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FINANCIAL REPORT  
2019

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May 2020

## **EURORDIS**

Association governed by the French law of

July 1, 1901

96, Rue Didot

75014 PARIS

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

For the year ended December 31, 2019

*This is a translation into English of the statutory auditor's 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 auditor's report includes information required by European regulation and French law, such as information about the appointment of the statutory auditors or verification of the management report and other documents provided to members.*

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

## EURORDIS

Association governed by the French law of July 1, 1901

96, Rue Didot  
75014 PARIS

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### **Statutory Auditor's report on the financial statements**

For the year ended December 31, 2019

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To the members of Eurordis,

#### **Opinion**

In compliance with the engagement entrusted to us by your members' meeting, we have audited the accompanying financial statements of EURORDIS for the year ended December 31, 2019. These financial statements were approved by the board of directors on April 17, 2020 on the basis of the information available at that date in the evolving context of the Covid-19 health crisis.

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, 2019 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 rules applicable to us, for the period from January 1, 2019 to the date of our report and specifically we did not provide any prohibited non-audit services in the French Code of ethics (*code de déontologie*) for statutory auditors.

## **Justification of Assessments**

In accordance with the requirements of article 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 assessments were made as part of our audit of the financial statements taken as a whole, approved in the conditions mentioned above, and therefore contributed to the opinion we formed which is expressed in the first part of this report.

## **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 approved on April 17, 2020, and in the other documents with respect to the financial position and the financial statements provided to the members.

With regard to the events which occurred and the facts known after the date the financial statements were approved by the board of directors relating to the impact of the Covid-19 crisis, the management indicated to us that they will be communicated to the members' meeting called to approve the financial statements.

## **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**

### ***Objectives and audit approach***

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.

### ***Detailed description of the statutory auditor's responsibilities***

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 12, 2020

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY

Assets	2018	2019	Ratio	Difference
<b>FIXED ASSETS</b>				
Intangible assets	0	815	NA	815
Tangible assets	86 067	88 925	3%	2 858
Financial assets	8 860	8 860	0%	0
<b>TOTAL</b>	<b>94 927</b>	<b>98 600</b>	<b>4%</b>	<b>3 674</b>
<b>CURRENT ASSETS</b>				
Account receivable due within one year	1 871 436	1 784 756	-5%	-86 680
Account receivable due after one year	2 528 980	1 721 743	-32%	-807 238
Liquid assets	2 395 715	2 361 153	-1%	-34 562
Prepaid expenses	25 735	30 001	17%	4 266
<b>TOTAL</b>	<b>6 821 867</b>	<b>5 897 653</b>	<b>-14%</b>	<b>-924 214</b>
<b>Conversion adjustment</b>	<b>0</b>	<b>0</b>	<b>NA</b>	<b>0</b>
<b>TOTAL ASSETS</b>	<b>6 916 793</b>	<b>5 996 253</b>	<b>-13%</b>	<b>-920 540</b>

Liabilities	2018	2019	Ratio	Difference
<b>ASSOCIATION FUNDS</b>				
Reserve	965 176	1 137 098	18%	171 922
Profit & loss for the year	171 922	142 575	-17%	-29 347
Subsidies of investment	0	0	NA	0
<b>TOTAL</b>	<b>1 137 098</b>	<b>1 279 674</b>	<b>13%</b>	<b>142 575</b>
Provisions for risk and charges	132 027	102 977	-22%	-29 050
Dedicated funds on grants	0	0	NA	0
<b>DEBTS</b>				
Bank loans and overdraft	13 504	0	-100%	-13 504
Trade creditors	301 003	201 477	-33%	-99 525
Tax payable and social liabilities	313 908	388 620	24%	74 712
Other debts	460 648	39 800	-91%	-420 848
Deferred income within one year	2 344 246	2 426 126	3%	81 881
Deferred income after one year	2 214 361	1 557 188	-30%	-657 173
<b>TOTAL</b>	<b>5 779 695</b>	<b>4 716 188</b>	<b>-18%</b>	<b>-1 063 507</b>
<b>Conversion adjustment</b>	<b>0</b>	<b>392</b>	<b>NA</b>	<b>392</b>
<b>TOTAL LIABILITIES</b>	<b>6 916 793</b>	<b>5 996 253</b>	<b>-13%</b>	<b>-920 540</b>

