
FINANCIAL REPORT 2022

May 2023



EURORDIS
RARE DISEASES EUROPE

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, 2022

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, 2022

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, 2022.

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, 2022 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, 2022 to the date of our report.

Justification of Assessments

In accordance with the requirements of Articles L. 823-9 and R. 823-7 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. 823-10-1 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 3, 2023

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY

Assets	2021	2022	Δ in euros	Δ in %
FIXED ASSETS				
Intangible assets	0	985	985	
Tangible assets	75 680	80 115	4 435	6%
Financial assets	8 860	8 860	0	0%
TOTAL	84 540	89 960	5 420	6%
CURRENT ASSETS				
Account receivable due within one year	1 118 371	1 754 491	636 121	57%
Account receivable due after one year	1 772 483	1 793 803	21 320	1%
Other receivables	90 423	66 666	-23 758	-26%
Liquid assets	2 606 286	2 440 211	-166 075	-6%
Prepaid expenses	41 671	29 684	-11 987	-29%
TOTAL	5 629 234	6 084 855	455 621	8%
Conversion adjustment	0	0	0	
TOTAL ASSETS	5 713 774	6 174 815	461 041	8%

Liabilities	2021	2022	Δ in euros	Δ in %
ASSOCIATION FUNDS				
Reserve	1 502 707	1 910 337	407 631	27%
Profit & loss for the year	407 631	2 032	-405 599	-100%
Subsidies of investment	0	0	0	
TOTAL	1 910 337	1 912 369	2 032	0%
Provisions for risk and charges	154 396	157 635	3 239	2%
Dedicated funds on grants	0	0	0	
DEBTS				
Bank loans and overdraft	0	0	0	
Trade creditors	265 702	193 781	-71 921	-27%
Tax payable and social liabilities	415 534	427 956	12 422	3%
Other debts	14 390	0	-14 390	-100%
Deferred income within one year	1 233 987	1 371 763	137 777	11%
Deferred income after one year	1 719 428	2 111 312	391 883	23%
TOTAL	3 803 437	4 262 446	459 009	12%
Conversion adjustment	0	0	0	
TOTAL LIABILITIES	5 713 774	6 174 815	461 041	8%

EURORDIS 2022 Financial status

(Profit and Loss including in kind contributions)

Revenue	2 021	2 022	Ratio	Δ in euros	Δ in %
Patient Organisations	976 134	1 064 197	16%	88 063	9%
Financial contributions	651 480	717 742	11%	66 262	10%
AFM Telethon	600 000	670 000	10%	70 000	12%
Other Patient Organisations	51 480	47 742	1%	-3 738	-7%
In kind contributions (AFM)	227 129	238 925	4%	11 796	5%
Membership fees	97 525	107 530	2%	10 005	10%
Individuals	749 919	901 118	14%	151 199	20%
Volunteers	706 376	848 851	13%	142 475	20%
Donations	43 543	52 267	1%	8 725	20%
European Commission	1 622 543	1 703 087	26%	80 544	5%
DG Research	456 758	694 028	11%	237 270	52%
DG Health and consumers	1 165 785	994 298	15%	-171 487	-15%
EMA contributions (*)		14 761	0%	14 761	
Corporates	2 241 028	2 378 856	37%	137 828	6%
Pharma. and Biotech Companies (**)	2 112 000	2 159 130	33%	47 130	2%
Other Health Sector Corporates (**)	106 500	219 369	3%	112 869	106%
Outside Health Sector Corporates	22 528	357	0%	-22 171	-98%
Not for Profit Organisations	355 042	311 206	5%	-43 836	-12%
Pharma. and Biotech Found.	12 000	121 073	2%	109 073	909%
Other Health Sector NPOs	68 614	56 751	1%	-11 863	-17%
Outside Health Sector NPOs	274 428	133 382	2%	-141 046	-51%
Event Fees	1 585	57 680	1%	56 095	3539%
Miscellaneous	24 163	50 408	1%	26 245	109%
Reimbursement	12 127	23 576	0%	11 449	94%
Others	12 036	26 832	0%	14 796	123%
Sub-total	5 970 413	6 466 552	100%	496 138	8%
Recovery of provisions	107 504	25 428		-82 075	-76%
Report of non-used income					
Total Revenue	6 077 917	6 491 980		414 063	7%

