
FINANCIAL REPORT 2023

May 2024



EURORDIS

Association governed by the French law of July 1, 1901

96, Rue Didot

75014 PARIS

Statutory auditor's report on the financial statements

For the year ended December 31, 2023

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.

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Statutory auditor's report on the financial statements

For the year ended December 31, 2023

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, 2023.

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, 2023 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, 2023 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 regulation 2022-04 described in the section change in accounting policy (“Changement de méthode”) of the notes to the financial statements and resulting in the presentation of a separate statement of benefits and resources from abroad.

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 22, 2024

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY



EURORDIS 2023 Financial Status
(Assets and Liabilities)

Assets	2022	2023	Δ in euros	Δ in %
FIXED ASSETS				
Intangible assets	985	985	0	0%
Tangible assets	80 115	58 431	-21 684	-27%
Financial assets	8 860	8 860	0	0%
TOTAL	89 960	68 276	-21 684	-24%
CURRENT ASSETS				
Account receivable due within one year	1 754 491	2 017 972	263 481	15%
Account receivable due after one year	1 793 803	1 048 613	-745 190	-42%
Other receivables	66 666	62 830	-3 836	-6%
Liquid assets	2 440 211	2 068 074	-372 137	-15%
Prepaid expenses	29 684	41 656	11 972	40%
TOTAL	6 084 855	5 239 145	-845 710	-14%
Conversion adjustment	0	0	0	
TOTAL ASSETS	6 174 815	5 307 421	-867 394	-14%

Liabilities	2022	2023	Δ in euros	Δ in %
ASSOCIATION FUNDS				
Reserve	1 910 337	1 912 369	2 032	0%
Profit & loss for the year	2 032	81 879	79 847	3930%
Subsidies of investment	0	0	0	
TOTAL	1 912 369	1 994 247	81 879	4%
Provisions for risk and charges	157 635	142 894	-14 740	-9%
Dedicated funds on grants	0	0	0	
DEBTS				
Bank loans and overdraft	0	0	0	
Trade creditors	193 781	143 110	-50 671	-26%
Tax payable and social liabilities	427 956	498 360	70 404	16%
Other debts	0	0	0	
Deferred income within one year	1 371 763	999 371	-372 392	-27%
Deferred income after one year	2 111 312	1 529 438	-581 874	-28%
TOTAL	4 262 446	3 313 173	-949 273	-22%
Conversion adjustment	0	0	0	
TOTAL LIABILITIES	6 174 815	5 307 421	-867 394	-14%

**Financial Status 2023
VS Financial Status 2022**
(Profit and Loss including in kind contributions)

Revenue	Fin. Status 2022	Fin. Status 2023	Ratio	Δ in euros	Δ in %
Patient Organisations	1 064 197	1 028 212	15%	-35 985	-3%
Financial contributions	717 742	670 000	10%		
AFM Telethon	670 000	670 000	10%	0	0%
Other Patient Organisations	47 742	0	0%	-47 742	
In kind contributions (AFM)	238 925	237 975	3%	-950	0%
Membership fees	107 530	120 237	2%	12 707	12%
Volunteers	848 851	617 435	9%	-231 416	-27%
European Commission	1 703 087	2 374 629	34%	671 542	39%
DG Research	694 028	1 025 545	15%	331 517	48%
DG Health and consumers	994 298	1 349 213	19%	354 915	36%
DG Employment	0	-129	0%	-129	
EMA contributions (*)	14 761	0	0%	-14 761	
Corporates	2 378 856	2 333 874	33%	-44 982	-2%
Pharma. and Biotech Companies (**)	2 159 130	2 251 565	32%	92 435	4%
Other Health Sector Corporates (**)	219 369	82 109	1%	-137 260	-63%
Outside Health Sector Corporates	357	200	0%	-157	-44%
Not for Profit Organisations	311 206	449 687	6%	138 481	44%
Pharma. and Biotech Found.	121 073	127 166	2%	6 093	5%
Other Health Sector NPOs	56 751	79 714	1%	22 963	40%
Outside Health Sector NPOs	133 382	242 808	3%	109 426	82%
Event Fees	57 680	96 750	1%	39 070	68%
Miscellaneous	102 675	97 583	1%	-5 092	-5%
Donations	52 267	13 122	0%	-39 145	-75%
Reimbursement	23 576	27 666	0%	4 090	17%
Others	26 832	56 795	1%	29 964	112%
Sub-total	6 466 552	6 998 170	100%	531 618	8%
Recovery of provisions	25 428	108 251	2%	82 822	326%
Report of non-used income	0	0	0%	0	
Total Revenue	6 491 980	7 106 420		614 440	9%

