

EURORDIS
FINANCIAL
REPORT 2018



Kacper from Poland is living
with Kawasaki disease.

FINANCIAL REPORT
2018

Bucharest, May 2019

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, 2018

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

Statutory Auditor's report on the financial statements

For the year ended December 31, 2018

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, 2018.

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, 2018 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, 2018 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, 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, 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

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 7, 2019

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY

Assets	2017	2018	Ratio	Difference
FIXED ASSETS				
Intangible assets	451	0	-100%	-451
Tangible assets	87 854	86 067	-2%	-1 787
Financial assets	8 860	8 860	0%	0
TOTAL	97 164	94 927	-2%	-2 238
CURRENT ASSETS				
Account receivable due within one year	714 080	1 871 436	162%	1 157 356
Account receivable due after one year	187 860	2 528 980	1246%	2 341 121
Liquid assets	1 016 385	2 395 715	136%	1 379 330
Prepaid expenses	28 752	25 735	-10%	-3 017
TOTAL	1 947 077	6 821 867	250%	4 874 789
TOTAL ASSETS	2 044 242	6 916 793	238%	4 872 552

Liabilities	2017	2018	Ratio	Difference
ASSOCIATION FUNDS				
Reserve	789 323	965 176	22%	175 854
Profit & loss for the year	175 854	171 922	-2%	-3 932
Subsidies of investment	0	0	NA	0
TOTAL	965 176	1 137 098	18%	171 922
Provisions for risk and charges	193 517	132 027	-32%	-61 490
Dedicated funds on grants	0	0	NA	0
DEBTS				
Bank loans and overdraft	0	13 504	NA	13 504
Trade creditors	200 005	301 003	50%	100 998
Tax payable and social liabilities	268 518	313 908	17%	45 389
Other debts	0	460 648	NA	460 648
Deferred income within one year	349 545	2 344 246	571%	1 994 700
Deferred income after one year	67 480	2 214 361	3182%	2 146 881
TOTAL	1 079 065	5 779 695	436%	4 700 630
TOTAL LIABILITIES	2 044 242	6 916 793	238%	4 872 552

Revenue	2017 Fin. Status	2018 Fin. Status	Ratio	Δ in euros	Δ in %
Patient Organisations	882 796	939 148	15%	56 352	6%
Financial contributions	654 500	683 500	11%		
<i>AFM Telethon</i>	634 500	634 500	10%		
<i>Other Patient Organisations</i>	20 000	49 000	1%	29 000	145%
In kind contributions (AFM)	172 746	196 053	3%	23 307	13%
Membership fees	55 550	59 595	1%	4 045	7%
Individuals	1 038 157	1 351 101	21%	312 944	30%
Volunteers	1 027 105	1 308 943	20%	281 838	27%
Donations	11 052	42 158	1%	31 106	281%
European Commission	1 392 730	1 666 814	26%	274 085	20%
DG Research	171 674	292 953	5%	121 278	71%
DG Health and consumers	916 035	1 104 339	17%	188 303	21%
DG Employment	239 273	223 300	3%	-15 973	-7%
EMA contributions (*)	65 747	46 223	1%	-19 524	-30%
National authorities		15 900	0%	15 900	
Grants from National authorities		15 900	0%	15 900	
Corporates	1 788 093	1 841 537	29%	53 444	3%
Pharma. and Biotech Companies	1 596 758	1 662 981	26%	66 223	4%
Other Health Sector Corporates	91 147	70 000	1%	-21 147	-23%
Outside Health Sector Corporates	100 188	108 556	2%	8 368	8%
Not for Profit Organisations	25 000	117 718	2%	92 718	371%
Pharma. and Biotech Found.					
Other Health Sector NPOs	20 000	102 718	2%	82 718	414%
Outside Health Sector NPOs	5 000	15 000	0%	10 000	200%
Event Fees	112 721	333 829	5%	221 108	196%
Miscellaneous	354 367	128 294	2%	-226 073	-64%
Reimbursement	322 569	112 987	2%	-209 582	-65%
Others	31 798	15 307	0%	-16 491	-52%
Sub-total	5 593 863	6 394 341	100%	800 478	14%
Recovery of provisions	24 350	103 517		79 167	325%
Report of non-used income					
Total Revenue	5 618 213	6 497 858		879 645	16%

