
FINANCIAL REPORT 2021

May 2022



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, 2021

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, 2021

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, 2021.

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, 2021 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, 2021 to the date of our report.

Justification of Assessments

Due to the global crisis related to the Covid-19 pandemic, the financial statements of this period have been prepared and audited under specific conditions. Indeed, this crisis and the exceptional measures taken in the context of the state of sanitary emergency have had numerous consequences for companies, particularly on their operations and their financing, and have led to greater uncertainties on their future prospects. Those measures, such as travel restrictions and remote working, have also had an impact on the companies' internal organization and the performance of the audits.

It is in this complex and evolving context that, 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 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 2, 2022

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY



EURORDIS 2021 Financial Status
(Assets and Liabilities)

Assets	2020	2021	Δ in euros	Δ in %
FIXED ASSETS				
Intangible assets	0	0	0	-100%
Tangible assets	85 562	75 680	-9 882	-12%
Financial assets	8 860	8 860	0	0%
TOTAL	94 422	84 540	-9 882	-10%
CURRENT ASSETS				
Account receivable due within one year	1 807 519	1 198 277	-609 242	-34%
Account receivable due after one year	1 199 841	1 772 483	572 642	48%
Other receivables	148 911	10 517	-138 393	-93%
Liquid assets	2 585 191	2 606 286	21 095	1%
Prepaid expenses	32 231	41 671	9 440	29%
TOTAL	5 773 693	5 629 234	-144 458	-3%
Conversion adjustment	13 903	0	-13 903	-100%
TOTAL ASSETS	5 882 018	5 713 774	-168 243	-3%

Liabilities	2020	2021	Δ in euros	Δ in %
ASSOCIATION FUNDS				
Reserve	1 279 674	1 502 707	223 033	17%
Profit & loss for the year	223 033	407 631	184 598	83%
Subsidies of investment	0	0	0	NA
TOTAL	1 502 707	1 910 337	407 631	27%
Provisions for risk and charges	209 658	154 396	-55 262	-26%
Dedicated funds on grants	0	0	0	NA
DEBTS				
Bank loans and overdraft	0	0	0	NA
Trade creditors	422 640	265 702	-156 938	-37%
Tax payable and social liabilities	443 341	415 534	-27 807	-6%
Other debts	14 750	14 390	-360	-2%
Deferred income within one year	2 089 082	1 233 987	-855 095	-41%
Deferred income after one year	1 199 841	1 719 428	519 588	43%
TOTAL	4 379 311	3 803 437	-575 874	-13%
Conversion adjustment	0	0	0	NA
TOTAL LIABILITIES	5 882 018	5 713 774	-168 243	-3%

2021 Financial Status VS 2020 Financial Status

(Profit and Loss including in kind contributions)

Revenue	2020 Fin. Status	2021 Fin. Status	Ratio	Δ in euros	Δ in %
Patient Organisations	994 846	976 134	16%	-18 712	-2%
Financial contributions	680 190	651 480	11%		
AFM Telethon	670 000	600 000	10%	-70 000	-10%
Other Patient Organisations	10 190	51 480	1%	41 290	405%
In kind contributions (AFM)	223 016	227 129	4%	4 113	2%
Membership fees	91 640	97 525	2%	5 885	6%
Individuals	944 954	749 919	13%	-195 036	-21%
Volunteers	938 141	706 376	12%	-231 765	-25%
Donations	6 813	43 543	1%	36 729	539%
European Commission	1 971 122	1 622 543	27%	-348 580	-18%
DG Research	651 397	456 758	8%	-194 639	-30%
DG Health and consumers	1 311 321	1 165 785	20%	-145 537	-11%
DG Employment					
EMA contributions (*)	8 404			-8 404	
National authorities					
Grants from National authorities					
Corporates	2 043 007	2 241 028	38%	198 021	10%
Pharma. and Biotech Companies (**)	1 859 360	2 112 000	35%	252 640	14%
Other Health Sector Corporates (**)	107 900	106 500	2%	-1 400	-1%
Outside Health Sector Corporates	75 747	22 528	0%	-53 219	-70%
Not for Profit Organisations	282 710	355 042	6%	72 332	26%
Pharma. and Biotech Found.	12 954	12 000	0%	-954	-7%
Other Health Sector NPOs	67 834	68 614	1%	780	1%
Outside Health Sector NPOs	201 922	274 428	5%	72 506	36%
Event Fees	249 888	1 585	0%	-248 303	-99%
Miscellaneous	22 568	24 163	0%	1 595	7%
Reimbursement	8 153	12 127	0%	3 975	49%
Others	14 415	12 036	0%	-2 379	-17%
Sub-total	6 509 096	5 970 413	100%	-538 682	-8%
Recovery of provisions		107 504		107 504	
Report of non-used income					
Total Revenue	6 509 096	6 077 917		-431 178	-7%