Expenses	2 021	2 022	Ratio	Δ in euros	Δ in %
Staff	3 578 630	3 852 318	60%	273 687	8%
Wages and charges	3 385 874	3 644 720	56%	258 846	8%
Other salaries	151 245	163 147	3%	11 902	8%
Training and other costs	41 511	44 451	1%	2 939	7%
Volunteers	706 376	848 851	13%	142 475	20%
Representatives and task forces	523 496	665 971	10%	142 475	27%
Projects, office and translators	182 880	182 880	3%		
Logistics	179 460	620 036	10%	440 576	246%
Travels and subsistence	56 687	294 761	5%	238 074	420%
Event logistics and catering	20 897	74 527	1%	53 630	257%
Virtual events	101 876	235 987	4%	134 111	132%
In kind contribution (*)		14 761	0%	14 761	
Services	1 033 718	1 025 623	16%	-8 095	-1%
Fees	540 910	295 067	5%	-245 842	-45%
Partners		161 755	3%	161 755	
Telecom and post	39 167	55 789	1%	16 621	42%
Rent	312 070	333 160	5%	21 090	7%
Other services	141 571	179 853	3%	38 282	27%
Purchase	88 382	85 143	1%	-3 239	-4%
Office furniture	34 284	28 189	0%	-6 095	-18%
Amortisation	33 469	33 398	1%	-71	0%
Communications, Publications	8 657	11 980	0%	3 323	38%
Other purchases	11 972	11 576	0%	-396	-3%
Miscellaneous	30 515	29 310	0%	-1 205	-4%
Financial expenses, Insurance, Tax	29 350	29 310	0%	-40	0%
Exceptional expenses	1 165			-1 165	
Sub-total	5 617 082	6 461 281	100%	844 199	15%
Contingency and loss provisions	53 205	28 667	0%	-24 538	-46%
Commitment on assigned income					
Total Expenses	5 670 287	6 489 948		819 662	14%
Result	407 631	2 032			

* covering travel/accommodation costs for EMA meetings

Foreword from the Treasurer

In many respects, 2022 has been an atypical year, both for EURORDIS and its Financial situation. Confronted with major uncertainties, the end result of a break-even position is a great achievement, showing the resilience of the organisation and its capacity to work cooperatively with many different partners to overcome the challenges it faced.

The year started with the unusual situation of a budget gap of more than 1MM€ as EU DG Santé cancelled its multi-year Operating Grant funding process end 2021. Thanks to continued push and collaboration with other NGOs, a 1-Year operating grant application covering only 10 months of expenses could be filed at the beginning of 2022. At that stage, we hoped that the DG Santé would set a path to a multiyear framework partnership agreement for 2023 onward but they have not. While we have secured a 1-year Operating Grant again in 2023, we need to face the renewed uncertainty in DG SANTE structural funding and we don't know at this stage how DG Santé intends to support the engagement of the civil society in achieving the objectives of the EU4 Health Programme from 2024 onward.

The Ukrainian situation also challenged our operations: how to support people fleeing the war and landing in unknown territories with difficult rare conditions? On an emergency basis, we established new funding patterns, governance models, and operating processes to support and directly help organisations and PLWRD in and around Ukraine. Patient and humanitarian organisations, foundations and Health sector corporations contributed to this fund. It is the first time that EURORDIS has collected money to redistribute it to other patient organisations, a new activity and process to be managed responsibly.

The 3rd challenge affecting our financial operations has been the sudden increase of inflation, with no significant short-term ability to adjust income due to our mostly annual contract frames. Inflation exceeded 10% in some of our office locations. Doing the right thing for our staff without endangering the organisation's viability has been and remains a core concern of the Board.

In this context, balancing the budget has been an unusually tough exercise. We feel proud of closing the year with no loss. We also see substantial reassurance in our governance processes and the confidence of a clean report from our External auditors.

Yet, with inflation, a break-even financial position means our reserves stayed at the same nominal level but have shrunk by some 10% in real term. As we navigate in a higher uncertainty environment, in particular with an increased budget and lower front-end payments from EU funded operating grant (now at 50% only vs. 70% in the past), our December 31 reserves cover only 31% of our anticipated annual needs, down from 36% last year.