Expenses	Fin. Status 2022	Fin. Status 2023	Ratio	Δ in euros	Δ in %
Staff	3 852 318	4 314 773	62%	462 456	12%
Wages and charges	3 644 720	4 047 531	58%	402 811	11%
Other salaries	163 147	226 401	3%	63 253	39%
Training and other costs	44 451	40 842	1%	-3 609	-8%
Volunteers	848 851	617 435	9%	-231 416	-27%
Representatives and task forces	665 971	617 435	9%	-48 536	-7%
Projects, office and translators	182 880	0	0%	-182 880	
Logistics	620 036	724 760	10%	104 724	17%
Travels and subsistence	294 761	462 238	7%	167 477	57%
Event logistics and catering	74 527	247 911	4%	173 384	233%
Virtual events	235 987	14 611	0%	-221 376	-94%
In kind contribution (*)	14 761	0	0%	-14 761	
Services	1 025 623	1 082 313	16%	56 689	6%
Fees	295 067	324 869	5%	29 802	10%
Partners	161 755	210 210	3%	48 456	30%
Telecom and post	55 789	39 950	1%	-15 838	-28%
Rent	333 160	333 572	5%	412	0%
Other services	179 853	173 710	2%	-6 143	-3%
Purchase	85 143	90 092	1%	4 949	6%
Office furniture	28 189	21 308	0%	-6 880	-24%
Amortisation	33 398	33 646	0%	248	1%
Communications, Publications	11 980	22 077	0%	10 097	84%
Other purchases	11 576	13 061	0%	1 485	13%
Miscellaneous	29 310	120 223	2%	90 912	310%
Financial expenses, Insurance, Tax	29 310	38 147	1%	8 836	30%
Exceptional expenses	0	82 076	1%	82 076	
Sub-total	6 461 281	6 949 596	100%	488 315	8%
Contingency and loss provisions	28 667	74 946	1%	46 279	161%
Commitment on assigned income	0	0	0%	0	
Total Expenses	6 489 948	7 024 542		534 593	8%
Result	2 032	81 879			

2023 Financial report

We finish 2023 with a profit of 81 879 euros; if it is allocated to the reserve, the reserve will then amount to 1 994 247 euros.

In the comments hereinafter, we will give you more details about the Assets and Liabilities and the Profit and Loss figures.

Assets and Liabilities (also named Balance sheet) are a picture of all our Assets and Liabilities. Assets are what we own – mainly cash at bank or to be received – Liabilities show where the money comes from – mainly deferred income.

On the other hand, Profit and Loss figures are the cumulation of all accounting movements incurred between the two pictures, therefore during the civil year.

Let's dive into it:

1. Assets and Liabilities

1.1. Assets

Current assets slightly decreased from 6 085 k€ in 2022 to 5 239 k€ in 2023.

	2022	2023	Difference	
Accounts receivable	3 614 960	3 129 415	-485 545	-13%
Liquid assets	2 440 211	2 068 074	-372 137	-15%
Prepaid expenses	29 684	41 656	11 972	40%
Total	6 084 855	5 239 145	-845 710	-14%

1.1.1. Accounts receivable

Accounts receivable are the total amount of monies to be received by EURORDIS in the context of grants when an agreement, often multi-annual, has been signed and the cash has not yet been transferred.

The bulk of this line comes from the European Commission (2 847 k€, 92%).

This decrease is due to the absence of the signing of significant pluriannual projects while the monies to be received from ongoing projects is decreasing.

1.1.2. Liquid assets

Liquid assets are cash in the bank. The level of liquidities is satisfactory at the end of 2023, yet in decrease compared to 2022.

One of the reasons for this decrease is the EJP-RD project. EJP-RD is a big project with 101 beneficiaries and a grant repartition specific to the project and managed by the French coordinator INSERM in agreement with all beneficiaries and at the advantage of Patient Organisation compared to Public Organisations.

However, the downside of this specific agreement is that every report takes an unusual amount of time, resulting in a delay in reimbursement of expenses.