Expenses	2020 Fin. Status	2021 Fin. Status	Ratio	Δ in euros	Δ in %
Staff	3 463 090	3 578 630	64%	115 540	3%
Wages and charges	3 267 267	3 385 874	60%	118 607	4%
Other salaries	151 983	151 245	3%	-738	0%
Training and other costs	43 841	41 511	1%	-2 330	-5%
Volunteers	938 141	706 376	13%	-231 765	-25%
Representatives and task forces	711 460	523 496	9%	-187 964	-26%
Projects, office and translators	226 681	182 880	3%	-43 801	-19%
Logistics	524 794	179 460	3%	-345 334	-66%
Travels and subsistence	154 222	56 687	1%	-97 535	-63%
Event logistics and catering	82 870	20 897	0%	-61 973	-75%
Virtual events	279 298	101 876	2%	-177 422	-64%
In kind contribution (*)	8 404			-8 404	
Services	1 006 938	1 033 718	18%	26 781	3%
Fees	553 899	540 910	10%	-12 989	-2%
Telecom and post	37 774	39 167	1%	1 393	4%
Rent	298 927	312 070	6%	13 143	4%
Other services	116 338	141 571	3%	25 233	22%
Purchase	96 432	88 382	2%	-8 050	-8%
Office furniture	29 097	34 284	1%	5 187	18%
Amortisation	35 700	33 469	1%	-2 231	-6%
Communications, Publications	18 300	8 657	0%	-9 643	-53%
Other purchases	13 334	11 972	0%	-1 362	-10%
Miscellaneous	132 386	30 515	1%	-101 871	-77%
Financial expenses, Insurance, Tax	29 463	29 350	1%	-113	0%
Exceptional expenses	102 923	1 165	0%	-101 758	-99%
Sub-total	6 161 781	5 617 082	100%	-544 699	-9%
Contingency and loss provisions	124 282	53 205	1%	-71 077	-57%
Commitment on assigned income					
Total Expenses	6 286 063	5 670 287		-615 776	-10%
Result	223 033	407 631			

2021 Financial report comments

1. Assets and Liabilities

1.1. Assets

Current assets slightly decreased from 5 774 k€ in 2020 to 5 648 k€ in 2021. This slight decrease is the result of a decrease in accounts receivable partially compensated by an increase of liquid assets.

	2020	2021	Difference	
Accounts receivable	3 156 270	2 981 277	-174 993	-6%
Liquid assets	2 585 191	2 606 286	21 095	1%
Prepaid expenses	32 231	41 671	9 440	29%
Total	5 773 693	5 629 234	-144 458	-3%

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 (2 479 k€, 83%).

Account receivable have decreased compared to 2020 even though several European Commission and foundation contracts were signed in 2021. It has only partially compensated the consumption of the ongoing contracts.

1.1.2. Liquid assets

Liquid assets are cash in the bank. The level of liquidities is satisfactory at the end of 2021.