More than ever, we will need to govern the organisation with a multi-annual budget, advance in identifying new sources of funding outside the health corporate sector, improve forward visibility on each source of funding, increase our agility to shift efforts during the year and leverage our strategic plan to focus on those activities where we have most ability to advance towards our vision of "a world where all people living with a rare disease can have longer and better lives and can achieve their full potential, in a society that values their well-being and leaves no one behind".

Alain Cornet, Treasurer

2022 Financial report comments

1. Assets and Liabilities

1.1. Assets

	2021	2022	Difference	
Accounts receivable	2 981 277	3 614 960	633 683	21%
Liquid assets	2 606 286	2 440 211	-166 075	-6%
Prepaid expenses	41 671	29 684	-11 987	-29%
Total	5 629 234	6 084 855	455 621	8%

Current assets increased from 5 629 k€ in 2021 to 6 085 k€ in 2022. This increase is the result of the signing of a significant pluriannual project funded by the European Commission DG Research, Remedi4All, beefing up our Accounts receivables.

2021 was a special year because we were lacking the first instalment of the European Commission DG SANTE Operating Grant 2022 for an amount of approximately 0.5 M€.

In 2022, we are in the same situation with an Operating Grant 2023 which will be signed during the year with a retroactive effect in January 2023. In addition, since the Operating Grant 2022, the first instalment has been reduced to 50% instead of 70%.

Had we signed the Operating Grant in due time, our assets would be greater by around 1.3M€, roughly split 50/50 between Accounts receivables and Liquid assets.

More details on this situation in the European Commission section.

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 (3 168 k€, 88%).

The increase is due to the signing of Remedi4All (an impact of 878k€ on the accounts receivable) attenuated by the funds received on other projects.

1.1.2. Liquid assets

Liquid assets are cash in the bank. The level of liquidities at the end of 2022 is satisfactory, it represents 5 months of functioning in 2023.

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 2021, they amounted to 1 910k€. The surplus of 2022 being very minimal they roughly remain at the same level (1 912 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 and provisions).

In 2023, this budget amounting to 6.2M€, a reserve of 1.9 M€ represents 31% of the annual expenses which is closer to 25% than 50%, therefore reasonable but on the low side in the uncertain context that we currently face.

1.2.2. Provisions

	2021	2022		
		Recoveries	New provisions	Balance
Provisions for risks	76 162	-15 142	28 667	89 687
Provision for retirement benefits	78 234	-10 286		67 948
Provisions for risks and charges	154 396	-25 428	28 667	157 635

We have recorded all necessary provisions corresponding to the activity in 2022. Of this, an amount of 83k€ represents non-French VAT due, which will be settled early 2023.

1.2.3. Trade creditors

2021	266 k€	5%
2022	194 k€	3%
difference	- 72 k€	- 27%

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

2021	2 953 k€	52%
2022	3 483 k€	56%
Difference	+ 530 k€	+ 18%

Deferred income refers to the part of grants already signed but that will be performed in the upcoming years (and hence for which the expenses are not totally incurred yet at the end of the accounting year). Contrary to the Accounts Receivable position, which accounts for the portion signed but not yet received in cash, the deferred income is an estimate of the income that we will record in the upcoming years when we also recognise the related expenses. The calculation of the income is based on the expenses that will be incurred to complete the committed action.

At the end of the year 2022, deferred income was mainly composed of the ongoing pluriannual EC projects (3 003 k€, 86% of total).

As we signed a significant 5-year project (Remedi4All) which started in September 2022, deferred income increased substantially (1 300 k€). This input is offset by the consumption of deferred income as we perform ongoing projects.

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 6 467 k€. This represents an increase of 496 k€ (+ 8%) compared to 2021.