Usually, a yearly report is filed 2 months after the end of the intermediary period and payment is made 2 to 3 months after. Which means that there is usually a delay of 5 months between the end of the intermediary period and the payment of the corresponding instalment.

In this specific situation this delay has been increased by 10 months.

Which means that it takes more than a year – almost a year and a half – for the coordinator to get the money from the EC and redistribute it to the beneficiary.

As a result, by the end of 2023, the cash burden on this specific project amounted to 245k€.

1.2. Liabilities

1.2.1. Association Funds

Association funds are the cumulative sum of all surplus / deficit since the creation of the association.

At the end of 2022, they amounted to 1 912k€. The surplus of 2023 increased them to 1 994 k€.

A level of Association Funds usually considered safe and acceptable is to be comprised between 1/4 and 1/2 of the annual budget (excluding in kind contributions).

In 2024, the total expenses excluding in-kind contributions before provisions amounts to 6.5M€; a reserve of 2 M€ represents 31% of the annual expenses which is closer to 25% than 50%, therefore safe enough but not ideal.

1.2.2. Provisions

	2022	2023		
		Recoveries	New provisions	Balance
Provisions for risks	89 686,54	-89 686,54	60 564,08	60 564,08
Provision for retirement benefits	67 948,00	0,00	14 382,00	82 330,00
Provisions for risks and charges	157 634,54	-89 686,54	74 946,08	142 894,08

We have recorded all necessary provisions corresponding to the activity in 2023 to be on the safe side.

1.2.3. Trade creditors

2 022	194 k€	3%
2 023	143 k€	3%
difference	-51 k€	-26%

Trade creditors are monies to be paid to suppliers for invoices that have been received (or are to be received) and have not been paid yet. This difference from one year to another is usually a conjectural phenomenon.

1.2.4. Deferred income

2 022	3 483 k€	56%
2 023	2 529 k€	48%
difference	-954 k€	-27%

Deferred income refers to the part of grants concerning the upcoming years (the part of the grant that has not been consumed yet). This is different from the accounts receivable which concerns the cash flow whereas the calculation of the deferred income is based on the expenses that occurred in the context of the action: the calculation of the grant is a percentage of direct costs + a percentage of overheads. These percentages differ from one contract to another.

At the end of the year 2023, deferred income was mainly composed of the ongoing pluriannual EC projects (2 149 k€, 85%).

Deferred income has significantly decreased compared to 2022 because the absence of signing of a new pluriannual project while ongoing projects are being consumed.

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 6 998 k€. This represents an increase of 532 k€ (+ 8%) compared to 2022.

The bulk of the increase is due to the increase of the DG SANTE and Private grants (+ 672 + 138 = 810 k€) compensated by the decrease of volunteers (-231 k€)

The breakdown of EURORDIS' revenue by sources is as follows:
(amounts are in thousands of euros, recovery of provisions is excluded¹)

	2022		2023		Difference	
<i>AFM-Téléthon</i>	909	14%	908	13%	-1	0%
<i>Membership fees</i>	108	2%	120	2%	13	12%
<i>Other donations (Ukraine)</i>	48	1%	0	0%	-48	-100%
<i>Volunteers</i>	849	13%	617	9%	-231	-27%
Patient Org. and Volunteers	1 913	30%	1 646	24%	-267	-14%
European Commission	1 703	26%	2 375	34%	672	39%
<i>Pharma. and Biotech Companies</i>	2 159	33%	2 252	32%	92	4%
<i>Other Health Sector Corporates</i>	219	3%	82	1%	-137	-63%
Health Sector Corporates	2 378	37%	2 334	33%	-45	-2%
Other Corporates	0	0%	0	0%	0	-44%
Foundations and NPOs	311	5%	450	6%	138	44%
Event fees	58	1%	97	1%	39	68%
Others	103	2%	98	1%	-5	-5%
Total	6 467	100%	6 998	100%	532	8%

Overall: The European Commission comes first with 34% followed by Health Sector Corporate donations (33%) and the Patient Organisations and volunteers (24%).

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%

¹ 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.

- 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.

If we exclude the volunteers from the analysis, the amount coming from the Health Sector represented 37% of the budget and the largest donor 2.7%. It is therefore compliant with our policy.