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 2020, they amounted to 1 503k€. Thanks to the surplus at the end of 2021, the Association Funds increased from 1 503 to 1 910 k€, signifying a 27% increase. This steady increase of the reserve results from management decisions to reinforce the financial sustainability of the organisation while evolving in a growingly uncertain environment (cf. §5 Risk going forward).

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 2022, the total budgeted expenses excluding in-kind contributions before provisions amounts to 5.5M€; a reserve of 1.9 M€ represents 34% of the annual expenses.

1.2.2. Provisions

	2020	2021		
		Recoveries	New provisions	Balance
Provisions for risks	132 903	-56 741		76 162
Provision for retirement benefits	76 755		1 479	78 234
Provisions for risks and charges	209 658	-56 741	1 479	154 396

We have recorded all necessary provisions corresponding to the activity in 2021 to be on the safe side.

1.2.3. Trade creditors

2020	423 k€	7%
2021	266 k€	5%
difference	- 157 k€	- 37%

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. In 2020, the amount was particularly high due to one invoice amounting to 150 k€ invoiced in 2020 and paid in 2021. We are now back to prior years' levels.

1.2.4. Deferred income

2020	3 289 k€	56%
2021	2 953 k€	52%
Difference	- 336 k€	- 10%

Deferred income refers to the part of grants concerning the upcoming years (the part of the grant that has not been earned yet). This is different from the accounts receivable which concerns the cash flow (i.e., the money received at the bank) whereas the calculation of the deferred income is based on the expenses that will occur 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.

Deferred income is mainly composed of the ongoing pluriannual EC projects (2 282 k€, 77%).

Deferred income has decreased compared to 2020 because the new EC pluriannual contracts signed in 2021 were lower than the consumption of deferred incomes from the previous years.

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 5 970 k€. This represents a significant decrease of 539 k€ (- 10%) compared to 2020.

The bulk of the decrease is due to:

- End of two projects funded by the European Commission (- 349 k€)
- No European Conference on Rare Diseases- ECRD – in 2021, and almost no Event fees (- 248k€)
- Reduction of time spent by volunteers (- 214k€)
- Reduction of AFM-Téléthon financial support (- 65K€)

Compensated by an increase of resources coming from the health sector (+ 251k€)

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

	2 020		2 021		Difference	
<i>AFM-Telethon</i>	893	14%	827	14%	-66	-7%
<i>Contributions from members</i>	102	2%	149	2%	47	46%
<i>Volunteers</i>	945	15%	750	13%	-195	-21%
Patient Org. and Volunteers	1 940	30%	1 726	29%	-214	-11%
European Commission	1 971	30%	1 623	27%	-349	-18%
National authorities	0	0%	0	0%	0	
<i>Pharma. and Biotech Companies</i>	1 859	29%	2 117	35%	258	14%
<i>Other Health Sector Corporates</i>	108	2%	102	2%	-6	-6%
Health Sector Corporates	1 967	30%	2 219	37%	251	13%
Other Corporates	76	1%	23	0%	-53	-70%
Foundations and NPOs	283	4%	355	6%	72	26%
Event fees	250	4%	2	0%	-248	-99%
Others	23	0%	24	0%	2	7%
Total	6 509	100%	5 970	100%	-539	-8%

Overall: The Health Sector Corporate donations come first with 37% followed by Patient Organisations and volunteers (29%) and the European Commission (27%).

In March 2022, the Board validated the new policy presented to the General Assembly in June 2021: 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, recognising the significant economic value contributed pro bono by the patient community.
- As a result, the health sector industry will consistently be well below 50% of total income including in kind contributions.

If we exclude the volunteers from the analysis of 2021, the amount coming from the Health Sector represented 42% of the budget and the largest donor 4.6%. It is therefore compliant with the new policy.

More details on revenues:

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.

2.1. Patient Organisations and Volunteers

2020	1 940 k€	30%
2021	1 726 k€	29%
difference	- 214 k€	- 11%

The Patient Organisations and Volunteers section (1 726k€) was in 2021 our second source of revenue after the Health Corporate sector (2 219k€). The larger part of it is in kind (volunteer contributions; Paris' office space kindly offered by AFM, 977 k€) and the main cash contribution is the annual support of AFM-Téléthon (600 k€).