Expenses	2017 Fin. Status	2018 Fin. Status	Ratio	Δ in euros	Δ in %
Staff	2 679 121	2 853 121	45%	174 000	6%
Wages and charges	2 462 084	2 590 889	41%	128 805	5%
Other salaries	202 612	246 030	4%	43 417	21%
Training and other costs	14 425	16 202	0%	1 777	12%
Volunteers	1 027 105	1 308 943	21%	281 838	27%
Representatives and task forces	824 521	1 099 370	17%	274 849	33%
Projects, office and translators	202 584	209 573	3%	6 989	3%
Logistics	803 912	1 032 220	16%	228 309	28%
Travels and subsistence	437 860	541 973	9%	104 113	24%
Event logistics and catering	300 305	444 025	7%	143 720	48%
In kind contribution (*)	65 747	46 223	1%	-19 524	-30%
Services	752 538	936 623	15%	184 085	24%
Fees	342 468	480 456	8%	137 988	40%
Partners					
Telecom and post	30 342	39 131	1%	8 789	29%
Rent	251 265	270 823	4%	19 558	8%
Other services	128 463	146 213	2%	17 750	14%
Purchase	104 751	120 571	2%	15 820	15%
Office furniture	26 509	31 938	1%	5 429	20%
Amortisation	32 998	36 923	1%	3 926	12%
Communications, Publications	34 536	37 572	1%	3 036	9%
Other purchases	10 709	14 138	0%	3 429	32%
Miscellaneous	17 034	32 432	1%	15 398	90%
Financial expenses, Insurance, Tax	17 034	32 432	1%	15 398	90%
Exceptional expenses					
Sub-total	5 384 461	6 283 910	100%	899 449	17%
Contingency and loss provisions	57 898	42 027	1%	-15 871	-27%
Commitment on assigned income					
Total Expenses	5 442 359	6 325 936		883 577	16%
Result	175 854	171 922			

* covering travel/accommodation costs for EMA meetings

1. Assets and Liabilities

1.1. Assets

Current assets increased from 1 947 to 6 822 k€.

	2017	2018	Difference	
Accounts receivable	901 940	4 400 417	3 498 477	388%
Liquid assets	1 016 385	2 395 715	1 379 330	136%
Prepaid expenses	28 752	25 735	-3 017	-10%
Total	1 947 077	6 821 867	4 874 789	250%

This 5 M€ increase comes from the fact that:

- In 2017, the Operating Grant for the year 2018 was exceptionally signed in 2018. As a result, 2017 had a particularly low level of accounts receivable (it should have been around 3M€).
- In 2018, EURORDIS signed numerous significant multi-year contracts (PARADIGM, Solve-RD, conect4children, Rare 2030, RDCODE, HTx, European Joint Programme on Rare Diseases)

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 (3 656 k€, 83%).

1.1.2. Liquid assets

Liquid assets are cash in the bank. The significant increase comes from the fact that, in the context of a multi-year European project, the European Commission would give a first instalment amounting from 35 to 75% of the overall amount, thus covering several years of functioning. On the contrary, the last instalment is vested sometimes one year – or even more – after the end of the project so we need to have a solid treasury when a multi-year project ends. This is a major – but predictable – source of variation of liquid assets for an organisation that receives grants from the European Commission.

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 2017, they amounted to 965k€. Thanks to the surplus at the end of 2018, the association funds increased from 965 to 1 137 k€, signifying a 18% increase.

