

EURORDIS  
**FINANCIAL**  
**REPORT** 2017



Living with Duchenne  
muscular dystrophy,  
Misha and his mother  
from Ukraine



## **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, 2017

*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, 2017

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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, 2017.

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, 2017 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, 2017 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.



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### *Statutory auditor's report on the 2017 financial statements*

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#### **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, and therefore contributed to the opinion we formed which is expressed in the first part of this report.

#### **Verification of the management report and other documents addressed to the members**

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 provided to the members with respect to the financial position and 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.

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*Statutory auditor's report on the 2017 financial statements*

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## **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;

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*Statutory auditor's report on the 2017 financial statements*

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- 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.

Neuilly-sur-Seine, Mai 2, 2018

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY





## EURORDIS 2017 Financial Report

(Assets and Liabilities)

Assets	2016	2017	Ratio	Difference
<b>FIXED ASSETS</b>				
Intangible assets	1 440	451	-69%	-990
Tangible assets	60 485	87 854	45%	27 369
Financial assets	18 649	8 860	-52%	-9 789
<b>TOTAL</b>	<b>80 574</b>	<b>97 164</b>	<b>21%</b>	<b>16 590</b>
<b>CURRENT ASSETS</b>				
Account receivable due within one year	1 445 919	714 080	-51%	-731 839
Account receivable due after one year	567 049	187 860	-67%	-379 189
Liquid assets	1 183 079	1 016 385	-14%	-166 694
Prepaid expenses	21 526	28 752	34%	7 226
<b>TOTAL</b>	<b>3 217 574</b>	<b>1 947 077</b>	<b>-39%</b>	<b>-1 270 497</b>
<b>TOTAL ASSETS</b>	<b>3 298 148</b>	<b>2 044 242</b>	<b>-38%</b>	<b>-1 253 906</b>

Liabilities	2016	2017	Ratio	Difference
<b>ASSOCIATION FUNDS</b>				
Reserve	878 740	789 323	-10%	-89 417
Profit & loss for the year	-89 417	175 854	-297%	265 271
Subsidies of investment	0	0	NA	0
<b>TOTAL</b>	<b>789 323</b>	<b>965 176</b>	<b>22%</b>	<b>175 854</b>
Provisions for risk and charges	159 969	193 517	21%	33 548
Dedicated funds on grants	0	0	NA	0
<b>DEBTS</b>				
Bank loans and overdraft	0	0	NA	0
Trade creditors	161 699	200 005	24%	38 305
Tax payable and social liabilities	256 229	268 518	5%	12 289
Other debts	0	0	NA	0
Deferred income within one year	1 326 902	349 545	-74%	-977 357
Deferred income after one year	604 026	67 480	-89%	-536 546
<b>TOTAL</b>	<b>2 508 825</b>	<b>1 079 065</b>	<b>-57%</b>	<b>-1 429 760</b>
<b>TOTAL LIABILITIES</b>	<b>3 298 148</b>	<b>2 044 242</b>	<b>-38%</b>	<b>-1 253 906</b>



## 2017 Fin. Status VS. 2016 Fin. Status

(P Profit and Loss including in kind contributions)