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

2020	893 k€	14%
2021	827 k€	14%
Difference	- 66 k€	- 7%

The AFM-Téléthon is a EURORDIS' co-founding member and by far the largest 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. From 2013 to 2018, it amounted to an annual support of 635 k€. We are very grateful to AFM-Téléthon who increased it by 5.5% to 670 k€ in 2019 and was able to maintain this amount in 2020. In 2021, because of COVID, AFM had to reduce the amount to 600 k€ hence the decrease.

The 2019-2022 AFM-Téléthon/EURORDIS Agreement was signed in 2019. The purpose of this grant is to support the 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 (227 k€) is based on current property prices.

2.1.2. Contributions from members

2020	102 k€	2%
2021	149 k€	2%
Difference	+ 47 k€	+ 46%

This line comprises the membership fees (92k€ in 2020 and 98k€ in 2021), contributions from the European Federations in the context of the EURORDIS EUROCA² programme (5 k€ in 2020 and 44 k€ in 2021) and 8 k€ corresponding to in kind training services performed by patient organisations in the context of the Open Academy programmes.

2.1.3. Volunteers and individual donors

2020	945 k€	15%
2021	750 k€	13%
Difference	- 195 k€	- 21%

We had a significant level of donations from individuals in 2021 (44 k€) but our main source of revenue from individuals remains in kind (volunteers, 706 k€).

The time donated by our volunteers decreased in 2020 because of COVID but not as much as we initially thought. The reason is that the very substantial time not spent in travels was partly compensated by activities to respond to the COVID crisis which generated additional information and advocacy work. In 2021, there was still no travels and the additional time spent on the new COVID phenomenon was no longer or less necessary, the quasi-exclusive usage of online meetings created a lassitude. The online meetings also became shorter and more efficient as people became used to the process. As a result, the time spent by volunteers decreased further. The work of the volunteers represented 7.6 full time equivalents (FTE), a total amount of 12,696 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 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

2020	1 971 k€	30%
2021	1 623 k€	27%
Difference	- 348 k€	- 18%

In 2021, EURORDIS operated nine ongoing EC projects from DG SANTE, DG RESEARCH and IMI-JU³ and negotiated one new EC grant.

Contracts running in 2021:

- the DG SANTE Operating Grant (annual, renewed every year since 2009);
- 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);

² CAB means Community Advisory Board

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 IMI-JU consortium grant Conect4Children (C4C) (multi-annual);
- the DG SANTE project grant RARE 2030 (multi-annual);
- the DG SANTE project grant RDCODE (multi-annual);
- the IMI-JU project grant Screen4Care (multi-annual);
- the DG RESEARCH project grant ERICA (multi-annual).

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

For the first time since its creation in 2009 there a disruption of the Operating Grant in 2022.

This is unprecedented and creates a high level of uncertainty in the Patient Organisation sector in Europe. It is further analysed in §5 "Risk going forward".

2.3. Health Sector Corporates

2020	1 967 k€	30%
2021	2 219 k€	37%
Difference	+ 252 k€	+ 13%

This line comprises 77 health sector companies including 66 pharmaceutical and biotech companies, and includes all fees received in the context of the Rare Impact project, regardless of their origin.

In 2018, EURORDIS associated with a for profit consultant (Dolon) and started a new kind of project in collaboration with several pharmaceutical or biotech companies, 1 trade organisation and 2 not-for-profit organisations. This project, called Rare Impact, ended in 2021. As this project could have a beneficial impact for both patients and drug manufacturers, we had to consider it as a for profit activity and EURORDIS has created a distinct for-profit sector in its accounting system.

In this context, the five largest contributors from the health sector are, in descending order: TAKEDA, SANOFI GENZYME, PFIZER, ROCHE and BRISTOL-MYERS SQUIBB.