1.2.2. Provisions

	2017	2018		
		Recoveries	New provisions	Balance
Provisions for risks	92 000	-50 000	0	42 000
Forecasted loss on EU Projects	52 895	-52 895	42 027	42 027
Provision for retirement benefits	48 622	-622	0	48 000
Provisions for risks and charges	193 517	-103 517	42 027	132 027

We have recovered

- A provision for risks
- The forecasted loss on RD-Action, the project being terminated in 2018

We have made

- A forecasted loss on the Joint Action on Rare Cancers where the EC grant is insufficient and we lack direct co-funding

1.2.3. Trade creditors

2017	200 k€	10%
2018	301 k€	4%
difference	+ 101 k€	+ 50%

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. The reason for this significant increase is a question of timing.

1.2.4. Deferred income

2017	417 k€	20%
2018	4 559 k€	66%
Difference	4 142 k€	+ 993%

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 pluri-annual EC projects (4 204 k€, 92%). It is exceptionally high at the end of 2018 thanks to the recent signature of multi-year projects with the European Commission.

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 6 394 k€. This represents an increase of 800 k€ (+ 13%) compared to 2017.

The bulk of the increase is due to:

- ECRD Vienna in 2018 when there was no ECRD in 2017 (+484 k€);
- Increase of the Operating Grant (+235 k€);
- Start of a new research project called Rare Impact (+168 k€).

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

	2017		2018		Difference	
AFM	807	14%	831	13%	23	3%
Contributions from members	76	1%	109	2%	33	44%
Volunteers	1 038	19%	1 351	21%	313	30%
Patient Org. and Volunteers	1 921	34%	2 290	36%	369	19%
European Commission	1 393	25%	1 667	26%	274	20%
National authorities	0	0%	16	0%	16	
Pharma. and Biotech Companies	1 597	29%	1 663	26%	66	4%
Other Health Sector Corporates	91	2%	70	1%	-21	-23%
Health Sector Corporates	1 688	30%	1 733	27%	45	3%
Other Corporates	100	2%	109	2%	8	8%
Foundations and NPOs	25	0%	118	2%	93	371%
Event fees	113	2%	334	5%	221	196%
Others	354	6%	128	2%	-226	-64%
Total	5 594	100%	6 394	100%	800	14%

Overall: 36% of revenues are contributed by our members and individuals, 27% by Health Sector Corporates and 26% from European Commission and Member States.

The proportion of funding by source fully complies with our *Policy on Financial Support by Commercial Companies*²: the level of revenues from Health Sector Corporates represents 27% and is spread across 72 different companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (36%).

¹ 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.

² for more details on policy and financial structure, see www.eurordis.org
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More details on revenues:

2.1. Patient Organisations and Individuals

2017	1 921 k€	34%
2018	2 290 k€	36%
difference	+ 369 k€	+ 19%

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)

2017	807 k€	14%
2018	831 k€	13%
Difference	+ 23 k€	+ 3%

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.

The 2014-2017 AFM-Téléthon/EURORDIS agreement was extended to 2018. 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 (196 k€) is based on current property prices and was updated this year, hence the +23k€ on the AFM-Téléthon line.

2.1.2. Contributions from members

2017	76 k€	1%
2018	109 k€	2%
Difference	+ 33 k€	+ 44%

This line comprises the membership fees (56k€ in 2017 and 60k€ in 2018) and contributions from the European Federations in the context of the EURORDIS EUROCAR programme in 2018 (CAR means Community Advisory Board).

Financially speaking, this new activity started in 2018. It consists in providing a framework and mentorship to groups of patient experts who need to interact with the sponsors of clinical research in order to help them design products that are adapted to the needs of the patients. In this context, the sponsors of clinical research (mainly drug manufacturers) would deal with the European Federations who select the patient experts and deal with them. EURORDIS' role is to define good standards and to provide the Community Advisory Boards with an expert who will act as a mentor. In 2018, the contribution from European Federations amounted to 49k€.

