
FINANCIAL REPORT 2020

June 2021



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, 2020

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 shareholders.

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, 2020

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, 2020.

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, 2020 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, 2020 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 2018-06 described in the sections accounting principles and methods (“Principes et méthodes comptables”) and information relating to the change in accounting policy (“Informations relatives au changement de méthode comptable”) of the appendix to the annual accounts. Our opinion is not modified in respect of this matter.

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, June 8, 2021

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY

Assets	2019	2020	Δ in euros	Δ in %
FIXED ASSETS				
Intangible assets	815	0	-815	-100%
Tangible assets	88 925	85 562	-3 363	-4%
Financial assets	8 860	8 860	0	0%
TOTAL	98 600	94 422	-4 178	-4%
CURRENT ASSETS				
Account receivable due within one year	1 600 803	1 706 466	105 664	7%
Account receivable due after one year	1 721 743	1 199 841	-521 902	-30%
Other receivables	183 953	249 964	66 010	36%
Liquid assets	2 361 153	2 585 191	224 038	9%
Prepaid expenses	30 001	32 231	2 230	7%
TOTAL	5 897 653	5 773 693	-123 961	-2%
Conversion adjustment	0	13 903	13 903	NA
TOTAL ASSETS	5 996 253	5 882 018	-114 236	-2%

Liabilities	2019	2020	Δ in euros	Δ in %
ASSOCIATION FUNDS				
Reserve	1 137 098	1 279 674	142 575	13%
Profit & loss for the year	142 575	223 033	80 457	56%
Subsidies of investment	0	0	0	NA
TOTAL	1 279 674	1 502 707	223 033	17%
Provisions for risk and charges	102 977	209 658	106 681	104%
Dedicated funds on grants	0	0	0	NA
DEBTS				
Bank loans and overdraft	0	0	0	NA
Trade creditors	201 477	422 640	221 163	110%
Tax payable and social liabilities	388 620	443 341	54 722	14%
Other debts	39 800	14 750	-25 050	-63%
Deferred income within one year	2 426 126	2 089 082	-337 044	-14%
Deferred income after one year	1 557 188	1 199 841	-357 347	-23%
TOTAL	4 716 188	4 379 311	-336 877	-7%
Conversion adjustment	392	0	-392	NA
TOTAL LIABILITIES	5 996 253	5 882 018	-114 236	-2%

Revenue	2019	2020	Ratio	Δ in euros	Δ in %
Patient Organisations	1 034 302	994 846	15%	-39 456	-4%
Financial contributions	744 300	680 190	10%		
AFM Telethon	670 000	670 000	10%		
Other Patient Organisations	74 300	10 190	0%	-64 110	-86%
In kind contributions (AFM)	210 677	223 016	3%	12 339	6%
Membership fees	79 325	91 640	1%	12 315	16%
Individuals	1 101 723	944 954	15%	-156 769	-14%
Volunteers	1 065 373	938 141	14%	-127 232	-12%
Donations	36 350	6 813	0%	-29 537	-81%
European Commission	1 830 597	1 971 122	30%	140 526	8%
DG Research	669 533	651 397	10%	-18 136	-3%
DG Health and consumers	1 141 056	1 311 321	20%	170 266	15%
DG Employment	-16 433			16 433	
EMA contributions (*)	36 441	8 404	0%	-28 037	-77%
Corporates	2 006 851	2 043 007	31%	36 156	2%
Pharma. and Biotech Companies	1 734 000	1 859 360	29%	125 360	7%
Other Health Sector Corporates	151 426	107 900	2%	-43 526	-29%
Outside Health Sector Corporates	121 426	75 747	1%	-45 679	-38%
Not for Profit Organisations	124 382	282 710	4%	158 327	127%
Pharma. and Biotech Found.		12 954	0%	12 954	
Other Health Sector NPOs	114 382	67 834	1%	-46 548	-41%
Outside Health Sector NPOs	10 000	201 922	3%	191 922	1919%
Event Fees	125 975	249 888	4%	123 913	98%
Miscellaneous	84 547	22 568	0%	-61 979	-73%
Reimbursement	67 513	8 153	0%	-59 360	-88%
Others	17 034	14 415	0%	-2 619	-15%
Sub-total	6 308 377	6 509 096	100%	200 718	3%
Recovery of provisions	42 027			-42 027	
Report of non-used income					
Total Revenue	6 350 404	6 509 096		158 692	2%