The percentage of this sector in the overall budget is 37% and the highest percentage of one Health Sector Company represents less than 4.0%.

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 (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)

2020	283 k€	4%
2021	355 k€	6%
difference	+ 72 k€	+ 26%

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

- Two contracts were signed with the Chan Zuckerberg Initiative (CZI) in 2020 (Facebook foundation) to support capacity building and Rare Disease Day. They have continued in 2021.

This section also contains grants from:

- The Russian organisation AIPM (Association of International Pharmaceutical Manufacturers),
- The Children's Hospital of Eastern Ontario covering direct costs of the internet platform RareConnect.org
- The Bertarelli Foundation in the context of the Black Pearl Awards

2.7. Event Fees

2020	250 k€	4%
2021	2 k€	0%
difference	- 248 k€	- 99%

There were no event fees in 2021 because of COVID.

3. Expenses

Operating expenses, including in-kind contributions, and excluding provisions, amounted to 5 617 k€, a decrease of 10% compared to 2020.

Unsurprisingly there was a very sharp decrease in logistics (-364 k€, no ECRD) and a decrease in volunteers (- 232 k€).

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

Expenses	2 020		2 021		Difference	
Staff costs	3 463	56%	3 579	64%	116	3%
Volunteers	938	15%	706	13%	-232	-25%
Logistics	525	9%	161	3%	-364	-69%
Services	1 007	16%	1 034	18%	27	3%
Others	229	4%	138	2%	-91	-40%
Total	6 162	100%	5 617	100%	-545	-10%

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.

More details on expenses:

3.1. Staff costs

2020	3 463 k€	56%
2021	3 579 k€	64%
Difference	+ 116 k€	+ 3%

The number of FTE⁶ was 48.0 in 2021 compared to 47.7 in 2020.

As at the end of the year, the team was composed of 49 staff members dispatched in 9 countries.

The main office is in France (31), followed by Belgium (6), Spain (6), Italy (1), Serbia (1), Germany (1), the United Kingdom of Great Britain and Northern Ireland (1), Romania (1) and Russia (1).

4 new positions were created in 2021 (in order of appearance):

- Rare Barometer Communications Junior Manager, Andrea Osvoll, Paris
- Compliance and Budget Manager, Imane Elgoumri, Paris
- Health & Social Sciences Project Senior Manager, Edith Gross, Paris
- Events Junior Manager, Anne L'Hévéder, Paris

4 positions were stopped:

- Open Academy Director, Raquel Castro, Barcelona (Responsibility transferred to the Event Director, Sharon Ashton)
- Project Senior Manager – Rare Impact, Karolina Hanslik, Brussels
- Public Affairs Manager - EU & National Integrated Advocacy, Kostas Aliagiannis, Brussels
- Patient Engagement Senior Manager – CABs, Rob Camp, Barcelona

Note on staff costs:

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

In France where the largest proportion of the staff is located, the net salary represented less than 50% of the staff costs in 2021 (48%), in Belgium and Spain a bit more than 50% (respectively 55% and 57%). 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 24 different nationalities. 90% 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 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 covid pandemic had deep running consequences and created a wave of high turnover which also affected EURORDIS during the second semester 2021. All vacant positions have been fulfilled at this time. The turnover has been used positively to adapt the human resource allocation and capacities.

3.2. Logistics

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

2020	525 k€	9%
2021	161 k€	3%
difference	- 364 k€	- 69%

This section comprises the costs related to the tenure of virtual conferences such as ECRD in 2020. The decrease comes from the drastic reduction of travels over the whole year compared to 3/4 of the year in 2020. In addition, there was no ECRD in 2021.

3.3. Services

2020	1 007 k€	16%
2021	1 034 k€	18%
Difference	+ 27 k€	+ 3%

There is no significant difference.

4. Result

The surplus amounted to 407 631 euros; we recommend allocating it to the reserve which will then amount to 1 910 337 euros.

5. Risk going forward

After 2 years of an unprecedented worldwide pandemic, we are currently facing a highly unusual and unpredictable combination of risk factors.