Revenue	2016 Fin. Status	2017 Fin. Status	Ratio	Δ in euros	Δ in %
<b>Patient Organisations</b>	<b>950 467</b>	<b>882 796</b>	<b>16%</b>	<b>-67 671</b>	<b>-7%</b>
Financial contributions	689 446	654 500	12%		
<i>AFM Telethon</i>	634 500	634 500	11%		
<i>Other Patient Organisations</i>	54 946	20 000	0%	-34 946	-64%
In kind contributions (AFM)	212 746	172 746	3%	-40 000	-19%
Membership fees	48 275	55 550	1%	7 275	15%
<b>Individuals</b>	<b>1 126 296</b>	<b>1 038 157</b>	<b>19%</b>	<b>-88 139</b>	<b>-8%</b>
Volunteers	1 113 885	1 027 105	18%	-86 780	-8%
Donations	12 411	11 052	0%	-1 359	-11%
<b>European Commission</b>	<b>1 768 718</b>	<b>1 392 730</b>	<b>25%</b>	<b>-375 989</b>	<b>-21%</b>
DG Research	421 710	171 674	3%	-250 036	-59%
DG Health and consumers	1 078 738	916 035	16%	-162 703	-15%
DG Employment	199 985	239 273	4%	39 288	20%
EMA contributions (*)	68 285	65 747	1%	-2 538	-4%
<b>National authorities</b>	<b>37 268</b>			<b>-37 268</b>	
Grants from National authorities	37 268			-37 268	
<b>Corporates</b>	<b>1 743 574</b>	<b>1 788 093</b>	<b>32%</b>	<b>44 519</b>	<b>3%</b>
Pharma. and Biotech Companies	1 443 631	1 596 758	29%	153 127	11%
Other Health Sector Corporates	90 812	91 147	2%	335	0%
Outside Health Sector Corporates	209 131	100 188	2%	-108 943	-52%
<b>Not for Profit Organisations</b>	<b>137 780</b>	<b>25 000</b>	<b>0%</b>	<b>-112 780</b>	<b>-82%</b>
Pharma. and Biotech Found.					
Other Health Sector NPOs	132 780	20 000	0%	-112 780	-85%
Outside Health Sector NPOs	5 000	5 000	0%		
<b>Event Fees</b>	<b>252 316</b>	<b>112 721</b>	<b>2%</b>	<b>-139 595</b>	<b>-55%</b>
<b>Miscellaneous</b>	<b>295 765</b>	<b>354 367</b>	<b>6%</b>	<b>58 602</b>	<b>20%</b>
Reimbursement	244 732	322 569	6%	77 838	32%
Others	51 033	31 798	1%	-19 236	-38%
<b>Sub-total</b>	<b>6 312 183</b>	<b>5 593 863</b>	<b>100%</b>	<b>-718 320</b>	<b>-11%</b>
<b>Recovery of provisions</b>		<b>24 350</b>		<b>24 350</b>	
<b>Report of non-used income</b>					
<b>Total Revenue</b>	<b>6 312 183</b>	<b>5 618 213</b>		<b>-693 970</b>	<b>-11%</b>

Expenses	2016 Fin. Status	2017 Fin. Status	Ratio	Δ in euros	Δ in %
<b>Staff</b>	<b>2 647 385</b>	<b>2 679 121</b>	<b>50%</b>	<b>31 736</b>	<b>1%</b>
Wages and charges	2 421 686	2 462 084	46%	40 398	2%
Other salaries	207 742	202 612	4%	-5 130	-2%
Training and other costs	17 957	14 425	0%	-3 532	-20%
<b>Volunteers</b>	<b>1 113 885</b>	<b>1 027 105</b>	<b>19%</b>	<b>-86 780</b>	<b>-8%</b>
Representatives and task forces	900 427	824 521	15%	-75 906	-8%
Projects, office and translators	213 458	202 584	4%	-10 874	-5%
<b>Logistics</b>	<b>1 291 930</b>	<b>803 912</b>	<b>15%</b>	<b>-488 018</b>	<b>-38%</b>
Travels and subsistence	615 190	437 860	8%	-177 330	-29%
Event logistics and catering	594 025	300 305	6%	-293 720	-49%
In kind contribution (*)	82 715	65 747	1%	-16 968	-21%
<b>Services</b>	<b>1 088 542</b>	<b>752 538</b>	<b>14%</b>	<b>-336 004</b>	<b>-31%</b>
Fees	631 475	342 468	6%	-289 007	-46%
EC projects partners					
Telecom and post	33 954	30 342	1%	-3 612	-11%
Rent	268 126	251 265	5%	-16 861	-6%
Other services	154 987	128 463	2%	-26 524	-17%
<b>Purchase</b>	<b>96 300</b>	<b>104 751</b>	<b>2%</b>	<b>8 451</b>	<b>9%</b>
Office furniture	25 264	26 509	0%	1 244	5%
Amortisation	29 136	32 998	1%	3 862	13%
Communications, Publications	29 022	34 536	1%	5 513	19%
Other purchases	12 878	10 709	0%	-2 169	-17%
<b>Miscellaneous</b>	<b>38 125</b>	<b>17 034</b>	<b>0%</b>	<b>-21 091</b>	<b>-55%</b>
Financial expenses, Insurance, Tax	38 125	17 034	0%	-21 091	-55%
Exceptional expenses					
<b>Sub-total</b>	<b>6 276 167</b>	<b>5 384 461</b>	<b>100%</b>	<b>-891 706</b>	<b>-14%</b>
<b>Contingency and loss provisions</b>	<b>125 434</b>	<b>57 898</b>	<b>1%</b>	<b>-67 536</b>	<b>-54%</b>
<b>Commitment on assigned income</b>					
<b>Total Expenses</b>	<b>6 401 601</b>	<b>5 442 359</b>		<b>-959 242</b>	<b>-15%</b>
<b>Result</b>	<b>-89 417</b>	<b>175 854</b>			