**2019 Financial Status  
VS 2018 Financial Status**  
(Profit and Loss including in kind contributions)

Revenue	2018 Fin. Status	2019 Fin. Status	Ratio	Δ in euros	Δ in %
<b>Patient Organisations</b>	<b>939 148</b>	<b>1 034 302</b>	<b>22%</b>	<b>95 154</b>	<b>10%</b>
Financial contributions	683 500	744 300	16%		
<i>AFM Telethon</i>	<i>634 500</i>	<i>670 000</i>	<i>14%</i>	<i>35 500</i>	<i>6%</i>
<i>Other Patient Organisations</i>	<i>49 000</i>	<i>74 300</i>	<i>2%</i>	<i>25 300</i>	<i>52%</i>
In kind contributions (AFM)	196 053	210 677	4%	14 624	7%
Membership fees	59 595	79 325	2%	19 730	33%
<b>Individuals</b>	<b>1 351 101</b>	<b>1 101 723</b>	<b>23%</b>	<b>-249 378</b>	<b>-18%</b>
Volunteers	1 308 943	1 065 373	22%	-243 570	-19%
Donations	42 158	36 350	1%	-5 808	-14%
<b>European Commission</b>	<b>1 666 814</b>	<b>1 830 597</b>	<b>38%</b>	<b>163 782</b>	<b>10%</b>
DG Research	292 953	669 533	14%	376 580	129%
DG Health and consumers	1 104 339	1 141 056	24%	36 717	3%
DG Employment	223 300	-16 433	0%	-239 733	-107%
EMA contributions (*)	46 223	36 441	1%	-9 782	-21%
<b>National authorities</b>	<b>15 900</b>			<b>-15 900</b>	
Grants from National authorities	15 900			-15 900	
<b>Corporates</b>	<b>1 841 537</b>	<b>2 006 851</b>	<b>42%</b>	<b>165 314</b>	<b>9%</b>
Pharma. and Biotech Companies	1 662 981	1 734 000	36%	71 019	4%
Other Health Sector Corporates	70 000	151 426	3%	81 426	116%
Outside Health Sector Corporates	108 556	121 426	3%	12 870	12%
<b>Not for Profit Organisations</b>	<b>117 718</b>	<b>124 382</b>	<b>3%</b>	<b>6 664</b>	<b>6%</b>
Pharma. and Biotech Found.					
Other Health Sector NPOs	102 718	114 382	2%	11 664	11%
Outside Health Sector NPOs	15 000	10 000	0%	-5 000	-33%
<b>Event Fees</b>	<b>333 829</b>	<b>125 975</b>	<b>3%</b>	<b>-207 854</b>	<b>-62%</b>
<b>Miscellaneous</b>	<b>128 294</b>	<b>84 547</b>	<b>2%</b>	<b>-43 747</b>	<b>-34%</b>
Reimbursement	112 987	67 513	1%	-45 474	-40%
Others	15 307	17 034	0%	1 727	11%
<b>Sub-total</b>	<b>6 394 341</b>	<b>6 308 377</b>	<b>132%</b>	<b>-85 964</b>	<b>-1%</b>
<b>Recovery of provisions</b>	<b>103 517</b>	<b>42 027</b>		<b>-61 490</b>	<b>-59%</b>
<b>Report of non-used income</b>					
<b>Total Revenue</b>	<b>6 497 858</b>	<b>6 350 404</b>		<b>-147 454</b>	<b>-2%</b>

