFM Telethon	670 000	670 000	10%		
Other Patient Organisations					
In kind contributions (AFM)	237 975	249 850	4%	11 875	5%
Membership fees	120 237	131 225	2%	10 988	9%
<b>Individuals</b>	<b>630 557</b>	<b>534 022</b>	<b>8%</b>	<b>-96 535</b>	<b>-15%</b>
Volunteers	617 435	508 047	8%	-109 389	-18%
Donations	13 122	25 975	0%	12 854	98%
<b>European Commission</b>	<b>2 374 629</b>	<b>2 309 048</b>	<b>35%</b>	<b>-65 581</b>	<b>-3%</b>
DG Research	1 025 545	923 006	14%	-102 540	-10%
DG Health and consumers	1 349 213	1 386 042	21%	36 829	3%
DG Employment	-129			129	
<b>National authorities</b>		<b>79 570</b>	<b>1%</b>	<b>79 570</b>	
Contracts with National authorities		79 570	1%	79 570	
<b>Corporates</b>	<b>2 333 874</b>	<b>2 022 785</b>	<b>31%</b>	<b>-311 089</b>	<b>-13%</b>
Pharma. and Biotech Companies	2 251 565	1 947 560	30%	-304 005	-14%
Other Health Sector Corporates	82 109	75 225	1%	-6 884	-8%
Outside Health Sector Corporates	200			-200	
<b>Not for Profit Organisations</b>	<b>449 687</b>	<b>333 294</b>	<b>5%</b>	<b>-116 393</b>	<b>-26%</b>
Pharma. and Biotech Found.	127 166	128 243	2%	1 078	1%
Other Health Sector NPOs	79 714	17 854	0%	-61 860	-78%
Outside Health Sector NPOs	242 808	187 197	3%	-55 611	-23%
<b>Event Fees</b>	<b>96 750</b>	<b>149 702</b>	<b>2%</b>	<b>52 952</b>	<b>55%</b>
<b>Miscellaneous</b>	<b>84 461</b>	<b>85 334</b>	<b>1%</b>	<b>873</b>	<b>1%</b>
Reimbursement	27 666	19 012	0%	-8 653	-31%
Others	56 795	66 322	1%	9 526	17%
<b>Sub-total</b>	<b>6 998 170</b>	<b>6 564 830</b>	<b>100%</b>	<b>-433 340</b>	<b>-6%</b>
<b>Recovery of provisions</b>	<b>108 251</b>	<b>150 589</b>		<b>42 339</b>	<b>39%</b>
<b>Report of non-used income</b>					
<b>Total Revenue</b>	<b>7 106 420</b>	<b>6 715 419</b>		<b>-391 001</b>	<b>-6%</b>

  

Expenses	Fin. Status 2023	Fin. Status 2024	Ratio	Δ in euros	Δ in %
<b>Staff</b>	<b>4 314 773</b>	<b>4 371 414</b>	<b>65%</b>	<b>56 641</b>	<b>1%</b>
Wages and charges	4 047 531	4 080 602	60%	33 071	1%
Other salaries	226 401	254 848	4%	28 447	13%
Training and other costs	40 842	35 965	1%	-4 876	-12%
<b>Volunteers</b>	<b>617 435</b>	<b>508 047</b>	<b>8%</b>	<b>-109 389</b>	<b>-18%</b>
Representatives and task forces	617 435	508 047	8%	-109 389	-18%
<b>Logistics</b>	<b>739 371</b>	<b>696 527</b>	<b>10%</b>	<b>-42 844</b>	<b>-6%</b>
Travels and subsistence	462 238	390 067	6%	-72 170	-16%
Event logistics and catering	262 522	306 460	5%	43 937	17%
<b>Services</b>	<b>1 082 313</b>	<b>1 027 659</b>	<b>15%</b>	<b>-54 654</b>	<b>-5%</b>
Fees	324 869	378 814	6%	53 944	17%
Partners	210 210	47 657	1%	-162 553	-77%
Telecom and post	39 950	36 393	1%	-3 558	-9%
Rent	333 572	347 870	5%	14 298	4%
Other services	173 710	216 925	3%	43 215	25%
<b>Purchase</b>	<b>90 092</b>	<b>113 878</b>	<b>2%</b>	<b>23 785</b>	<b>26%</b>
Office furniture	21 308	25 429	0%	4 121	19%
Amortisation	33 646	63 352	1%	29 706	88%
Communications, Publications	22 077	9 036	0%	-13 041	-59%
Other purchases	13 061	16 060	0%	2 999	23%
<b>Miscellaneous</b>	<b>120 223</b>	<b>32 157</b>	<b>0%</b>	<b>-88 065</b>	<b>-73%</b>
Financial expenses, Insurance, Tax	38 147	32 157	0%	-5 989	-16%
Exceptional expenses	82 076			-82 076	
<b>Sub-total</b>	<b>6 964 207</b>	<b>6 749 681</b>	<b>100%</b>	<b>-214 526</b>	<b>-3%</b>
<b>Contingency and loss provisions</b>	<b>74 946</b>	<b>311 339</b>	<b>5%</b>	<b>236 393</b>	<b>315%</b>
<b>Commitment on assigned income</b>					
<b>Total Expenses</b>	<b>7 024 542</b>	<b>7 061 020</b>		<b>36 478</b>	<b>1%</b>
<b>Result</b>	<b>81 879</b>	<b>-345 601</b>			