2.1.3. Individuals

2017	1 038 k€	19%
2018	1 351 k€	21%
Difference	+ 313 k€	+ 30%

We had some donations from individuals in 2018 but our main source of revenue from individuals remains in kind (volunteers).

The dedication of our volunteers significantly grew in 2018. Their incredible work represented 12.7 full time equivalents (fte), a total amount of 21,471 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 2018, volunteers mainly worked on matters pertaining to public affairs (7.6 fte), orphan medicinal products (1.7 fte) and moderation of the rareconnect.org website (2.6 fte).

2.2. European Commission

2017	1 393 k€	25%
2018	1 667 k€	26%
Difference	+ 274 k€	+ 20%

In 2018, EURORDIS ran eight, closed two and negotiated five EC grants from DG SANTE, DG RESEARCH, DG EMPLOYMENT and IMI-JU³, .

Contracts running in 2018:

- 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 DG RESEARCH Grants RD-CONNECT and Solve-RD,
- the IMI-JU Grants PARADIGM and conect4children,
- the DG EMPLOYMENT Grant INNOVCare.

³ IMI-JU is a Joint Undertaking between DG Research and the European Federation of Pharmaceutical Industries and Associations (EFPIA) called "Innovative Medicine Initiative". In the budget, the contribution from EC is recorded under chapter "DG Research".

Contracts negotiated in 2018 for 2019:

- the DG SANTE Operating Grant
- the DG SANTE RDCODE and Rare 2030 projects
- the DG RESEARCH HTx project and the European Joint Programme on Rare Diseases

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

2017	1 688 k€	30%
2018	1 733 k€	27%
Difference	+ 45 k€	+ 3%

This line comprises 72 health sector companies including 61 pharmaceutical and biotech companies.

In 2018, EURORDIS has associated with a for profit consultant (Dolon) and started a new kind of project in collaboration with 16 pharmaceutical or biotech companies, 1 trade organisation and 2 not-for-profit organisations. This project is called Rare Impact and will last for 2 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 420 k€ of which 168 k€ related to 2018. 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 declares 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: 1st PFIZER, 2nd SHIRE, 3rd CELGENE, 4th NOVARTIS and 5th SANOFI GENZYME.

The percentage of each of the 72 health sector companies in the overall budget comprises between 0.02% and 2.6%.

The guarantees of our independence with the health corporate sector are (1) high standard in our governance, (2) balance revenues between our different sources⁴ (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.

2.4. Foundations and Not for Profit Organisations (NPOs)

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

2017	25 k€	0%
2018	118 k€	2%
difference	+ 93 k€	+ 371%

- 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 Children's Hospital of Eastern Ontario covering direct costs of the internet platform RareConnect.org

2.7. Event Fees

2017	113 k€	2%
2018	334 k€	5%
difference	+ 221 k€	+ 196%

In 2018, event fees were mainly composed of:

- The European Conference on Rare Diseases (240 k€),
- The Black Pearl Award event (61k€).
- The EURORDIS Round Table of Companies (30 k€);

3. Expenses

Operating expenses, including in-kind contributions and excluding provisions, amounted to 6 284 k€, which shows an increase of 17% compared to 2017.

The increase is due to:

- ECRD 2018 Vienna (+ 356 k€),
- Volunteers (+ 282 k€),
- ePAGs (+ 145k€)
- Creation of EUROcab (+53 k€)

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

Expenses	2017		2018		Difference	
Staff costs	2 679	50%	2 853	45%	174	6%
Volunteers	1 027	19%	1 309	21%	282	27%
Logistics	804	15%	1 032	16%	228	28%
Services	753	14%	937	15%	184	24%
Others	122	2%	153	2%	31	26%
Total	5 384	100%	6 284	100%	899	17%

More details on expenses:

⁵ 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.

3.1. Staff costs

2017	2 679 k€	50%
2018	2 853 k€	45%
difference	+ 174 k€	+ 6%

The number of FTE⁶ was 45 in 2018.