Expenses	2018 Fin. Status	2019 Fin. Status	Ratio	Δ in euros	Δ in %
<b>Staff</b>	<b>2 853 121</b>	<b>3 146 198</b>	<b>68%</b>	<b>293 078</b>	<b>10%</b>
Wages and charges	2 590 889	2 898 112	63%	307 223	12%
Other salaries	246 030	231 883	5%	-14 146	-6%
Training and other costs	16 202	16 203	0%	1	0%
<b>Volunteers</b>	<b>1 308 943</b>	<b>1 065 373</b>	<b>23%</b>	<b>-243 570</b>	<b>-19%</b>
Representatives and task forces	1 099 370	820 511	18%	-278 859	-25%
Projects, office and translators	209 573	244 862	5%	35 289	17%
<b>Logistics</b>	<b>1 032 220</b>	<b>827 005</b>	<b>18%</b>	<b>-205 215</b>	<b>-20%</b>
Travels and subsistence	541 973	517 319	11%	-24 654	-5%
Event logistics and catering	444 025	273 245	6%	-170 779	-38%
In kind contribution (*)	46 223	36 441	1%	-9 782	-21%
<b>Services</b>	<b>936 623</b>	<b>992 460</b>	<b>21%</b>	<b>55 837</b>	<b>6%</b>
Fees	480 456	522 345	11%	41 889	9%
Partners		15	0%	15	
Telecom and post	39 131	34 073	1%	-5 058	-13%
Rent	270 823	327 406	7%	56 583	21%
Other services	146 213	108 622	2%	-37 591	-26%
<b>Purchase</b>	<b>120 571</b>	<b>125 161</b>	<b>3%</b>	<b>4 590</b>	<b>4%</b>
Office furniture	31 938	33 257	1%	1 320	4%
Amortisation	36 923	37 439	1%	516	1%
Communications, Publications	37 572	39 824	1%	2 252	6%
Other purchases	14 138	14 640	0%	502	4%
<b>Miscellaneous</b>	<b>32 432</b>	<b>19 256</b>	<b>0%</b>	<b>-13 176</b>	<b>-41%</b>
Financial expenses, Insurance, Tax	32 432	19 256	0%	-13 176	-41%
Exceptional expenses					
<b>Sub-total</b>	<b>6 283 910</b>	<b>6 175 453</b>	<b>133%</b>	<b>-108 457</b>	<b>-2%</b>
<b>Contingency and loss provisions</b>	<b>42 027</b>	<b>32 376</b>	<b>1%</b>	<b>-9 651</b>	<b>-23%</b>
<b>Commitment on assigned income</b>					
<b>Total Expenses</b>	<b>6 325 936</b>	<b>6 207 829</b>		<b>-118 108</b>	<b>-2%</b>
<b>Result</b>	<b>171 922</b>	<b>142 575</b>			

\* covering travel/accommodation costs for EMA meetings



### 1. Assets and Liabilities

#### 1.1. Assets

Current assets decreased from 6 822 in 2018 to 5 878 k€ in 2019, due to the decrease in accounts receivable.

	2018	2019	Difference	
Accounts receivable	4 400 417	3 487 100	-913 316	-21%
Liquid assets	2 395 715	2 361 153	-34 562	-1%
Prepaid expenses	25 735	30 001	4 266	17%
<b>Total</b>	<b>6 821 867</b>	<b>5 878 255</b>	<b>-943 612</b>	<b>-14%</b>

##### 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 (3 148 k€, 90%).

Account receivable have decreased compared to 2018 because no new pluriannual contracts have been signed in 2019.

##### 1.1.2. Liquid assets

Liquid assets are cash in the bank. The level of liquidities is satisfactory at the end of the 2019.

### 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 2018, they amounted to 1 137k€. Thanks to the surplus at the end of 2019, the Association Funds increased from 1 137 to 1 280 k€, signifying a 13% 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 2019, the total expenses excluding in-kind contributions amounted to 4.6 M€; they amount to 5.3 M€ in the Budget 2020; a reserve of 1.3 M€ is equal to respectively 28% and 25% of the 2019 and 2020 annual expenses.

EURORDIS is at a low though acceptable level. With the current uncertainties in its environment over the years 2021 and 2022, EURORDIS would be in a safer position with a higher level of reserves.