## 2024 Financial report

EURORDIS concluded 2024 with a deficit of 345 601 euros. If this amount is allocated to the reserve, the total reserve will stand at 1 648 646 euros.

The following sections provide detailed insights into our Assets and Liabilities, as well as our Profit and Loss figures.

### **1. Assets and Liabilities (Balance Sheet)**

Assets represent what we own, primarily cash or funds to be received. Liabilities reflect the origin of these funds, mainly in the form of deferred income. Profit and Loss, on the other hand, summarises all accounting transactions over the course of the calendar year.

#### **1.1. Assets**

Current assets increased from 5 239 k€ in 2023 to 5 773 k€ in 2024.

	2023	2024	Difference	
Accounts receivable	3 129 415	3 980 340	850 925	27%
Liquid assets	2 068 074	1 760 319	-307 755	-15%
Prepaid expenses	41 656	32 049	-9 607	-23%
<b>Total</b>	<b>5 239 145</b>	<b>5 772 708</b>	<b>533 563</b>	<b>10%</b>

##### **1.1.1. Accounts receivable**

Accounts receivable consist of funds owed to EURORDIS through signed (often multi-annual) grant agreements where payments are pending. The European Commission is the main source, representing 3,685k€ or 94% of the total.

This 27% increase is primarily due to two significant multi-year projects signed in 2024: ERDERA and RealiseD.

##### **1.1.2. Liquid assets**

Liquid assets refer to cash in the bank. While still at a satisfactory level, liquidities decreased in 2024, mainly due to the year's deficit.



## 1.2. Liabilities

### 1.2.1. Association Funds

Association funds reflect the accumulated surplus or deficit since EURORDIS' inception. As of end-2024, these stood at 1 649k€.

A safe reserve level is typically between 25% and 50% of the annual budget (excluding in-kind contributions). In 2025, projected expenses excluding in-kind contributions are 4.4M€, down 30% from 2024. A 1.6M€ reserve equals 37% of that budget—within the acceptable range, though not overly comfortable.

### 1.2.2. Provisions

	2023	2024		
		Recoveries	New provisions	Balance
Provisions for risks	79 963	-68 259	253 293	264 997
Provision for retirement benefits	82 330	-82 330	58 046	58 046
<b>Provisions for risks and charges</b>	<b>162 293</b>	<b>-150 589</b>	<b>311 339</b>	<b>323 043</b>

All necessary 2024-related provisions have been accounted for. Of the 253k€ in new provisions, 226k€ are set aside due to a potential ineligibility of “bonuses” under the 2021–2023 Operating Grants. This issue was raised by EU grant auditors and is pending confirmation from HaDEA. Possible write-downs of receivables are included in this table of provisions for risks and charges.

### 1.2.3. Trade creditors

2 023	143 k€	3%
2 024	126 k€	2%
difference	-17 k€	-12%

Trade creditors represent amounts owed to suppliers for received (or pending) invoices. Year-to-year fluctuations are generally situational.