As at the end of the year, the team was composed of 40 staff members dispatched in 7 countries. The main office is in France (22), followed by Spain (9), Belgium (5), Serbia (1), Switzerland (1), Germany (1) and the United Kingdom of Great Britain and Northern Ireland (1).

7 new positions were created in 2018 (in order of appearance):

- Patient Engagement Senior Manager - CABs, Rob Camp, Barcelona
- ERN & Healthcare Director, Inés Hernando, Brussels
- Research & Policy Project Manager, Gulcin Gumus, Barcelona
- Communications Junior Manager, Lucy Michaeloudis, Paris
- Patient Engagement Junior Manager, Maria Cavaller, Barcelona
- Public Health Policy Advisor - Rare2o3o Project Lead, Anna Kole, Paris (28-month contract)
- Team Assistant & Office Manager, Katarzyna Radwan, Brussels

2 positions were stopped:

- Operations & Projects Manager, Mathieu Boudes, Paris
- RareConnect Manager, Tihana Kreso, Zagreb

We hired Martina Bergna to replace Emilie Zingg in the Events Junior Manager position in Paris. Céline Schwob was hired as Corporate Relations Manager in Paris, as a partial replacement for Jill Bonjean, Corporate and Foundations Relations Director.

Until the end of 2018 we still graciously ran the payroll of Iolanda Arbiol from the “Plataforma Malalties Minoritàries” in Barcelona; expenses were covered by revenues from Plataforma. Iolanda’s salary is counted in the Financial Report’s figures and FTE but is not part of the year-end counting as she does not belong to the EURORDIS team.

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 2018 (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 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 or Belgrade.

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

⁶ 1 full time equivalent = 1 people on a full time position during one year
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All EURORDIS' staff members speak at least 2 languages, often 3 to 5, altogether the staff team speaks 15 languages and comprises 16 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

2017	804 k€	15%
2018	1 032 k€	16%
difference	+ 228 k€	+ 28%

The increase comes from the fact that there was no ECRD in 2017 so in comparison it creates an increase of 306 k€ on ECRD 2018. This increase is compensated by the absence of Multi-Stakeholder Symposium in 2018 compared to 2017 (-101 k€).