The bulk of the increase is due to:

- Increase of the AFM Grant (+ 82k€)
- Increase of the number of in kind volunteers at the Therapeutic Action Group (+ 145 k€)
- Increase of Private and Public grants (+ 175 k€)

The breakdown of EURORDIS' revenue by sources is as follows:

(amounts are in thousands of euros, recovery of provisions is excluded¹)

	2021		2022		Difference	
<i>AFM-Telethon</i>	827	14%	909	14%	82	10%
<i>Contributions from members</i>	149	2%	155	2%	6	4%
<i>Volunteers</i>	750	13%	901	14%	151	20%
Patient Org. and Volunteers	1 726	29%	1 965	30%	239	14%
European Commission	1 623	27%	1 703	26%	81	5%
National authorities	0	0%	0	0%	0	0%
<i>Pharma. and Biotech Companies</i>	2 112	35%	2 159	33%	47	2%
<i>Other Health Sector Corporates</i>	107	2%	219	3%	113	106%
Health Sector Corporates	2 219	37%	2 378	37%	160	7%
Other Corporates	23	0%	0	0%	-22	-98%
Foundations and NPOs	355	6%	311	5%	-44	-12%
Event fees	2	0%	58	1%	56	3539%
Others	24	0%	50	1%	26	109%
Total	5 970	100%	6 467	100%	496	8%

Compared to a total budget including volunteers, the Health Sector Corporate donations come first with 37% followed by Patient Organisation and volunteers (30%) and the European Commission (26%).

In July 2020, the Board decided on a temporary exception on EURORDIS' funding rules². The Board of March 2022 has permanently validated the new policy:

"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."

If we exclude the volunteers from the analysis, the amount coming from the Health Sector represented 45% of the budget and the largest donor 3.2%. It is therefore compliant with the new policy.

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.

² Initially the rule was that the amount coming from the Health Sector Industry cannot be greater than the amount coming from the Patient Organisation Sector, in kind contributions included.

More details on revenues:

2.1. Patient Organisations and Volunteers

2021	1 726 k€	29%
2022	1 965 k€	30%
difference	+ 239 k€	+ 14%

The Patient Organisations and Volunteers section (1 965k€) was in 2022 our second source of revenue after the Health Corporate sector (2 378k€). This PO and volunteers' income is largely composed of in kind contributions (volunteer contributions and Paris' office space kindly offered by AFM, 1 087 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)

2021	827 k€	14%
2022	909 k€	14%
Difference	+ 82 k€	+ 10%

The AFM-Téléthon is a EURORDIS' co-founding member and by far the main patient organisation to contribute to EURORDIS' budget, both in cash and in kind with the putting at disposal of our Paris offices. 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 its advocacy activities with no conflict of interest with both the private-for-profit sector and public institutions. Since 2013, has AFM funded a total of 5 785 k€ cash support to EURORDIS. After a modest reduction of their financial support in 2020 due to COVID, AFM increased its support back to 670 k€ in 2020, a very appreciated addition in 2022.

The 2019-2022 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 (239 k€) is based on current property prices.

2.1.2. Contributions from other Patient Organisations

2021	149 k€	2%
2022	155 k€	2%
Difference	+ 6 k€	+ 4%

This line comprises the membership fees (98k€ in 2021 and 108k€ in 2022).

In 2022, the remainder comes from a contribution from Global Genes (47k€) and Agrenska (1k€) in the context of the refugee crisis in Poland due to the war in Ukraine.

2.1.3. Volunteers and individual donors

2021	750 k€	13%
2022	901 k€	14%
Difference	+ 151 k€	+ 20%

We had a significant level of donations from individuals in 2022 (52 k€) but our main source of revenue from individuals remains in kind (volunteers, 849 k€).

After a significant reduction of Volunteering hours in 2020 due to COVID lower travel time partly compensated by additional COVID related advocacy work, 2021 was only partly back, reflecting the quasi-exclusive usage of online meetings and the “zoom fatigue” impacting the volunteering volume. In 2022, activity progressively came back to a normal level and additional work in the Therapeutic Action Group brought back volunteering to 8.6 full time equivalents (FTE), a total amount of 14,817 hours.

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 time offered by 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

2021	1 623 k€	27%
2022	1 703 k€	26%
Difference	+ 81 k€	+ 5%

In 2022, EURORDIS operated nine EC projects from DG SANTE, DG RESEARCH and IMI-JU³ and negotiated three new EC grants.