(\*) covering travel/accommodation costs for EMA meetings



## 2017 Financial report comments

### 1. Assets and Liabilities

#### 1.1. Assets

Current assets decreased from 3 218 k€ to 1 947 k€.

	2016	2017	Difference	
Accounts receivable	2 012 968	901 940	-1 111 028	-55%
Liquid assets	1 183 079	1 016 385	-166 694	-14%
Prepaid expenses	21 526	28 752	7 226	34%
<b>Total</b>	<b>3 217 574</b>	<b>1 947 077</b>	<b>-1 270 497</b>	<b>-39%</b>

This 1,270 k€ decrease mainly comes from the fact that we had no new multiannual project signed in 2017 and the Operating Grant 2018 has still not been signed with the European Commission.

##### 1.1.1. Accounts receivable

Accounts receivable are monies to be received in the context of grants when an agreement has been signed and the cash has not yet been transferred.

The bulk of this line comes from the European Commission (597 k€, 70%).

##### 1.1.2. Liquid assets

Liquid assets are cash in the bank. The decrease is not significant.

### 1.2. Liabilities

#### 1.2.1. Association Funds

Association funds are the cumulative sum of all surplus / deficit since the creation of EURORDIS. At the end of 2016, they amounted to 789k€. Thanks to the surplus at the end of 2017, the association funds increased from 789 k€ to 965 k€, signifying a 22% increase. The 2017 surplus compensates the loss of 2016: the cumulated deficit 2016 and surplus 2017 over the two years means a yearly average 43k€ surplus.

### 1.2.2. Provisions

	2016	2017		
		Recoveries	New provisions	Balance
Provisions for charges	24 350	-24 350	0	0
Provisions for risks	92 000	0	0	92 000
Forecasted loss on RD-Action	0	0	52 895	52 895
Provision for retirement benefits	43 619	0	5 003	48 622
<b>Provisions for risks and charges</b>	<b>159 969</b>	<b>-24 350</b>	<b>57 898</b>	<b>193 517</b>

We have made

- a forecasted loss on RD-Action where the EC grant is insufficient and we lack direct co-funding,
- a provision for retirement benefits (regulatory provision)

### 1.2.3. Trade creditors

2016	162 k€	5%
2017	200 k€	10%
difference	+ 38 k€	+ 24%

Trade creditors are monies to be paid to suppliers for invoices that have been received (or to be received) and have not been paid yet. The situation at the end of 2017 was average compared to previous years.

### 1.2.4. Deferred income

2016	1 931 k€	59%
2017	417 k€	20%
Difference	- 1 514 k€	- 78%

Deferred income refers to the part of grants concerning the incoming 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 pluri-annual EC projects (288 k€, 69%). It is exceptionally low at the end of 2017 as we had no new pluri-annual contract signed in 2017, also because the 2018 Operating Grant had not been signed on 31/12/2017.



## 2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 5 594 k€. This represents a decrease of 718 k€ (- 13%) compared to 2016.