3.3. Services

2017	753 k€	14%
2018	937 k€	15%
Difference	+ 184 k€	+ 24%

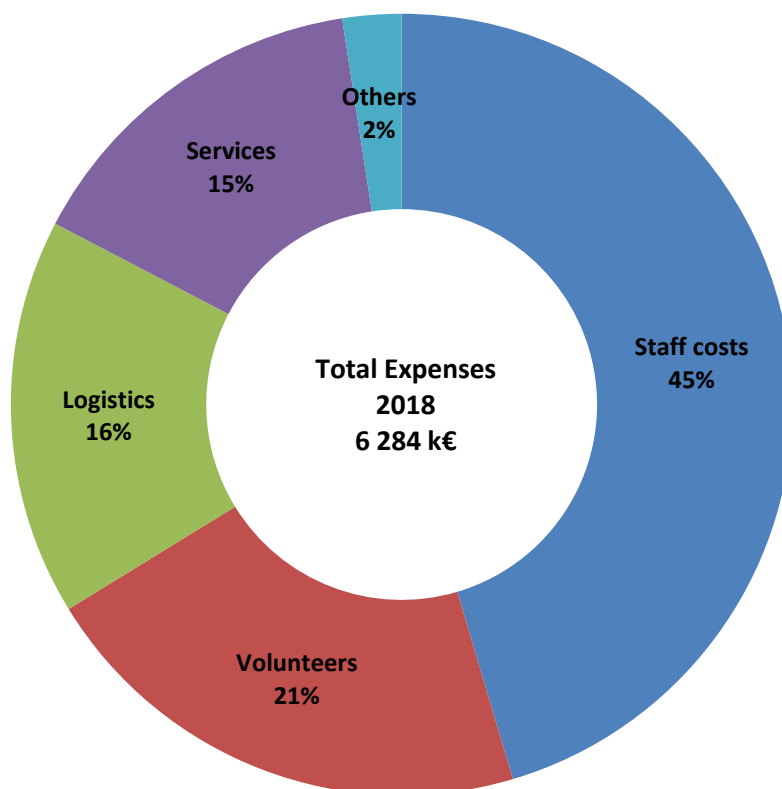
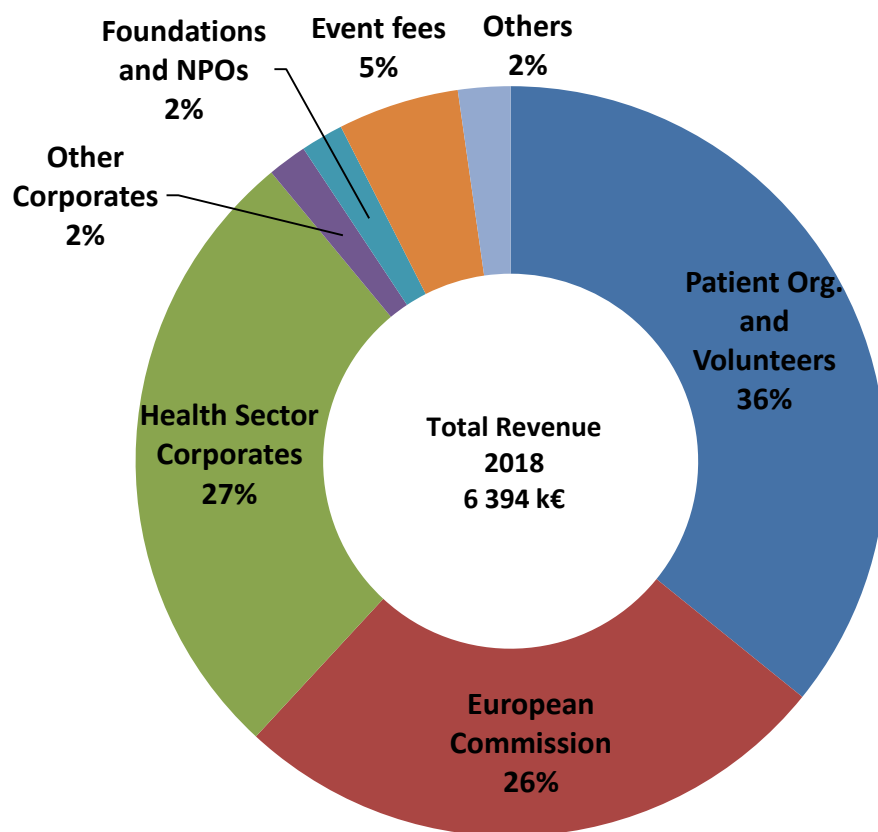
The main reasons for the difference between 2018 and 2017 are:

- The revamping of EURORDIS' contact database
- The Rare Disease Day videos and strategic review
- ECRD 2018

4. Result

The surplus amounted to 171 922 euros, we suggest allocating it to the reserve which will then amount to 1 137 098 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 slightly better than in 2017 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 continuation of the DG SANTE Health Programme from 2022 onward.



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 2018-2011* (Framework Partnership Agreement)
 - o from 01-Jan-18 to 31-Dec-21
 - o EURORDIS sole beneficiary
- *EURORDIS SGA 2018* (Specific Grant Agreement)
 - o from 01-Jan-18 to 31-Dec-18
 - 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
- *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

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.

9 of them have already taken place

ECRD 2018, in Vienna (co-organised by EURORDIS and DIA)

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 tenth will take place in May 2020 in Stockholm.

EMA: European Medicines Agency



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Laura from Spain is living
with arthrogryposis
multiplex congenita.