Contracts running in 2022:

- the DG SANTE Operating Grant (exceptionally 10 months in 2022, renewed every year since 2009 except in January and February 2022);

³ 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 RESEARCH project grant Solve-RD (multi-annual);
- the DG RESEARCH project grant HTx (multi-annual);
- the DG RESEARCH consortium European Joint Programme on Rare Diseases (multi-annual);
- the IMI-JU consortium grant Conect4Children (C4C) (multi-annual);
- the DG RESEARCH project grant REMEDI4ALL (multi-annual);
- the IMI-JU project grant Screen4Care (multi-annual);
- the IMI-JU project grant FACILITATE (multi-annual);
- the DG RESEARCH project grant ERICA (multi-annual).

The DG SANTE Operating Grant used to be embedded in a Framework Partnership Agreement (FPA) which lasted from 2018 to 2021.

For the second time since its creation in 2009, there is currently – March 2023 – no DG SANTE Operating Grant in force but a positive external evaluation puts us on the safe side, it is very likely that the contract will be signed before the end of the month of April, and contrary to 2022 will be retroactive to January 1.

The long-awaited Operating Grant FPA 2022-2025 was not in the 2021 DG SANTE Work Programme which was published very late in 2021. A short-term Operating Grant was finally reintroduced in the Work Plan 2022 for a partial funding in 2022. Likewise, the Work Plan 2023 introduced another short term one-year Operating Grant. This time the release date of the call for proposal was anticipated in a way that the retroactive start can be the 1st of January 2023. This repeated situation increases the already high level of uncertainty in the Patient Organisation sector in Europe. It is further analysed in §5 “Risk going forward”.

In addition to the Operating Grant 2023, EURORDIS started the negotiation of 2 other grants started in 2023:

- the DG RESEARCH project more-EUROPA (multi-annual);
- the DG SANTE project EUCAPA (multi-annual)

2.3. Health Sector Corporates

2021	2 219 k€	37%
2022	2 378 k€	37%
Difference	+ 160 k€	+ 7%

This line comprises 77 health sector companies including 65 pharmaceutical and biotech companies.

In this context, the five largest contributors from the Health sector are, in descending order: 1st TAKEDA, 2nd PFIZER, 3rd ROCHE, 4th ILLUMINA and 5th NOVARTIS and HORIZON THERAPEUTICS.

The percentage of this sector in the overall budget, including in kind & volunteering is 37% and the highest percentage of one Health Sector Company represents less than 3.0%.

The guarantees of our independence from the health corporate sector are (1) high standards in our governance, (2) balanced revenues between our different sources⁴ (3) the limitation of the health sector corporates incomes, (4) the diversity and limited amount of each single corporate donor and

⁴ i.e., Patient Organisations & Volunteers, Public income, Corporate income, revenues generated by our activities

(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)

2021	355 k€	6%
2022	311 k€	5%
difference	- 44 k€	- 12%

As part of its desire to further diversify its sources of income, EURORDIS is actively seeking non-Pharma non-EU financial support. This is a difficult path, in which progress is slow, but an essential need for our long-term independence.

- No new contract has been signed with the Chan and Zuckerberg Initiative for 2022 (-123k€) but a new grant has been contracted in 2023.
- Two significant three-year contracts have been signed with the IPSEN Foundation for a total amount of 360k€. They support activities in the context of the Heath Data advocacy and the Rare Disease Day. The impact on 2022 was 102k€.

This section also contains grants from:

- The Boston Scientific Foundation (32k€)
- The Singapore Red Cross with a grant amounting to SGD 100k which was partly consumed in 2022 (31k€)
- The Children's Hospital of Eastern Ontario covering direct costs of the internet platform RareConnect.org (15k€)
- The Bertarelli Foundation in the context of the Black Pearl Awards (10k€)

2.7. Event Fees

2021	2 k€	0%
2022	58 k€	0%
Difference	+ 56 k€	+ 3539%

There were no event fees in 2021 because of COVID, in 2022 we had some event fees in the context of our online European Conference on Rare Diseases (ECDRD2022).

3. Expenses

Operating expenses, including in-kind contributions, and excluding provisions, amounted to 6 461 k€, an increase of 15% compared to 2021.

Unsurprisingly there was a very sharp increase in logistics (+441 k€) as travel resumed post-COVID.