More details on revenues:

2.1. Patient Organisations and Volunteers

2 022	1 913 k€	30%
2 023	1 646 k€	24%
difference	-267 k€	-31%

The Patient Organisations and Volunteers section (1 646k€) was in 2023 our third source of revenue. The larger part of it is in kind (volunteer contributions; Paris' office space kindly offered by AFM, 855 k€) and the main cash contribution is the annual support of AFM-Téléthon (670 k€).

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

2 022	909 k€	14%
2 023	908 k€	13%
difference	-1 k€	0%

The AFM-Téléthon is a EURORDIS' co-founding member and by far the main patient organisation to contribute to EURORDIS' budget. Its grant enables us to maintain the independence of EURORDIS' core activities while using this financial support as leverage to develop and diversify our sources of revenue.

We are very grateful to AFM-Téléthon's donors: without all their individual gifts EURORDIS would not be able to conduct our advocacy activities with no conflict of interest with both the private-for-profit sector and public institutions. Since 2013, it amounted to 635 k€. AFM-Téléthon increased it by 5.5% to 670 k€ in 2019 and has been able to maintain this amount since 2020 except in 2021, because of COVID, AFM had to reduce the amount to 600 k€.

The 2019-2023 AFM-Téléthon/EURORDIS Agreement was signed in 2019. The purpose of this grant is focussed on core operations (governance, membership, advocacy, therapeutic development, 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.

In addition to the money granted, the AFM-Téléthon provides us with office space for our Paris-based staff at the Rare Disease Platform. The valuation of this in-kind contribution (238 k€) is based on current property prices.

2.1.2. Contributions from other Patient Organisations

Other POs	Membership fees	Global Genes Ukraine	Total	Ratio
2022	108 k€	48 k€	155 k€	2%
2023	120 k€	0 k€	120 k€	2%
difference	13 k€	-48 k€	-35 k€	-23%

This line comprises the membership fees (108k€ in 2022 and 120k€ in 2023) and a one-shot Global Genes donation for Ukraine.

2.1.3. Volunteers

2 022	849 k€	13%
2 023	617 k€	9%
difference	-231 k€	-27%

The work of the volunteers represented 5.5 full time equivalents (FTE), a total amount of 9,499 hours.

The activity of the Rare Connect website was too low in 2023 for the moderators, therefore, no moderator activity has been taking place this year. Rare Connect was officially retired on December 5th, 2023. This end of activity explains most of the difference (183k€ out of 231k€).

Time spent by volunteers is validated by the volunteer him/herself (> 90%) or estimated by project managers (< 10%). The overall process is validated by our 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

2 022	1 703 k€	26%
2 023	2 375 k€	34%
difference	672 k€	39%

In 2023, the level of EC projects has been exceptionally high. EURORDIS operated eleven ongoing EC projects from DG SANTE, DG RESEARCH and IMI-JU² and negotiated four new EC grants.

Contracts running in 2023:

- the DG SANTE Operating Grant (2023);
- the DG RESEARCH project grant Solve-RD;
- the DG RESEARCH project grant HTx;
- the DG RESEARCH project European Joint Programme on Rare Diseases;
- 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;

² 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".

- the DG SANTE project EUCAPA;
- the DG RESEARCH project more-Europa.

EURORDIS started the negotiation of four other grants to be started in 2024:

- the DG RESEARCH project Join4ATMP;
- the DG RESEARCH project ERDERA (continuation of EJP-RD, multi-annual)
- the DG SANTE project JARDIN in which EURORDIS act as a subcontractor of two public bodies in France and Austria
- the EJP-RD project LIVES in which EURORDIS acts as a subcontractor

2.3. Health Sector Corporates

2 022	2 378 k€	37%
2 023	2 334 k€	33%
difference	-45 k€	-58%

This line comprises 76 health sector companies including 68 pharmaceutical and biotech companies.

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

The percentage of this sector in the overall budget Including in kind contributions and volunteering is 33% and the highest percentage of one Health Sector Company represents 2.4%.

The guarantees of our independence from the health corporate sector are (1) high standards in our governance, (2) balanced revenues between our different sources³ (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)

2 022	311 k€	5%
2 023	450 k€	6%
difference	138 k€	44%

- Two 200 k\$ contracts have been signed with the Chan and Zuckerberg Initiative for 2023 and 2024, hence the increase.
- 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 are continuing.

2.7. Event Fees

2 022	58 k€	1%
2 023	97 k€	1%
difference	39 k€	68%

After two years without any Black Pearl Award ceremony, the attendance to the 2023 session was exceptional (89k€), hence the increase.