Expenses	2019	2020	Ratio	Δ in euros	Δ in %
Staff	3 146 198	3 463 090	56%	316 892	10%
Wages and charges	2 898 112	3 267 267	53%	369 155	13%
Other salaries	231 883	151 983	2%	-79 901	-34%
Training and other costs	16 203	43 841	1%	27 638	171%
Volunteers	1 065 373	938 141	15%	-127 232	-12%
Representatives and task forces	820 511	711 460	12%	-109 051	-13%
Projects, office and translators	244 862	226 681	4%	-18 181	-7%
Logistics	827 005	524 794	9%	-302 211	-37%
Travels and subsistence	517 319	154 222	3%	-363 097	-70%
Event logistics and catering	273 245	82 870	1%	-190 375	-70%
Virtual events		279 298	5%	279 298	
In kind contribution (*)	36 441	8 404	0%	-28 037	-77%
Services	992 445	1 006 938	16%	14 493	1%
Fees	522 345	553 899	9%	31 554	6%
Telecom and post	34 073	37 774	1%	3 701	11%
Rent	327 406	298 927	5%	-28 478	-9%
Other services	108 622	116 338	2%	7 716	7%
Purchase	125 161	96 432	2%	-28 729	-23%
Office furniture	33 257	29 097	0%	-4 161	-13%
Amortisation	37 439	35 700	1%	-1 739	-5%
Communications, Publications	39 824	18 300	0%	-21 524	-54%
Other purchases	14 640	13 334	0%	-1 306	-9%
Miscellaneous	19 271	132 386	2%	113 115	587%
Financial expenses, Insurance, Tax	19 271	29 463	0%	10 192	53%
Exceptional expenses		102 923	2%	102 923	
Sub-total	6 175 453	6 161 781	100%	-13 672	0%
Contingency and loss provisions	32 376	124 282	2%	91 906	284%
Commitment on assigned income					
Total Expenses	6 207 829	6 286 063		78 234	1%
Result	142 575	223 033			

* covering travel/accommodation costs for EMA meetings

1. Assets and Liabilities

1.1. Assets

Current assets slightly decreased from 5 898 k€ in 2019 to 5 774 k€ in 2020. This slight decrease is the result of a decrease in accounts receivable partially compensated by an increase of liquid assets.

	2019	2020	Difference	
Accounts receivable	3 506 499	3 156 270	-350 229	-10%
Liquid assets	2 361 153	2 585 191	224 038	9%
Prepaid expenses	30 001	32 231	2 230	7%
Total	5 897 653	5 773 693	-123 961	-2%

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 (2 475 k€, 71%).

Account receivable have decreased compared to 2019 because no new pluriannual EC contract was signed in 2020.

1.1.2. Liquid assets

Liquid assets are cash in the bank. The level of liquidities is satisfactory at the end of 2020.

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 2019, they amounted to 1 280k€. Thanks to the surplus at the end of 2020, the Association Funds increased from 1 280 to 1 503 k€, signifying a 17% increase. A modest and steady increase of the reserve is a sign of good management.

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).

For 2020 and 2021, the total expenses excluding in-kind contributions before provisions amounts to 5M€; a reserve of 1.5 M€ represents 30% of the annual expenses.

1.2.2. Provisions

	2019	2020		
		Recoveries	New provisions	Balance
Provisions for risks	42 000	0	90 903	132 903
Provision for retirement benefits	60 977	0	15 778	76 755
Provisions for risks and charges	102 977	0	106 681	209 658

There was no recovery of provision in 2020. We have recorded all necessary provisions corresponding to the activity in 2020 to be on the safe side.