### 1.2.2. Provisions

	2018	2019		
		Recoveries	New provisions	Balance
Provisions for risks	42 000	0	0	42 000
Forecasted loss on EU Projects	42 027	-42 027	19 398	19 398
Provision for retirement benefits	48 000	0	12 977	60 977
<b>Provisions for risks and charges</b>	<b>132 027</b>	<b>-42 027</b>	<b>32 375</b>	<b>122 375</b>

We have recovered the forecasted loss on the Rare Cancers Joint Action, the project being terminated in 2019 and made a forecasted loss on the Joint Action on Rare Diseases given the delay in the payment of the last instalment.

### 1.2.3. Trade creditors

2018	301 k€	4%
2019	201 k€	3%
difference	- 100 k€	- 33%

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.

### 1.2.4. Deferred income

2018	4 559 k€	66%
2019	3 962 k€	66%
Difference	- 597 k€	- 13%

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 (3 744 k€, 94%).

Deferred income has decreased compared to 2018 because no new pluriannual contracts have been signed in 2019 while the 2019 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 6 308 k€. This represents a decrease of 86 k€ (- 1%) compared to 2018.

The bulk of the decrease is due to:

- Less volunteer contribution in 2019 compared to 2018 (-249 k€);
- no ECRD in 2019 when there was an ECRD in 2018 (-208 k€ on Event fees);

partly compensated by an increase in:

- European Commission (+164 k€);
- and Health Sector Corporates (+152 k€).

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

	2018		2019		Difference	
<i>AFM-Telethon</i>	831	13%	881	14%	50	6%
<i>Contributions from members</i>	109	2%	154	2%	45	41%
<i>Volunteers</i>	1 351	21%	1 102	17%	-249	-18%
Patient Org. and Volunteers	2 290	36%	2 136	34%	-154	-7%
European Commission	1 667	26%	1 831	29%	164	10%
National authorities	16	0%	0	0%	-16	-100%
<i>Pharma. and Biotech Companies</i>	1 663	26%	1 734	27%	71	4%
<i>Other Health Sector Corporates</i>	70	1%	151	2%	81	116%
Health Sector Corporates	1 733	27%	1 885	30%	152	9%
Other Corporates	109	2%	121	2%	13	12%
Foundations and NPOs	118	2%	124	2%	7	6%
Event fees	334	5%	126	2%	-208	-62%
Others	128	2%	85	1%	-44	-34%
<b>Total</b>	<b>6 394</b>	<b>100%</b>	<b>6 308</b>	<b>100%</b>	<b>-86</b>	<b>-1%</b>

Overall: 34% of revenues are contributed by our members and individuals, 29% from European Commission and 30% by Health Sector Corporates.

The proportion of funding by source fully complies with our *Policy on Financial Support by Commercial Companies*<sup>2</sup>: the level of revenues from Health Sector Corporates represents 30% and is spread across 70 different companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (34%).

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

<sup>2</sup> for more details on policy and financial structure, see [www.eurordis.org](http://www.eurordis.org)

More details on revenues:

## 2.1. Patient Organisations and Individuals

2018	2 290 k€	36%
2019	2 136 k€	34%
difference	- 154 k€	- 7%

The Patient Organisations and Individuals section is our largest source of revenue covering a third of our expenses. The larger part of it is in kind (volunteer contributions; Paris' office space kindly offered by AFM, 1 276 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)

2018	831 k€	13%
2019	881 k€	14%
Difference	+ 50 k€	+ 6%

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. 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 focused 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 (211 k€) is based on current property prices and was updated again in 2019.

### 2.1.2. Contributions from members

2018	109 k€	2%
2019	154 k€	2%
Difference	+ 45 k€	+ 41%

This line comprises the membership fees (60k€ in 2018 and 79k€ in 2019), contributions from the European Federations in the context of the EURORDIS EUROCRAB<sup>3</sup> programme (49 k€ in 2018 and 71 k€ in 2019) and 3 k€ corresponding to in kind training services performed by patient organisations in the context of the Open Academy programmes.