### 1.2.4. Deferred income

2 023	2 529 k€	48%
2 024	3 058 k€	53%
difference	529 k€	21%

Deferred income consists of grant amounts allocated to future years and not yet expended. Unlike receivables, which are cash-based, deferred income is calculated on eligible expenses (direct + overhead costs) as per contract terms.

At end-2024, 2,625k€ (86%) of deferred income was linked to multi-year EC projects.

The increase from 2023 is due to the launch of the ERDERA and Realised projects.

## 2. Revenue

Total revenue, including in-kind contributions and excluding provision recovery, reached 6 565k€ in 2024, a 6% decrease (-433k€) from 2023. The decline primarily stems from reduced contributions from Health Sector Corporates and NPOs.

The breakdown of EURORDIS' revenue by sources is as follows:  
(amounts are in thousands of euros, recovery of provisions is excluded<sup>1</sup>)

	2023		2024		Difference	
<i>AFM</i>	908	13%	920	14%	12	1%
<i>Membership fees and grants</i>	120	2%	131	2%	11	9%
<i>Volunteers</i>	617	9%	508	8%	-109	-18%
Patient Org. and Volunteers	1 646	24%	1 559	24%	-87	-5%
European Commission	2 375	34%	2 389	36%	14	1%
<i>Pharma. and Biotech Companies</i>	2 252	32%	1 948	30%	-304	-14%
<i>Other Health Sector Corporates</i>	82	1%	75	1%	-7	-8%
Health Sector Corporates	2 334	33%	2 023	31%	-311	-13%
Other Corporates	0	0%			0	-100%
Foundations and NPOs	450	6%	333	5%	-116	-26%
Event fees	97	1%	150	2%	53	55%
Others	98	1%	111	2%	14	14%
<b>Total</b>	<b>6 998</b>	<b>100%</b>	<b>6 565</b>	<b>100%</b>	<b>-433</b>	<b>-6%</b>

Overall: The European Commission comes first with 36% followed by Health Sector Corporate donations (31%) and the Patient Organisations and volunteers (24%).

Our policy is that, compared to a total income budget including in kind contribution except volunteers and excluding recovery of provisions,

- the target “health sector industry” funding shall not be greater than 45% (+/-5%)
- No single industry partner shall contribute more than 5%
- EURORDIS will continue to include the Fair market value of volunteers in its financial statements and ratios, recognizing the significant value contributed pro bono by the patient community.
- As a result, our Health Sector industry will consistently be well below 50% of total income including in kind contributions.

On this basis, the amount coming from the Health Sector represented 33% of the budget excluding volunteers and the largest donor 2.7%. It is therefore compliant with our policy.

More details on revenues:

### 2.1. Patient Organisations and Volunteers (1 585k€)

Half of this revenue is in-kind (758k€ from volunteer efforts and office space from AFM). The largest cash donor is AFM-Téléthon (670k€).

#### 2.1.1. Association Française contre les Myopathies (AFM – Téléthon)

<sup>1</sup> Recovery of provisions is excluded from this table to better analyse the evolution of the revenue by the source of funding. For more information, please see 1.2.2. Provisions above.

AFM-Téléthon, a co-founding member, provides critical support to EURORDIS' core functions and independence. Since 2013, their grant was 635k€, increased to 670k€ in 2019 and maintained, except in 2021 (600k€ due to COVID).

An agreement covering 2019–2023 was extended to 2024. It supports governance, membership, advocacy, therapeutic development, and management. Together with the participation of volunteers and high standard of good governance, it is our best guarantee of independence with respect to public institutions and commercial companies.

AFM also provides office space in Paris valued at 250k€.

### **2.1.3. Volunteers**

Volunteers contributed 7,816 hours, equivalent to 4.6 FTE. Time contributions are validated by the volunteers (>90%) or estimated by project managers (<10%) and confirmed by auditors.

This source of revenue is the one we cherish the most because it consists of the time of people directly concerned by our cause: their wide range of diseases and cultures, their diversified skills, background, and expertise are something money cannot buy.

## **2.2. European Commission**

In 2024, the level of EC projects was still exceptionally high (36%). EURORDIS operated thirteen ongoing EC projects from DG SANTE, DG RESEARCH and IMI-JU<sup>2</sup> and negotiated one new EC grants.