1.2.3. Trade creditors

2019	201 k€	3%
2020	423 k€	7%
difference	+ 221 k€	+ 110%

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 significant increase is a conjectural phenomenon due to one invoice amounting to 150 k€ invoiced in 2020 and paid in 2021.

1.2.4. Deferred income

2019	3 983 k€	66%
2020	3 289 k€	56%
Difference	- 694 k€	- 17%

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.

Deferred income is mainly composed of the ongoing pluriannual EC projects (2 865 k€, 87%).

Deferred income has decreased compared to 2019 because no new EC pluriannual contracts were signed in 2020 while the 2020 part of the different multi-annual agreements has been consumed.

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 6 509 k€. This represents a slight increase of 201 k€ (+ 3%) compared to 2019.

The bulk of the increase is due to:

- Two contracts signed with the Chan and Zuckerberg Initiative foundation (+158k€)
- Peak activity of the Rare2030 foresight EC project (+141k€)
- More event fees (+124 k€) and Health Corporate sector donations due to ECRD2020 (+82k€)

Compensated by a decrease of resources coming from the patient organisations at large:

- Less volunteer contribution in 2020 compared to 2019 (-157 k€), mostly attributed to less travel during the pandemic
- Fewer contributions from members (-52 k€) due to a sharp decrease of incomes related to the Community Advisory Board mentoring activity (CABs, -66 k€)

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

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

	2 019		2 020		Difference	
<i>AFM-Telethon</i>	881	14%	893	14%	12	1%
<i>Contributions from members</i>	154	2%	102	2%	-52	-34%
<i>Volunteers</i>	1 102	17%	945	15%	-157	-14%
Patient Org. and Volunteers	2 136	34%	1 940	30%	-196	-9%
European Commission	1 831	29%	1 971	30%	141	8%
National authorities	0	0%	0	0%	0	
<i>Pharma. and Biotech Companies</i>	1 734	27%	1 859	29%	125	7%
<i>Other Health Sector Corporates</i>	151	2%	108	2%	-44	-29%
Health Sector Corporates	1 885	30%	1 967	30%	82	4%
Other Corporates	121	2%	76	1%	-46	-38%
Foundations and NPOs	124	2%	283	4%	158	127%
Event fees	126	2%	250	4%	124	98%
Others	85	1%	23	0%	-62	-73%
Total	6 308	100%	6 509	100%	201	3%

Overall: an equal share of revenues is contributed by our members and volunteers (30%), the European Commission (30%) and the Health Sector Corporates (30%).

In July 2020, the Board authorized a deviation to our Policy on Financial Support by Commercial Companies², allowing the amounts received from the Health Sector Corporates to be slightly above the amount received by Patient Organisations and Volunteers (1 940 vs 1 967), as the latter were directly affected by the pandemic.

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 for more details on policy and financial structure, see www.eurordis.org

More details on revenues:

2.1. Patient Organisations and Volunteers

2019	2 136 k€	34%
2020	1 940 k€	30%
difference	- 196 k€	- 9%

The Patient Organisations and Volunteers section was in 2020 our third source of revenue after the European Commission (1 971k€) and the Health Corporate sector (1967k€). The larger part of it is in kind (volunteer contributions; Paris' office space kindly offered by AFM, 1 161 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)

2019	881 k€	14%
2020	893 k€	14%
Difference	+ 12 k€	+ 1%

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.

Since 2013, it amounted to 635 k€. We are very grateful to AFM-Téléthon who increased it by 5.5% to 670 k€ in 2019 and has been able to maintain this amount in 2020. We are also 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.

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 (223 k€) is based on current property prices and was updated again in 2020.

2.1.2. Contributions from members

2019	154 k€	2%
2020	102 k€	2%
Difference	- 52 k€	- 34%

This line comprises the membership fees (79k€ in 2019 and 92k€ in 2020), contributions from the European Federations in the context of the EURORDIS EUROCA³ programme (71 k€ in 2019 and 5 k€ in 2020) and 5 k€ corresponding to in kind training services performed by patient organisations in the context of the Open Academy programmes.