### 2.1.3. Individuals

2018	1 351 k€	21%
2019	1 102 k€	18%
Difference	- 249 k€	- 18%

We had some donations from individuals in 2019 but our main source of revenue from individuals remains in kind (volunteers).

The dedication of our volunteers decreased in 2019 because of some variations but it's still comparable with the level of 2017. Their work represented 10.7 full time equivalents (fte), a total amount of 18,067 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.

In 2019, volunteers mainly worked on matters pertaining to public affairs (5.7 fte), orphan medicinal products (0.8 fte) and moderation of the rareconnect.org website (2.9 fte).

## 2.2. European Commission

2018	1 667 k€	26%
2019	1 831 k€	29%
Difference	+ 164 k€	+ 10%

In 2019, EURORDIS ran nine, closed three and negotiated one EC grants from DG SANTE, DG RESEARCH and IMI-JU<sup>4</sup>, .

Contracts running in 2019:

- the DG SANTE Operating Grant (annual, renewed every year since 2009);
- the DG SANTE Joint Action on Rare Cancers (JARC) (ended in 2019);
- 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 (started 2019, multiannual);

<sup>3</sup> CAB means Community Advisory Board

<sup>4</sup> IMI-JU is a Joint Undertaking between DG Research and the European Federation of Pharmaceutical Industries and Associations (EFPIA) called "Innovative Medicine Initiative". In the budget, the contribution from EC is recorded under chapter "DG Research".

- the IMI-JU consortium grants PARADIGM (multi-annual)
- the IMI-JU consortium grant Conect4Children (C4C) (started 2019, multi-annual);
- the DG SANTE project grant RARE 2030 (started 2019, multi-annual)
- the DG SANTE project grant RDCODE (multi-annual).

Contracts negotiated in 2019 for 2020:

- the DG SANTE Operating Grant 2020

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

2018	1 733 k€	27%
2019	1 885 k€	30%
Difference	+ 152 k€	+ 9%

This line comprises 70 health sector companies including 61 pharmaceutical and biotech companies.

In 2018, EURORDIS associated with a for profit consultant (Dolon) and started a new kind of project in collaboration with 18 pharmaceutical or biotech companies, 1 trade organisation and 2 not-for-profit organisations. This project, called Rare Impact, will last for 2 and a half years. Its objective is to identify and validate the challenges to patients' access to gene and cell therapies as well as solutions that will help patients to access these life-changing treatments. The overall amount vested to EURORDIS is 480 k€ of which 216 k€ related to 2019. If the project is successful it will have a beneficial impact for both patients and drug manufacturers. For this reason, we had to consider it as a for profit activity and have created a for profit distinct sector in our accounting system. It is the first time that EURORDIS has declared a for profit activity to the French government.

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

In this context, the five largest contributors from the Health sector are, in descending order: 1<sup>st</sup> TAKEDA, 2<sup>nd</sup> PFIZER, 3<sup>rd</sup> NOVARTIS, 4<sup>th</sup> CELGENE and 5<sup>th</sup> SANOFI GENZYME.

The percentage of each of the 69 health sector companies in the overall budget comprises between 0.08% and 3.2%.

The guarantees of our independence with the health corporate sector are (1) high standard in our governance, (2) balance revenues between our different sources<sup>5</sup> (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.

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<sup>5</sup> i.e. Patient Organisations & Volunteers, Public funding, Corporate & other private funding, revenues generated by our activities

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

2018	118 k€	2%
2019	124 k€	2%
difference	+ 7 k€	+ 6%

- 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

2018	334 k€	5%
2019	126 k€	2%
difference	- 208 k€	- 62%

In 2019, event fees were mainly composed of:

- the Black Pearl Award event (61 k€);
- the Multi-Stakeholder Symposium (50 k€);
- the EURORDIS Round Table of Companies (8 k€).

## 3. Expenses

Operating expenses, including in-kind contributions and excluding provisions, amounted to 6 175 k€, which shows a decrease of 2% compared to 2018.

The decrease is due to:

- Volunteers (- 244 k€),
- no ECRD in 2019 (- 205 k€),

compensated by an increase in staff costs.