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

3. Expenses

Operating expenses, including in-kind contributions, and excluding provisions, amounted to 6 950 k€, which shows an increase of 7% compared to 2022.

The breakdown of EURORDIS expenses is as follows
(in thousands of euros, provisions excluded⁴)

Expenses	2022		2023		Difference	
Staff costs	3 852	60%	4 315	62%	462	12%
Volunteers	849	13%	617	9%	-231	-27%
Logistics	620	10%	725	10%	105	17%
Services	1 026	16%	1 082	16%	57	6%
Others	114	2%	210	3%	96	84%
Total	6 461	100%	6 950	100%	488	7%

More details on expenses:

3.1. Staff costs

2 022	3 852 k€	60%
2 023	4 315 k€	62%
difference	462 k€	12%

The number of FTE⁵ was 49.1 in 2023 compared to 48.7 in 2022.

As at the end of the year, the team was composed of 59 staff members across five countries.

The main office is in France (36), followed by Spain (9) and Belgium (8).

One new position was created in 2023:

Human Resources Director, Sarah Didier, Paris (consultant in 2023, permanent staff contract in 2024)

Two positions were stopped:

- Health and Social Science Project Senior Manager, Edith Gross, Paris
- Rare Disease Day Senior Manager, Estelle Dubois, 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 2023 (45.5%), in Belgium and Spain a little more than 50% (50.4% and 55.3% 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 19 languages and comprises 19 different nationalities. Most of them have a high-level academic background with a master's degree (in Science or Business Administration) or a PhD (in Science or Philosophy). 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

⁴ 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.

⁵ 1 full time equivalent = one person in a full-time position for one year

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.

The usually high level of turnover noted throughout 2021 and 2022 settled down significantly in 2023.

3.2. Logistics

2 022	620 k€	10%
2 023	725 k€	10%
difference	105 k€	17%

Even though 2023 was a non ECRD year, the expenses related to logistics increased compared to the previous year because 2022 was still partially COVID.

There was a face-to-face BPA ceremony as well as a winter and a summer school, compared to online versions in 2022, hence the increase.

3.3. Services

2 022	1 026 k€	16%
2 023	1 082 k€	15%
difference	57 k€	6%

There is no significant difference.

4. Result

The surplus amounted to 81 879 euros; we recommend allocating it to the reserve which will then amount to 1 994 247 euros.

5. Risk going forward

Compared to the 2022 General Assembly, the situation is now more favourable:

- Inflation has been contained
- We had a full year Operating grant in 2023 and 2024 and we will be able to apply for a framework partnership agreement in 2025 and 2026
- COVID19 does not represent a risk anymore

However, the inflation and growth of the team has led to a significant growth in expenses. We currently spend half a million each month and our deferred income is decreasing. More than ever, a strategic focus on consolidation of our income and management of expenses will be required to balance our financials. We trust that we will achieve this.

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 2023* (Specific Grant Agreement)
 - o from 01-Mar-22 to 31-Dec-22
 - 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-Mar-24 to 28-Feb-27
 - 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
 - o EURORDIS co-beneficiary
- *JOIN4ATMP* (Map, Join, and drive European activities for advanced therapy medicinal product development and implementation for patient and society benefit)
 - o from 01-Jan-24 to 31-Dec-26
 - o EURORDIS co-beneficiary
- *ERDERA* (The European Rare Diseases Research Alliance)
 - o from 01-Sep-24 to 31-Aug-31
 - o EURORDIS co-beneficiary

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

- *connect4children* (Collaborative Network for European Clinical Trials For Children)
 - o From 01-May-18 to 30-Apr-25
 - o EURORDIS co-beneficiary
- *Screen4Care* (Shortening the path to rare disease diagnosis by using newborn genetic screening and digital technologies)
 - o from 01-Oct-21 to 30-Sep-26
 - o EURORDIS co-beneficiary
- *FACILITATE* (Framework for Clinical trial participants data reutilisation for a fully transparent and ethical ecosystem)
 - o from 01-Jan-22 to 31-Dec-25
 - o EURORDIS co-beneficiary

ECRD: European Conference on Rare Diseases.

Eleven of them have already taken place

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 twelfth will take place in May 2024 on the internet.

EMA: European Medicines Agency