The bulk of the decrease is due to:

- No ECRD in 2017, compared to the ECRD 2016 Edinburgh-related EC and town grants and event fees (-354 k€);
- End of the EUPATI project and related grants (-256 k€);
- Decrease of the participation of volunteers (-88 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>)

	2016		2017		Difference	
<i>AFM</i>	847	13%	807	14%	-40	-5%
<i>Membership fees and grants</i>	103	2%	76	1%	-28	-37%
<i>Volunteers</i>	1 126	18%	1 038	19%	-88	-8%
Patient Org. and Volunteers	2 077	33%	1 921	34%	-156	-8%
European Commission	1 769	28%	1 393	25%	-376	-27%
National authorities	37	1%	0	0%	-37	
<i>Pharma. and Biotech Companies</i>	1 444	23%	1 597	29%	153	10%
<i>Other Health Sector Corporates</i>	91	1%	91	2%	0	0%
Health Sector Corporates	1 534	24%	1 688	30%	153	9%
Other Corporates	209	3%	100	2%	-109	-109%
Foundations and NPOs	138	2%	25	0%	-113	-451%
Event fees	252	4%	113	2%	-140	-124%
Others	296	5%	354	6%	59	17%
<b>Total</b>	<b>6 312</b>	<b>100%</b>	<b>5 594</b>	<b>100%</b>	<b>-718</b>	<b>-13%</b>

Overall: 34% of revenues are contributed by our members and individuals, 30% by Health Sector Corporates and 25% from European Commission and Member States. The situation where Health Sector Corporates represent more than European Commission already happened in 2002, 2006, 2008 and 2012.

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 72 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

2016	2 077 k€	33%
2017	1 921 k€	34%
difference	- 156 k€	- 8%

The Patient Organisations and Individuals section is our largest source of revenue covering more than a third of our expenses. The larger part of it is in kind (volunteer contributions; Paris' office space kindly offered by AFM) and the main cash contribution is the annual support of AFM-Téléthon.

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

2016	847 k€	13%
2017	807 k€	14%
Difference	- 40 k€	- 5%

The AFM-Téléthon 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 amounts to 635 k€. We are very grateful to all AFM-Téléthon donors: without all these individual gifts, EURORDIS would not be able to leverage the funds that enable us to conduct our advocacy activities with no conflict of interest with both the private-for-profit sector and public institutions.

In the framework of the 2016-2017 AFM-Téléthon/EURORDIS agreement, 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 (172 k€) is based on current property prices that are updated every third year.

### 2.1.2. Individuals

2016	1 126 k€	18%
2017	1 038 k€	19%
Difference	- 88 k€	- 8%

We had some donations from individuals in 2017 but our main source of revenue from individuals remains in kind (volunteers).

The dedication of our volunteers continues to grow and diversify. In 2017, their work represented 9.6 full time equivalents (fte), a total amount of 16,551 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 is something money cannot buy.

In 2017, volunteers mainly worked on matters pertaining to public affairs (5 fte), orphan medicinal products (2 fte) and moderation of the rareconnect.org website (2.6 fte).

## 2.2. European Commission

2016	1 769 k€	28%
2017	1 393 k€	25%
Difference	+ 376 k€	- 21%

In 2017, EURORDIS ran nine different EC grants from DG SANTE, DG RESEARCH, DG EMPLOYMENT and IMI-JU<sup>3</sup>.

In addition to

- the DG SANTE Operating Grant (which has been renewed every year since 2009);
- the DG SANTE Joint Actions on Rare Diseases (RD-ACTION) and Rare Cancers (JARC);
- the IMI-JU Grants (EUPATI, WEB-RADR, ADAPT-SMART);
- the DG RESEARCH Grants (RD-CONNECT and Genetic Clinic of the Future),
- the DG EMPLOYMENT Grant INNOVCare.

The DG SANTE Operating Grant is embedded in a Framework Partnership Agreement (FPA) which lasted from 2015 to 2017. It means that the support of recurrent activities by DG SANTE is possible over those three years, however, the annual amount of financial support is not granted and is reevaluated every year.

It was 770 k€ in 2015, 792 k€ in 2016 and 2017. Usually the applicant is informed in the last quarter of the amount granted for the upcoming year.