The breakdown of EURORDIS expenses is as follows  
(in thousands of euros, provisions excluded<sup>6</sup>)

Expenses	2018		2019		Difference	
Staff costs	2 853	45%	3 146	51%	293	10%
Volunteers	1 309	21%	1 065	17%	-244	-19%
Logistics	1 032	16%	827	13%	-205	-20%
Services	937	15%	992	16%	56	6%
Others	153	2%	144	2%	-9	-6%
<b>Total</b>	<b>6 284</b>	<b>100%</b>	<b>6 175</b>	<b>100%</b>	<b>-108</b>	<b>-2%</b>

<sup>6</sup> Recovery of provisions is excluded from this table in order 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

2018	2 853 k€	45%
2019	3 146 k€	51%
Difference	+ 293 k€	+ 10%

The number of FTE<sup>7</sup> was 48 in 2019.

As at the end of the year, the team was composed of 47 staff members dispatched in 7 countries.

The main office is in France (28), followed by Spain (9), Belgium (6), Serbia (1), Switzerland (1), Germany (1) and the United Kingdom of Great Britain and Northern Ireland (1).

6 new positions were created in 2019 (in order of appearance):

- Project Senior Manager - Rare Impact, Karolina Hanslik, Brussels (limited contract)
- Patient Engagement Manager - ERN & Healthcare / ePAGs, Anne-Laure Aslanian, Barcelona
- Chief Operating Officer, Michael Wilbur, Paris
- Corporate Relations Assistant, Hlawulani Mkhabela, Paris
- Development Relations Senior Manager, Brian Howard, Paris
- Patient Experience Survey Research Executive, Jessie Dubief, Paris (limited contract)

2 positions were stopped:

- Social Policy Senior Advisor, Annette Dumas, Brussels (limited contract)
- Web Communications Senior Manager & Rare Connect Leader, Denis Costello, Barcelona

#### 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 2019 (46%), in Belgium and Spain a bit more than 50% (respectively 53% and 57%). The regulatory taxes cover health, retirement and unemployment benefit systems as well as income taxes.

In order to have an idea of the purchasing power, one needs to take into account the renting costs of an apartment and cost of living. In Paris a yearly 10k€ rent allows a single person to live modestly in a 30 or 40 m<sup>2</sup> apartment but not a couple to raise a family. Cost of daily life are comparable in Paris, Brussels and London, but are much higher than in Barcelona, Cologne or Belgrade.

Overall, EURORDIS staff salaries are comparable and often lower than other European rare disease patient groups and other health NGOs.

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 retainment policy.

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<sup>7</sup> 1 full time equivalent = 1 people on a full time position during one year



### 3.2. Logistics

2018	1 032 k€	16%
2019	828 k€	13%
difference	- 205 k€	- 20%

The decrease comes from the fact that there was no ECRD in 2019.

### 3.3. Services

2018	937 k€	15%
2019	992 k€	16%
Difference	+ 56 k€	+ 6%

The main reasons for the difference between 2019 and 2018 comes from an increase in in kind contributions (+138 k€) compensated by the absence of ECRD (-33 k€) and Rare Disease Day video in 2019 (-35 k€).

## 4. Result

The surplus amounted to 142 575 euros, we recommend allocating it to the reserve which will then amount to 1 279 674 euros.

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

In the context of the current COVID-19 outbreak the 2020 budget was thoroughly reviewed.