Contracts running in 2024:

- the DG SANTE Operating Grant (2024);
- the DG RESEARCH project grant HTx;
- the DG RESEARCH project European Joint Programme on Rare Diseases;
- the DG RESEARCH project ERDERA (continuation of EJP-RD, multi-annual);
- the IMI-JU project Conect4Children (C4C);
- the DG RESEARCH project grant REMEDI4ALL;
- the IMI-JU project Screen4Care;
- the IMI-JU project FACILITATE;
- the DG RESEARCH project grant ERICA;
- the DG SANTE project EUCAPA;
- the DG RESEARCH project more-Europa;
- the DG RESEARCH project Join4ATMP;
- the EJP-RD project LIVES in which EURORDIS acts as a subcontractor;
- the DG SANTE joint action JARDIN in which EURORDIS acts as a subcontractor;

EURORDIS completed in 2024 the negotiation of one other grant to be started in 2025:

- the IMI-JU project Realised.

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<sup>2</sup> IMI-JU is a Joint Undertaking between DG Research and the European Federation of Pharmaceutical Industries and Associations (EFPIA) called "Innovative Medicine Initiative". In the budget, the contribution from EC is recorded under chapter "DG Research". This joint undertaking has been rebranded IMI-JU (Innovative Health Initiative) to recognise the involvement of "cross-sectoral discoveries, such as medical device / drug combinations or diagnostics based on artificial intelligence".

## 2.3. Health Sector Corporates

This line includes 71 health sector companies, of which 65 are pharmaceutical and biotech firms.

The five largest contributors from the health sector are, in descending order: 1<sup>st</sup> TAKEDA, 2<sup>nd</sup> PFIZER, 3<sup>rd</sup> SANOFI, 4<sup>th</sup> ROCHE and 5<sup>th</sup> ALEXION.

The percentage of this sector in the total budget (including in kind contributions and volunteering) is 31% and the highest percentage of one Health Sector Company represents 2.6%.

The guarantees of our independence from the health corporate sector are (1) high standards in our governance, (2) balanced revenues between our different sources<sup>3</sup>, (3) the limitation of the health sector corporates incomes, (4) the diversity and limited amount of each single corporate donor and (5) our Policy of Relationship with Commercial Companies and our practices on prevention of potential competing interest.

## 2.4. Foundations and Not for Profit Organisations (NPOs)

The bulk of this line comes from a 200 k\$ contract signed with the Chan and Zuckerberg Initiative in 2023 and mostly used in 2024.

Two significant three-year contracts with Fondation Ipsen under the aegis of “Fondation de France” to support activities in the context of the Health Data programme and Rare Disease Day were continuing in 2024.

## 2.5. Event Fees

This line is mainly composed of ECRD – the European Conference on Rare Diseases (89 k€), the Black Pearl Award event (48 k€) and ERTC – EURORDIS Round Table of Companies ticket sales (12 k€).

## 3. Expenses

Operating expenses, including in-kind contributions, and excluding provisions, totalled 6 750 k€ in 2024, a 3% decrease from 2023.

The breakdown of EURORDIS expenses is as follows  
(in thousands of euros, provisions excluded<sup>4</sup>)

Expenses	Fin. Status 2023		Fin. Status 2024		Difference	
Staff costs	4 315	62%	4 371	65%	57	1%
Volunteers	617	9%	508	8%	-109	-18%
Logistics	725	10%	697	10%	-28	-4%
Services	1 082	16%	1 028	15%	-55	-5%
Others	210	3%	146	2%	-64	-31%
<b>Total</b>	<b>6 950</b>	<b>100%</b>	<b>6 750</b>	<b>100%</b>	<b>-200</b>	<b>-3%</b>

<sup>3</sup> i.e., Patient Organisations & Volunteers, Public income, Corporate income, revenues generated by our activities

<sup>4</sup> Recovery of provisions is excluded from this table to better analyse the evolution of the revenue by the source of funding.  
For more information, please see 1.2.2. Provisions above.

More details on expenses:

### 3.1. Staff costs

The number of FTE<sup>5</sup> was 49.17 in 2024, down from 51.18 in 2023.