2.1.3. Volunteers

2019	1 102 k€	17%
2020	945 k€	15%
Difference	- 157 k€	- 14%

We had some donations from individuals in 2020 but our main source of revenue from individuals remains in kind (volunteers).

The time donated by our volunteers decreased in 2020 because of COVID but not as much as we initially thought. The reason for this relative decrease is that the very substantial time not spent in travels was only partly compensated by COVID generated additional advocacy work. As such, more time has been spent advocating than in the past. The work of the volunteers represented 9.4 full time equivalents (FTE), a total amount of 15,768 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

2019	1 831 k€	29%
2020	1 971 k€	30%
Difference	+ 141 k€	+ 8%

In 2020, EURORDIS operated eight ongoing EC projects from DG SANTE, DG RESEARCH and IMI-JU⁴ and negotiated one new EC grant.

Contracts running in 2020:

- 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);
- the IMI-JU consortium grant PARADIGM (ended in 2020)
- the IMI-JU consortium grant Conect4Children (C4C) (multi-annual);
- the DG SANTE project grant RARE 2030 (multi-annual)

³ CAB means Community Advisory Board

⁴ 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 grant RDCODE (multi-annual).

Contracts negotiated in 2020 for 2021:

- the DG SANTE Operating Grant 2021

The DG SANTE Operating Grant is embedded in a Framework Partnership Agreement (FPA) which lasts from 2018 to 2021. It means that the support of recurrent activities by DG SANTE is possible over those four years, however, the annual amount of financial support is not guaranteed and is revaluated every year.

2.3. Health Sector Corporates

2019	1 885 k€	30%
2020	1 967 k€	30%
Difference	+ 82 k€	+ 4%

This line comprises 75 health sector companies including 66 pharmaceutical and biotech companies.

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, lasted 2 years. It has been renewed for one year 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 for profit distinct sector in its accounting system.

For transparency purpose, the fees received in the context of the Rare Impact project are mixed with the donations received from the companies.

In this context, the five largest contributors from the Health sector are, in descending order: 1st TAKEDA, 2nd PFIZER, 3rd ROCHE, 4th BRISTOL-MYERS SQUIBB and 5th SANOFI GENZYME.

The percentage of this sector in the overall budget is 30% and the highest percentage of one Health Sector Company represents less than 2.8%.

The guarantees of our independence from the health corporate sector are (1) high standards in our governance, (2) balanced revenues between our different sources⁵ (3) the limitation of the health sector corporates incomes compared to Patient Organisation origin, (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.

In 2020, because of the decrease in the volunteer time and CABs, the amount coming from the health sector corporations has overtaken the amount coming from the Patient Organisation sector for the first time.

⁵ i.e., Patient Organisations & Volunteers, Public income, Corporate income, revenues generated by our activities

2.4. Foundations and Not for Profit Organisations (NPOs)

2019	124 k€	2%
2020	283 k€	4%
difference	+ 158 k€	+ 127%

- Two contracts have been signed with the Chan and Zuckerberg Initiative (Facebook foundation) to support capacity building and Rare Disease Day, hence the significant increase in that NPO section

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

2019	126 k€	2%
2020	250 k€	4%
difference	+ 124 k€	+ 98%

In 2020, event fees were mainly generated by ECRD 2020.

3. Expenses

Operating expenses, including in-kind contributions, and excluding provisions, amounted to 6 162 k€, which shows a very slight decrease compared to 2019.

Unsurprisingly there was a very sharp decrease in logistics (-302 k€) and a decrease in volunteers (- 127 k€) compensated by an increase in staff costs (+317 k€) and exceptional expenses (+103 k€).

The breakdown of EURORDIS expenses is as follows
(in thousands of euros, provisions excluded⁶)

Expenses	2 019		2 020		Difference	
Staff costs	3 146	51%	3 463	56%	317	10%
Volunteers	1 065	17%	938	15%	-127	-12%
Logistics	827	13%	525	9%	-302	-37%
Services	992	16%	1 007	16%	14	1%
Others	144	2%	229	4%	84	58%
Total	6 175	100%	6 162	100%	-14	0%

⁶ 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

2019	3 146 k€	51%
2020	3 463 k€	56%
Difference	+ 317 k€	+ 10%

The number of FTE⁷ was 47.7 in 2020 compared to 43.9 in 2019.