In 2017, the EURORDIS FPA Application was successful and the FPA 2018-2021 was renewed. However, the Specific Grant Agreement (SGA) for 2018 was not signed. At the date of the General Assembly, 10 May 2018, the SGA 2018 will certainly have not been signed yet. The reason for the delay comes from an irregularity in the process of the grant allocation by the DG SANTE agency, CHAFEA, to the NGOs. After two NGOs lodged an official complain, the whole process was frozen. The SGA will be signed before 30 June 2018 with an exceptional retroactive effect since January 2018. However, no NGO has the certainty that it will be granted an SGA, and if granted, it has uncertainty until June 2018 of the amount of the grant, therefore, the whole sector is either slowing down its activity or taking the risk to have expenses not covered by the Operating Grant.

<sup>3</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".

### 2.3. National authorities

2016	37 k€	1%
2017	0 k€	0%
Difference	- 37 k€	N/A

In 2016 the amount came from the grant from the city of Edinburgh in the context of the ECRD 2016, Edinburgh. There was no new national grant in 2017.

### 2.4. Health Sector Corporates

2016	1 534 k€	24%
2017	1 688 k€	30%
Difference	+ 154 k€	+ 10%

This line comprises 64 pharmaceutical companies and 8 health sector firms outside the pharmaceutical or biotechnology sector.

The level of contribution from the Health Sector Corporations has grown despite the decrease of the overall budget.

The growth comes from the increase of the EURORDIS Round Table of Companies (ERTC), which now comprises 67 companies directly involved in rare disease therapies.

The five largest donors are, in descending order: 1<sup>st</sup> SHIRE and PFIZER, 3<sup>rd</sup> CELGENE, 4<sup>th</sup> VERTEX, 5<sup>th</sup> NOVARTIS.

The percentage of each of the 64 pharmaceutical companies in the overall budget comprises between 0.04% and 2.3%.

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>4</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.

### 2.5. Other Corporates

2016	209 k€	3%
2017	100 k€	2%
difference	- 109 k€	- 52%

This funding comes from in kind services:

- DLA Piper UK LLP for legal services,
- Burson Marsteller, Media Planet, Reflex Media and Publicis Lifebrand on Communications,
- Google AdWords, Trommons, Translators without borders on RareConnect.

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<sup>4</sup> i.e. Patient Organisations & Volunteers, Public funding, Corporate & other private funding, revenues generated by our activities



The reduction of the envelope comes from the Google AdWords account, which has been shut down for technical reasons. It was 109k€ in 2016, compared to 6k€ in 2017.

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

2016	138 k€	2%
2017	25 k€	0.4%
difference	- 113 k€	- 82%

NPO grants came from Health Sector organisations:

- the Russian organisation AIPM (Association of International Pharmaceutical Manufacturers),
- Kindness for Kids, a German based foundation which aims at increasing the quality of life of children with rare diseases.

The European syndicate of pharmaceutical industries (EFPIA) used to contribute to the EUPATI project which ended in January 2017, hence the significant decrease.

## 2.7. Event Fees

2016	252 k€	4%
2017	113 k€	2%
difference	- 139 k€	- 55%

In 2017, event fees was mainly composed of:

- The Multi-Stakeholders Symposium (59 k€),
- The Black Pearl Award event (40k€).

The difference comes from the absence of a European Conference on Rare Diseases (ECRD) in 2017.

### 3. Expenses

Operating expenses, including in-kind contributions and excluding provisions, amounted to 5 384 k€, which shows a decrease of 17% compared to 2016.

The decrease is due to:

- The absence of ECRD in 2017 (- 337 k€),
- The transfer of RareConnect to the Children's Hospital of Eastern Ontario – CHEO (- 242k€)
- And the end of EUPATI (- 196k€)

The breakdown of EURORDIS expenses is as follows  
(in thousands of euros, provisions excluded<sup>5</sup>)

Expenses	2 015		2 016		Difference	
Staff costs	2 647	42%	2 679	50%	32	1%
Volunteers	1 114	18%	1 027	19%	-87	-8%
Logistics	1 292	21%	804	15%	-488	-38%
Services	1 089	17%	753	14%	-336	-31%
Others	134	2%	122	2%	-13	-9%
<b>Total</b>	<b>6 276</b>	<b>100%</b>	<b>5 384</b>	<b>100%</b>	<b>-892</b>	<b>-17%</b>

The Expenses table of the profit and loss table has been reshaped in order to better identify the logistics costs. Beforehand, the costs associated to the venue, catering, technicians, etc. were included in the “Services” section, they are now together with the travel and subsistence allowances, creating a comprehensive and coherent “Logistics” section.