As at the end of the year, the team was composed of 50 staff members across five countries.

The main office is in France (30), followed by Spain (10) and Belgium (6).

No new positions were created in 2024.

Six positions were stopped:

- Ukraine Response Programme Manager, Hanna Boiko, Brussels
- Accounting Manager, Annie Rahajarizafy, Paris
- Events Director, Sharon Ashton-Sirot, UK
- Operations Junior Manager, Rahul Waslekar, Paris
- Web Technology Junior Manager, Imène El Aini, Paris
- Communications Junior Manager, Lise Pernin, Paris

#### Note on staff costs:

This line comprises all costs related to salaries including all employee and employer taxes.

In France, where staff is mainly present, the net salary represented less than 50% of the staff costs in 2024 (44.1%), in Belgium and Spain a little more than 50% (53.4% and 54.3% respectively). The regulatory taxes cover health, retirement, and unemployment benefit systems as well as income taxes.

All EURORDIS staff members speak at least two languages, often 3 to 5, altogether the staff team speaks 15 languages and comprises 16 different nationalities. Most of them have a high-level academic background with a master's degree (in Science or Business Administration) or a PhD. All EURORDIS staff are expected to have a specific expertise in their domain, to know rare diseases, to be able to work with volunteers and support patient empowerment and patient engagement, to be able to contribute to public affairs and work with all stakeholders to support patient advocacy. These positions require a long-term commitment and a retention policy.

### 3.2. Logistics

Even though 2024 was an ECRD year, the expenses related to logistics decreased compared to the previous year because of the restructuring plan (please see section 5 hereafter) which resulted in several face-to-face events being replaced by online meetings.

### 3.3. Services

There is no significant difference.

### 3.4. Provisions

As highlighted in 1.2.2 above, we have established a significant 225k€ provision to cover for the possible rejection by HaDEA of the amounts charged to the operating grant in 2021, 2022 and 2023

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<sup>5</sup> 1 full time equivalent = one person in a full-time position for one year  
Page 13 / 16

for employee “bonusses”, which have been challenged by their auditors. While we still believe we have fair chances of prevailing, the difficult context under which we operate led us to ere on the cautious side and reserve it in full. This was partly offset by reductions in reserve for retirement benefit and other risks and charges (-64k), resulting in a net P&L change of 160.5k€

#### **4. Result**

The total year shows a net deficit amounting to 345 601 euros including the 225 k€ HaDEA Audit provision. We recommend allocating this loss to the historical reserve, reducing it to 1 648 646 euros.

#### **5. Risk going forward**

In 2024, EURORDIS missed the opportunity to apply for the DG SANTE Operating Grant 2025-26 Framework Partnership Agreement (FPA). This application was meant to select the health NGOs which will be able to apply for a Specific Grant Agreement (SGA). In short, FPA has no budget and workplan and only gives the right to apply later to a yearly SGA which has the budget and workplan components.

Missing an FPA has a greater impact than missing an SGA because it is pluriannual (in this specific case, 2 years but it has previously been 3 or 4 years). As the SGA 2024 amounted to 1 358 k€, the loss over the two years could be estimated around 2 700 k€.

In this context, EURORDIS implemented a plan to reduce its costs (unfortunately mostly salaries)and several positions have been stopped in 2024, with few additional ones eliminated early 2025.

Unfortunately for the other patient organisations in the European Union, it looks like there will be no SGA (and hence Operating Grants) in 2025 even for the organisations that had a successful FPA. In this new context, having missed the 2025-26 FPA appears as having given us a head start, and avoided much additional costs, forcing us to anticipate on this loss right from June 2024 rather than suffering unrecoverable expenses for a significant part of 2025. Had we been successful at application for the 2025-26 FPA, we would still be waiting for the 2025 Work Programme and a possible SGA call and incurring months of delay in the adjustment of our budget.

## Glossary

*AFM-Téléthon*: Association Française contre les Myopathies (French Muscular Dystrophy Association) which imported the Telethon from the United States in 1986 and has organised this fund-raising event every year since.