As at the end of the year, the team was composed of 49 staff members dispatched in 6 countries.

The main office is in France (28), followed by Belgium (9), Spain (9), Serbia (1), Germany (1) and the United Kingdom of Great Britain and Northern Ireland (1).

4 new positions were created in 2020 (in order of appearance):

- Public Affairs Manager - EU & National Integrated Advocacy, Kostas Aligiannis, Brussels
- Open Academy Manager - eLearning & Outreach, Alejandro Cuenca, Barcelona
- Operations Junior Manager, Adrien Ruez, Paris
- Campaign & Digital Communications Senior Manager, Pamela Marinou, Paris (limited contract)

1 position was stopped:

- Patient Engagement Manager, Elisa Ferrer, Barcelona

1 position has been temporarily interrupted since February 2020:

- Development Relations Senior Manager, Brian Howard, 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 represented, the net salary represented less than 50% of the staff costs in 2020 (46%), in Belgium and Spain a bit more than 50% (respectively 55% and 56%). 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 16 languages and comprises 15 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 engagement, to be able to contribute to public affairs and work with all stakeholders to support patient advocacy. These positions require a long-term commitment and a retention policy.

3.2. Logistics

2019	827 k€	13%
2020	525 k€	9%
difference	- 302 k€	- 37%

The decrease comes from the drastic reduction of travels. We have recorded in logistics all the costs associated with our virtual events. Virtual conference venue, video, etc.

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

3.3. Services

2019	992 k€	16%
2020	1 007 k€	16%
Difference	+ 14 k€	+ 1%

There is no significant difference.

3.4. Exceptional expenses

Despite our best efforts, we have not been able to recuperate the 103 k€ vested to the Stockholm venue for the ECRD2020 conference. The loss of our two first instalments to the physical venue has been recorded in exceptional expenses. We secured a last-minute virtual venue which was recorded in logistics.