The breakdown of EURORDIS expenses is as follows
(in thousands of euros, provisions excluded⁵)

Expenses	2021		2022		Difference	
Staff costs	3 579	64%	3 852	60%	274	8%
Volunteers	706	13%	849	13%	142	20%
Logistics	179	3%	620	10%	441	246%
Services	1 034	18%	1 026	16%	-8	-1%
Others	119	2%	114	2%	-4	-4%
Total	5 617	100%	6 461	100%	844	15%

More details on expenses:

3.1. Staff costs

2021	3 579 k€	64%
2022	3 852 k€	60%
Difference	+ 274 k€	+ 8 %

The number of FTE⁶ was 48.7 in 2022 compared to 48.0 in 2021.
As at the end of the year, the team was composed of 55 staff members.
The main offices are in France (33), Spain (9) and Belgium (6).

7 new positions were created in 2022 (in order of appearance):

- Patient Data Director, Jelena Malinina, Brussels
- Senior Project Manager, EURORDIS Ukraine Response, Anastasiia Saliuk, Paris
- Drug Repurposing Project Senior Manager, Claudia Fuchs, Bolzano
- Social Policy & Initiatives Director, Raquel Castro, Barcelona
- Patient Engagement & Training Manager, Judit Baijet, Barcelona
- Office Assistant, Aminata Doumbia, Paris
- Communications Junior Manager, Rhiannon Walls, Paris

4 positions were stopped:

- Public Health Policy Director, Anna Kole, Paris
- Public Health Policy Junior Manager, Julien Delaye, Brussels
- Rare Connect Manager, Sandra Pavlovic, Belgrade
- Rare Diseases International Executive Director, Flaminia Macchia, Brussels

Note on staff costs:

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

⁵ 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.

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

In France, where staff is mainly present, the net salary represented less than 50% of the staff costs in 2022 (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 2 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. 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.

Like many organisations, EURORDIS continued to face a usually high level of turnover during the first semester of 2022.

3.2. Logistics

2021	179 k€	3%
2022	620 k€	10%
difference	+ 441 k€	+ 246%

This section comprises the costs related to the tenure of virtual conferences such as ECRD in 2022 as well as travel expenses.

The increase comes from:

- The organisation of an event in Dubai together with Rare Diseases International and Agrenska as members of the NGO Committee for Rare Diseases. The event was offered in kind by Alexion. Each organisation displays a third of this contribution in their accounts (116k€).
- The European Conference for Rare Diseases 2022 organised online (95k€).
- The rest comes from many meetings which were held face-to-face (Round table of companies, Board of Directors, Committees at the European Medicines Agency, etc.) compared to online in 2021.

3.3. Services

2021	1 034 k€	18%
2022	1 026 k€	16%
Difference	- 8 k€	- 1%

The main category of expenses is renting costs, the most significant part of which is an in-kind contribution from the AFM-Téléthon in Paris (office space, 239k€).

The second biggest operating expense has been the distribution of grants to patient organisations in the context of the EURORDIS Ukraine Response project (162k€).

Other operating expenses are:

- IT maintenance, software, development (135k€)
- Translations, graphics, videos and hosting (110k€)
- Consulting (86k€)
- Accounting, payroll management, recruitment and legal advice (85k€)
- Telecommunication and post (56k€)

4. Result

The surplus amounted to 2 k€; we recommend allocating it to the reserve which will then amount to 1 912 k€.

5. Risk going forward

While we thought uncertainty would largely reduce after 2 years of an unprecedented worldwide pandemic, we currently face a highly unusual and unpredictable combination of risk factors.

(1) Renewed unpredictability of DG SANTE Operating Grant, (2) the situation in Ukraine and corresponding flux of refugees and finally (3) a high level of inflation due to both the end of the COVID crisis and the start of the crisis in Ukraine.

Of these, the situation of the DG SANTE Operating Grant requires additional background:

Usually, the Work Programme of a given year sets the path for the upcoming years.