More details on expenses:

#### 3.1. Staff costs

2016	2 647 k€	42%
2017	2 679 k€	50%
difference	+ 32 k€	+ 1%

The number of FTE<sup>6</sup> was 40 in 2017.

As of end of year, the team was composed of 38 staff members dispatched in 8 countries.

The main office is in France (23), followed by Spain (6), Belgium (4), Serbia (1), Switzerland (1), Germany (1), Croatia (1) and the United Kingdom of Great Britain and Northern Ireland (1).

2 new positions were created in 2017 (in order of appearance):

- Social Projects Assistant Manager, Aline Schnieder, Barcelona
- Patient Engagement Manager - HTA, Matteo Scarabelli, Paris

3 positions were stopped:

- Web Technology Manager (Rare Connect), Laura Amorini, Barcelona
- Rare Connect Manager, Robert Pleticha, Barcelona
- RareConnect Manager, Igor Ban, Belgrade

<sup>5</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>6</sup> 1 full time equivalent = 1 people on a full time position during one year

We hired Simone Boselli to replace Jean-Louis Roux in the Public Affairs Director position in Brussels.

We still run the payroll of Iolanda Arbiol from the “Plataforma Malalties Minoritàries” in Barcelona; expenses are covered by revenues from Plataforma. Maria Mavris who was working for the European Medicine Agency has resigned from EURORDIS as she is now a permanent staff of the agency. Iolanda and Maria’s salaries are counted in the Financial Report’s figures and FTE but are not part of the year-end counting.

#### 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 represents less than 50% of the staff costs (44%), in Belgium and Spain a bit more than 50% (respectively 53% and 57%). 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 m2 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, Zagreb 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 14 languages and comprises 17 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.

### **3.2. Logistics**

2016	1 292 k€	21%
2017	804 k€	15%
difference	- 488 k€	- 38%

- No ECRD in 2017 (- 335 k€),
- No EUPATI trainings in 2017 (- 135 k€)

### **3.3. Services**

2016	1 089 k€	17%
2017	753 k€	14%
Difference	- 336 k€	- 31%

The main reason for the difference between 2017 and 2016 is the transfer of RareConnect to the Children's Hospital of Eastern Ontario (- 187 k€).

Out of the 753 k€ in 2017, 276 k€ are provided in kind (Paris office space by AFM, in kind services from Publicis Lifebrand, etc.).