*EC*: European Commission

*DG SANTE*: Health and Food Safety Directorate-General of EC

Ongoing Projects:

- *EURORDIS SGA 2024* (Specific Grant Agreement)
  - o from 01-Mar-24 to 31-Dec-24
  - o EURORDIS sole beneficiary
- *EUCAPA* (European Capacity Building for Patients)
  - o From 01-Mar-23 to 28-Feb-25
  - o EURORDIS main beneficiary
- *JARDIN* (Joint Action on integration of ERNs into national healthcare systems)
  - o from 01-Jan-24 to 31-Dec-26
  - o EURORDIS sub-contractor

*DG RESEARCH*: Research and Innovation Directorate-General of EC

Ongoing Projects:

- *Solve-RD* (Solving the unsolved Rare Diseases)
  - o from 01-Jan-18 to 31-Mar-24
  - o EURORDIS co-beneficiary
- *HTx* (Next Generation Health Technology Assessment to support patient-centred, societally oriented, real-time decision-making on access and reimbursement for health technologies throughout Europe)
  - o from 01-Jan-19 to 30-Jun-24
  - o EURORDIS co-beneficiary
- *EJP RD* (European Joint Programme on Rare Diseases)
  - o from 01-Jan-19 to 31-Aug-24
  - o EURORDIS co-beneficiary
- *ERICA* (European rare disease research coordination and support action)
  - o from 01-Mar-21 to 28-Feb-25
  - o EURORDIS co-beneficiary
- *REMEDi4ALL* (Building a sustainable European innovation platform to enhance the repurposing of medicines for all)
  - o from 01-Sep-22 to 31-Aug-27
  - o EURORDIS co-beneficiary
- *LIVES* (Quality of life of patients living with vascular LIVER diseases)
  - o From 01-Sep-22 to 31-Mar-25
  - o EURORDIS sub-contractor
- *MoreEUROPA* (More Effectively Using Registries to support PATient-centered Regulatory and HTA decision-making)
  - o from 01-Mar-23 to 31-Mar-28

- EURORDIS co-beneficiary
- *JOIN4ATMP* (Map, Join, and drive European activities for advanced therapy medicinal product development and implementation for patient and society benefit)
  - from 01-Jan-24 to 31-Dec-26
  - EURORDIS co-beneficiary
- *ERDERA* (The European Rare Diseases Research Alliance)
  - from 01-Sep-24 to 31-Aug-31
  - EURORDIS co-beneficiary

IMI/IHI-JU Innovative Medicine Initiative, a DG RESEARCH / EFPIA Joint Undertaking

- *conect4children* (Collaborative Network for European Clinical Trials For Children)
  - From 01-May-18 to 30-Apr-25
  - EURORDIS co-beneficiary
- *Screen4Care* (Shortening the path to rare disease diagnosis by using newborn genetic screening and digital technologies)
  - from 01-Oct-21 to 30-Sep-26
  - EURORDIS co-beneficiary
- *FACILITATE* (Framework for Clinical trial participants data reutilisation for a fully transparent and ethical ecosystem)
  - from 01-Jan-22 to 31-Dec-25
  - EURORDIS co-beneficiary
- *Realised* (Transforming Clinical Trials for Ultra-Rare Diseases)
  - from 01-Jan-25 to 31-Dec-29
  - EURORDIS co-beneficiary

*ECRD*: European Conference on Rare Diseases.

Twelve of them have already taken place

ECRD 2024, hybrid in Brussels

ECRD 2022, Internet

ECRD 2020, Internet

ECRD 2018, in Vienna (co-organised by EURORDIS and DIA)

ECRD 2016, in Edinburgh (co-organised by EURORDIS and DIA)

ECRD 2014, in Berlin (co-organised by EURORDIS and DIA)

ECRD 2012, in Brussels (co-organised by EURORDIS and DIA)

ECRD 2010, in Krakow (organised by EURORDIS and partners)

ECRD 2007, in Lisbon (organised by EURORDIS and partners)

ECRD 2005, in Luxembourg (organised EURORDIS and partners)

ECRD 2003, in Evry (France, organised by Alliance Maladies Rares)

ECRD 2001, in Copenhagen (organised by Rare Disorders Denmark)

The thirteenth will take place in June 2026 in Prague.

*EMA*: European Medicines Agency