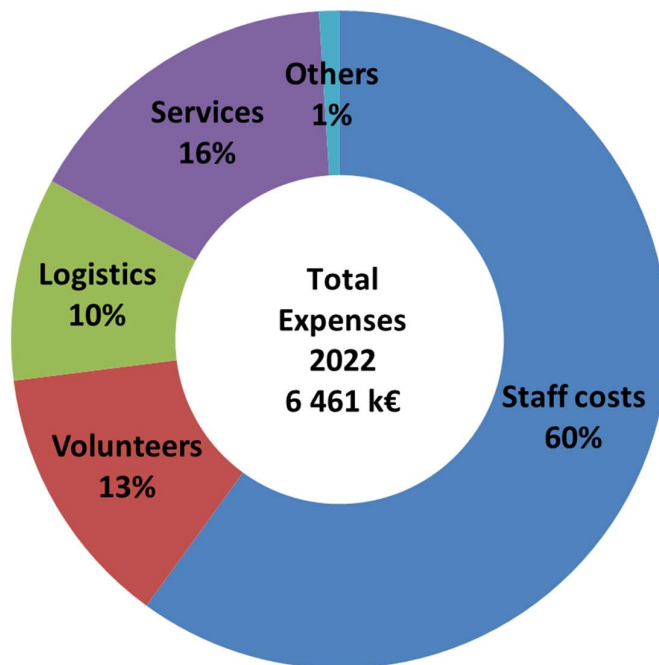
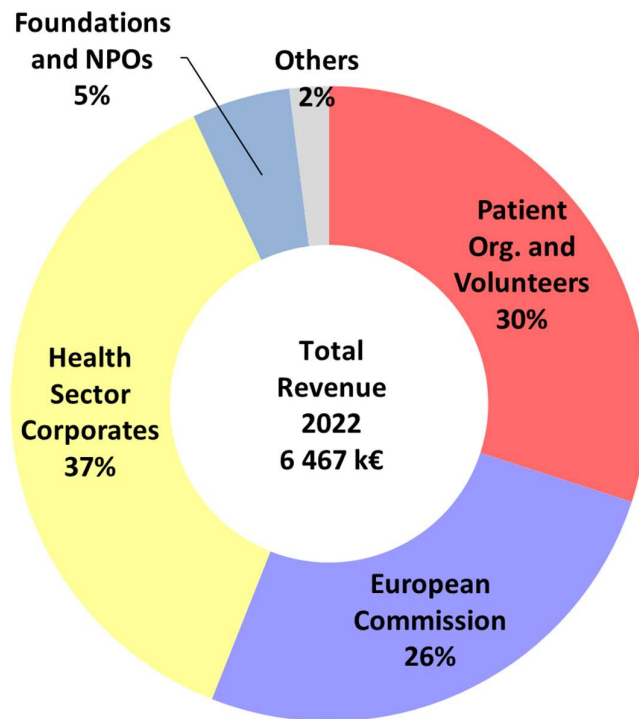
The long-awaited Operating Grant FPA 2022-2025 was not in the 2021 DG SANTE Work Programme which was published very late in 2021. Operating Grants were finally reintroduced in the Work Plan 2022 as a 1-year event with a partial retroactive funding in 2022.

For year 2023, the call for proposal was published, again as a 1-Year event, in December 2022, therefore, the grant in 2023 will be able to cover the entire year for the organisations that, like us, were able to submit their application before 31/12/2022.

EURORDIS passed the evaluation positively and will therefore be funded in 2023.

In terms of perspectives, the multiannual framework has not been relaunched in the DG SANTE 2023 Work Programme and we still don't know what DG SANTE's plans for the Operating Grants are for 2024 and forward.

This high and renewed level of uncertainty is difficult to deal with in any circumstances. It is even more difficult to understand in the current economical and geopolitical context.



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 2022* (Specific Grant Agreement)
 - o from 01-Mar-22 to 31-Dec-22
 - o EURORDIS sole beneficiary

DG RESEARCH: Research and Innovation Directorate-General of EC

Ongoing Projects:

- *Solve-RD* (Solving the unsolved Rare Diseases)
 - o from 01-Jan-18 to 30-Jun-23
 - 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 31-Dec-23
 - o EURORDIS co-beneficiary
- *EJP RD* (European Joint Programme on Rare Diseases)
 - o from 01-Jan-19 to 31-Dec-23
 - 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

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

- *conect4children* (Collaborative Network for European Clinical Trials For Children)
 - o From 01-May-18 to 30-Apr-24
 - 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.

11 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