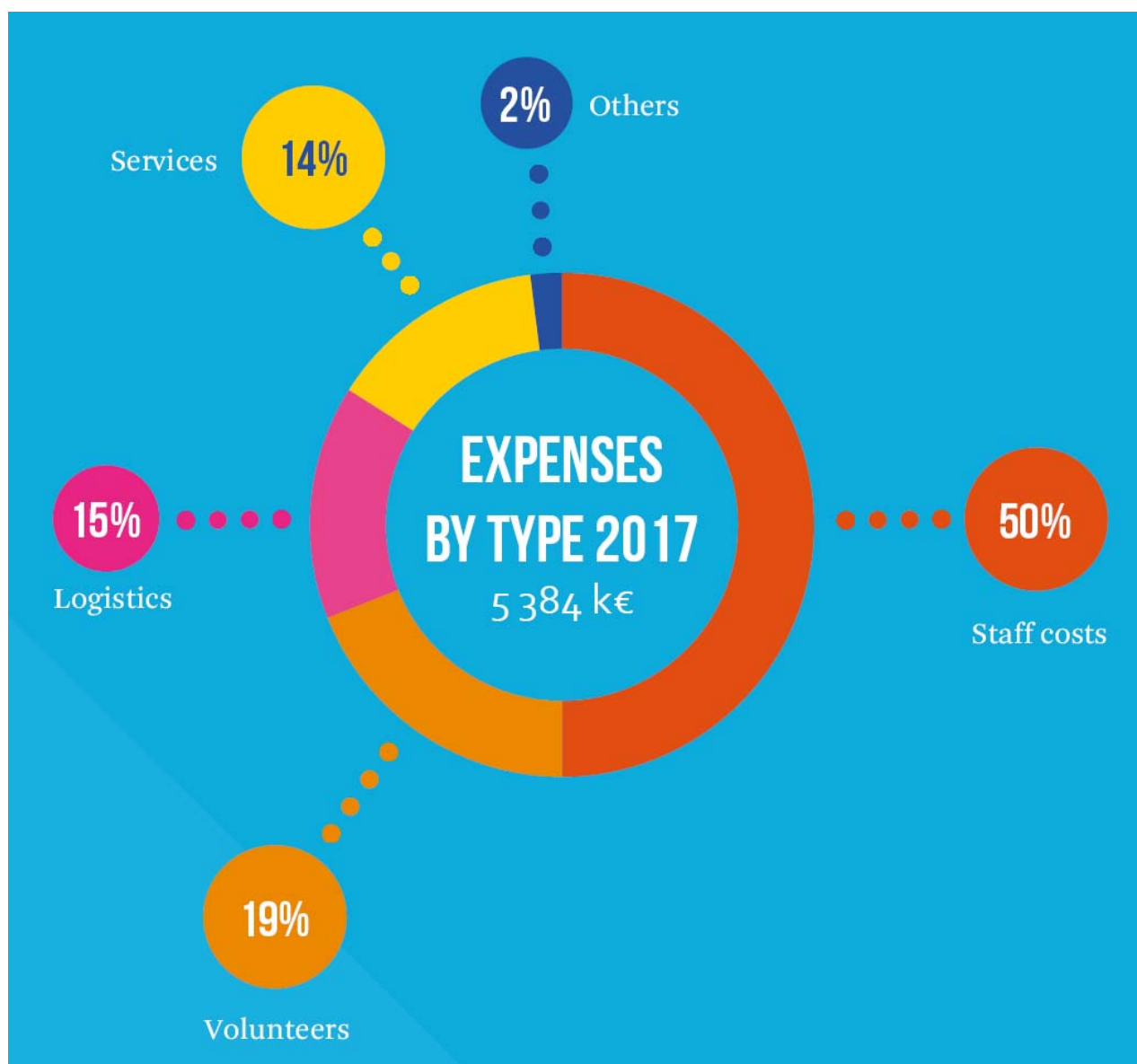
#### 4. Result

The surplus amounted to 175 854 euros, we suggest allocating it to the reserve which will amount to 965 176 euros.

If we refer to EURORDIS' policy, which is to have reserves representing from 3 to 6 months of low-level activity, the situation is better than in 2016 but is not safe enough yet. EURORDIS would need to have a higher level of reserve, even more so because of the uncertainties around the Operating Grant from DG SANTE.







## 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 2015-2017** (Framework Partnership Agreement)
  - o from 01-Jan-15 to 31-Dec-17
  - o EURORDIS sole beneficiary
- **EURORDIS SGA 2017** (Specific Grant Agreement)
  - o from 01-Jan-17 to 31-Dec-17
  - 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

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

Ongoing Projects:

- *RD Connect* (An integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research)
  - o from 01-Nov-12 to 30-Oct-18
  - o EURORDIS co-beneficiary
- *Genetic Clinic of the Future* (A stepping stone approach towards the Genetics Clinic of the Future)
  - o from 01-Dec-14 to 31-May-17
  - o EURORDIS co-beneficiary

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

- *Web-Radr* (Recognising Adverse Drug Reactions)
  - o from 01-Sep-14 to 31-Aug-17
  - o EURORDIS co-beneficiary
- *Adapt-Smart* (Accelerated Development of Appropriate Patient Therapies)
  - o From 01-Jul-15 to 31-Dec-17
  - o EURORDIS co-beneficiary

*DG EMPLOYMENT*: Employment, Social Affairs & Inclusion Directorate-General of EC

- *INNOVCare* (Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions)
  - o From 01-Oct-15 to 30-Sep-18
  - o EURORDIS co-beneficiary

*ECRD*: European Conference on Rare Diseases.

8 of them have already taken place

ECRD 2017, 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 ninth will take place in May 2018 in Vienna.

*EMA*: European Medicines Agency





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