(1) Unpredictability of DG SANTE Operating Grant, (2) uncertainties on the capacity to restart face-to-face meetings and training as well as missions (3) the situation in Ukraine and corresponding flux of refugees impacting families living with a rare disease and finally (4) a high level of inflation due to both the end of the COVID crisis and the start of the crisis in Ukraine.

More explanations on the DG SANTE Operating Grant

Usually, the EU Public Health Programmes' Work Programme -managed by DG Sante- of a given year sets the path for the upcoming years.

For the first time since its creation in 2009 there is a disruption of the Operating Grant. The European Union has adopted a new public health programme called EU4Health for the period 2021-2027, with higher ambition and a 10 times higher budget. This programme had a strong support from health NGOs and patient groups; it is managed by the DG Sante, under the supervision of a Steering Committee of the 27 Member states. However, the long-awaited Operating Grant FPA 2022-2025 was not in the 2021 Work Programme which was published very late in 2021, therefore creating a disruption between 2021 and 2022, with severe impact on health NGOs.

After a strong advocacy work of health NGOs, the European Parliament, and some Member states, it was finally reintroduced in the Work Programme 2022 with a partial retroactive funding in 2022. There is currently an operating grant application process ongoing but for one partial year only, and as of March 2022, there is no certitude to have funding decisions before June 2022.

Consequently, Patient Organisations must spend money on activities that may not be covered if the evaluation of the 2022 Operating Grant fails. The level of financial risk is increased but as EURORDIS has never failed this application so far, we feel confident that our application will be well received.

In terms of perspectives, the multiannual framework may be relaunched in the DG SANTE 2023 Work Programme, but we currently have no guarantee on the upcoming funding strategy.

This unusual level of uncertainty is difficult to deal with in any circumstances. It is even more difficult to understand in the context of a worldwide pandemic crisis affecting all the public health strategies and even more so the most vulnerable population of which the people living with Rare Diseases are part.

Another significant risk will be the magnitude of Cost-of-living increases. As our grants have been calculated prior to the Energy price hikes and their impact on other goods and services early 2022, we will need to identify ways to reduce this expected 4-6% cost increase through optimisation of our expenses.

In this context, the Board of Directors has analysed several scenarios and defined some pathways to reduce activities in the short term in case the combination of inflation and lack of Operating Grant puts the financial health of the organisation at risk.

Glossary

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

EC: European Commission

DG SANTE: Health and Food Safety Directorate-General of EC, Santé is the French word for Health

Ongoing Projects:

- *EURORDIS FPA 2018-2021* (Framework Partnership Agreement)
 - o from 01-Jan-18 to 31-Dec-21
 - o EURORDIS sole beneficiary
- *EURORDIS SGA 2021* (Specific Grant Agreement)
 - o from 01-Jan-20 to 31-Dec-20
 - o EURORDIS sole beneficiary
- *RARE2030* (a participatory foresight study for policy-making rare diseases)
 - o from 01-Jan-19 to 31-Mar-21
 - o EURORDIS coordinator
- *RDCODE* (Codification for Rare Diseases)
 - o from 01-Jan-19 to Dec-Jun-21
 - o EURORDIS co-beneficiary

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

- *Solve-RD* (Solving the unsolved Rare Diseases)
 - from 01-Jan-18 to 31-Dec-22
 - 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)
 - from 01-Jan-19 to 31-Dec-23
 - EURORDIS co-beneficiary
- *EJP RD* (European Joint Programme on Rare Diseases)
 - from 01-Jan-19 to 31-Dec-23
 - EURORDIS co-beneficiary
- *ERICA* (European Rare Disease research Coordination and support Action)
 - from 01-Mar-21 to 28-Feb-25
 - 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-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

ECRD: European Conference on Rare Diseases.

10 of them have already taken place

ECRD 2021, 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 eleventh will take place in May 2022 on the internet.

EMA: European Medicines Agency