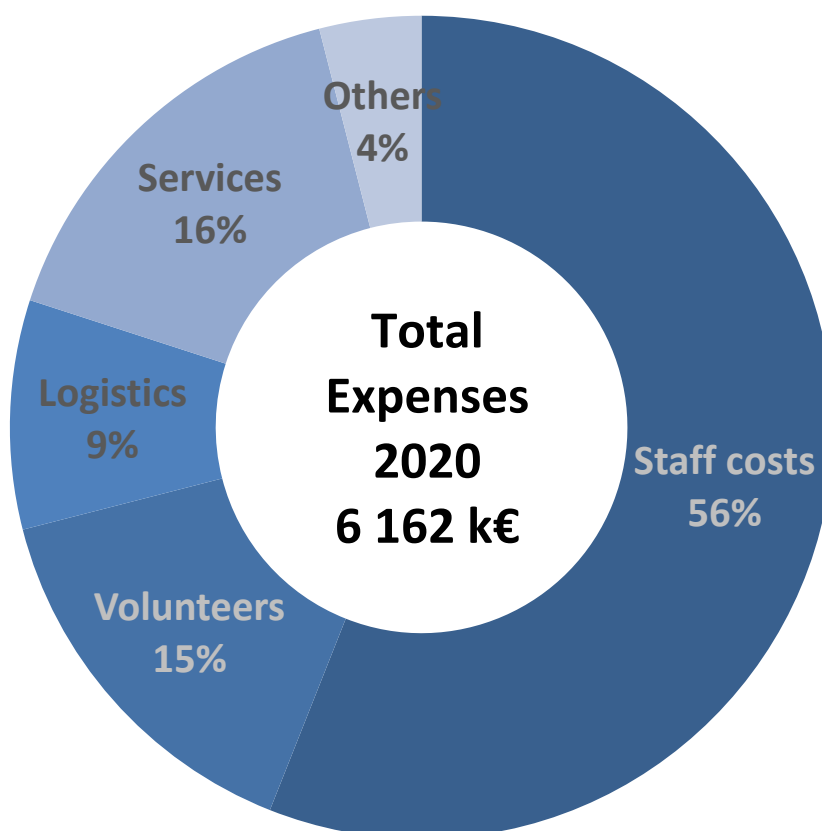
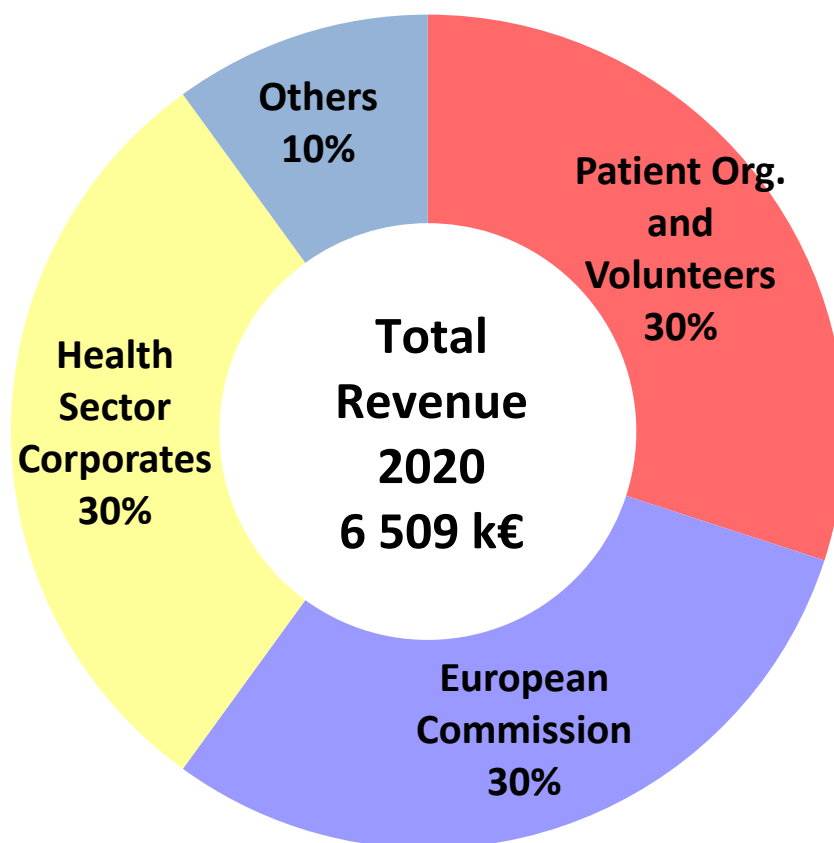
4. Result

The surplus amounted to 223 033 euros; we recommend allocating it to the reserve which will then amount to 1 502 707 euros.

5. Comment on exceptional circumstances due to the COVID-19 crisis

In the context of the current COVID-19 outbreak the 2021 operating grant has been totally reshaped and accepted by the European Commission during the negotiation to adapt to the situation.

EURORDIS does not foresee any significant shortfall in its Action Plan in 2021.



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

Ongoing Projects:

- *EURORDIS FPA 2018-2021* (Framework Partnership Agreement)
 - o from 01-Jan-18 to 31-Dec-21
 - o EURORDIS sole beneficiary
- *EURORDIS SGA 2020* (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 30-Jun-21
 - o EURORDIS co-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 31-Dec-22
 - 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

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

- *PARADIGM* (Patients Active in Research and Dialogues for an Improved Generation of Medicines: Advancing meaningful patient engagement in the life cycle of medicines for better health outcomes)
 - o from 01-Mar-18 to 31-Aug-20
 - o EURORDIS co-beneficiary
- *conect4children* (COllaborative Network for European Clinical Trials For Children)
 - o From 01-May-18 to 30-Apr-24
 - o EURORDIS co-beneficiary

ECRD: European Conference on Rare Diseases.

10 of them have already taken place

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 eleventh will take place in May 2022 on the internet.

EMA: European Medicines Agency