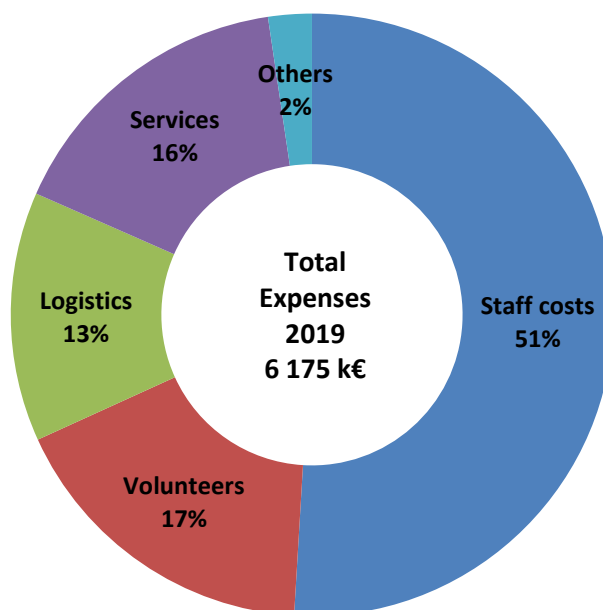
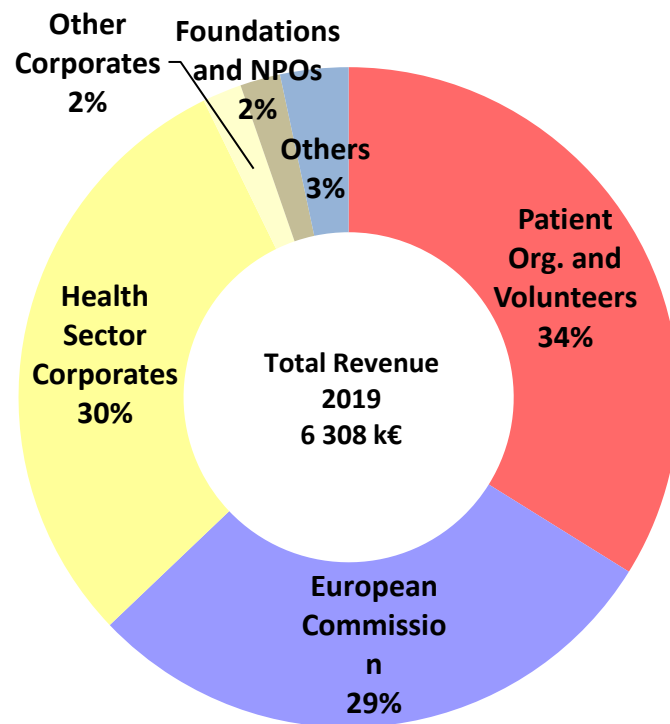
The main impacts were moving ECRD 2020 and all other trainings, workshops or meetings online as well as no staff or volunteer travel until the end of August 2020.

Planned revenues have been reduced in consequence in EU funded projects as well as in new private revenues. There is, at this moment, no message from the recurrent sources of funding that the expectations for 2020 should be revised.

EURORDIS' staff team is dispersed across 7 countries, the Board of Directors in 12 countries and the volunteers in more than 30 countries. Therefore EURORDIS has, along the years, developed the capacity to work remotely. The overall IT infrastructure was upgraded early in 2020 to enable the entire team to work from home or from any other place. In consequence, EURORDIS' theoretical work capacity is overall preserved.

Given the special context of sheltered-at-home measures and schools closed, the staff work capacity has been maintained at 80% on average during the confinement period.

EURORDIS does not foresee any significant shortfall in its Action Plan in 2020 even though some priorities have been downsized or deferred so as to be able to take on the challenges caused by the worldwide outbreak to the Rare Diseases community.



## 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 2019* (Specific Grant Agreement)
  - o from 01-Jan-19 to 31-Dec-19
  - o EURORDIS sole beneficiary
- *RD-ACTION* (Data and Policies for Rare Diseases – Joint Action)
  - o from 01-Jun-15 to 31-May-18
  - o EURORDIS co-beneficiary
- *JARC* (Joint Action on Rare Cancers)
  - o from 01-Oct-16 to 30-Sep-19
  - o EURORDIS co-beneficiary
- *RARE2030* (a participatory foresight study for policy-making rare diseases)
  - o from 01-Jan-19 to 31-Dec-20
  - 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-24
  - o EURORDIS co-beneficiary
- *EJP RD* (European Joint Programme on Rare Diseases)
  - o from 01-Jan-19 to 31-Dec-24
  - 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.

9 of them have already taken place

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 tenth will take place in May 2020 on the internet.

*EMA*: European Medicines Agency