



EURORDIS
Rare Diseases Europe

FINANCIAL REPORT

2015

European Organisation
for Rare Diseases

The Voice of Rare Disease
Patients in Europe

eurordis.org



EURORDIS

Association governed by the French law of July 1, 1901

96, rue Didot
75014 PARIS

STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2015

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STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2015

In compliance with the assignment entrusted to us by the Members' meeting, we hereby report to you, for the year ended December 31, 2015, on :

- the audit of the accompanying financial statements of the EURORDIS Association,
- the justification of our assessments,
- the specific procedures and disclosures required by law.

These financial statements have been approved by the Association's Board of Directors. Our role is to express an opinion on these financial statements, based on our audit.

I. Opinion on the financial statements

We conducted our audit in accordance with professional practice standards applicable in France. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, using sample testing techniques or other selection methods, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made, as well as evaluating the overall financial statement presentation. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

In our opinion, the financial statements give a true and fair view of the EURORDIS Association's financial position and its assets and liabilities as of December 31, 2015 and the results of its operations for the year then ended, in accordance with French accounting regulations.

Société anonyme au capital de 1 723 040 €
Société d'Expertise Comptable inscrite au Tableau de l'Ordre du Conseil Régional de Paris Ile-de-France
Société de Commissaires aux Comptes, membre de la Compagnie régionale de Versailles
572 028 041 RCS Nanterre
TVA : FR 02 572 028 041

II. Justification of assessments

Pursuant to the provisions of Article L.823-9 of the French Commercial Code on the justification of our assessments, we hereby inform you that our assessments covered the accounting policies implemented by your Association. We have verified the appropriateness of these accounting policies and the disclosures in the Notes.

The assessments on these matters were performed in the context of our audit approach for the financial statements taken as a whole, and therefore contributed to the opinion we expressed in the first part of this report.

III. Specific procedures and disclosures

We have also performed the other procedures required by law in accordance with professional standards applicable in France.

We have no comment to make as to the fair presentation and consistency with the financial statements of the information given in the Board of Directors' financial report and in the documents addressed to the Members with respect to the financial position and the financial statements.

Neuilly-sur-Seine, May 11, 2016

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY

This is a free translation into English of the original Statutory Auditor's report issued in the French language and is provided solely for the convenience of English-speaking readers. This report should be read in conjunction and construed in accordance with French law and professional auditing standards applicable in France.

Assets	2014	2015	Ratio	Difference
FIXED ASSETS				
Intangible assets	0	2 461	NA	2 461
Tangible assets	49 752	60 529	22%	10 777
Financial assets	3 917	14 649	274%	10 732
TOTAL	53 669	77 639	45%	23 971
CURRENT ASSETS				
Account receivable due within one year	1 080 900	1 736 560	61%	655 660
Account receivable due after one year	567 049	730 641	29%	163 592
Liquid assets	806 268	1 285 153	59%	478 886
Prepaid expenses	48 420	93 612	93%	45 192
TOTAL	2 502 637	3 845 967	54%	1 343 329
TOTAL ASSETS	2 556 306	3 923 606	53%	1 367 300

Liabilities	2014	2015	Ratio	Difference
ASSOCIATION FUNDS				
Reserve	625 736	825 571	32%	199 835
Profit & loss for the year	199 835	53 169	-73%	-146 665
Subsidies of investment	0	0	NA	0
TOTAL	825 571	878 740	6%	53 169
Provisions for risk and charges	37 807	34 535	-9%	-3 272
Dedicated funds on grants	0	0	NA	0
DEBTS				
Bank loans and overdraft	0	0	NA	0
Trade creditors	173 341	140 739	-19%	-32 602
Tax payable and social liabilities	266 857	276 248	4%	9 391
Other debts	29 364	0	-100%	-29 364
Deferred income within one year	619 341	1 767 835	185%	1 148 494
Deferred income after one year	604 026	825 509	37%	221 483
TOTAL	1 730 736	3 044 866	76%	1 314 131
TOTAL LIABILITIES	2 556 306	3 923 606	53%	1 367 300

**2015 Financial Status VS.
2014 Financial Status**
(Profit and Loss including in kind contributions)

Revenue	2014 Fin. Status	2015 Fin. Status	Ratio	Δ in euros	Δ in %
Patient Organisations	889 922	855 856	17%	-34 066	-4%
Financial contributions	674 196	635 400	12%		
AFM Telethon	634 500	634 500	12%		
Other Members	39 696	900	0%	-38 796	-98%
In kind contributions (AFM)	172 746	172 746	3%		
Membership fees	42 980	47 710	1%	4 730	11%
Individuals	829 963	997 913	20%	167 950	20%
Volunteers	823 876	986 216	19%	162 340	20%
Donations	6 087	11 697	0%	5 610	92%
European Commission	1 358 072	1 504 585	30%	146 513	11%
DG Research	246 980	408 958	8%	161 979	66%
DG Health and consumers	1 042 230	1 004 106	20%	-38 124	-4%
DG Employment		25 135	0%	25 135	
EMA contributions (*)	68 862	66 385	1%	-2 477	-4%
National authorities	22 961	10 979	0%	-11 982	-52%
Grants from National authorities	22 961	10 979	0%	-11 982	-52%
Corporates	1 195 979	1 408 296	28%	212 317	18%
Pharma. and Biotech Companies	1 073 156	1 213 005	24%	139 849	13%
Other Health Sector Corporates	30 405	43 000	1%	12 595	41%
Outside Health Sector Corporates	92 418	152 291	3%	59 873	65%
Not for Profit Organisations	50 694	97 848	2%	47 154	93%
Pharma. and Biotech Found.					
Other Health Sector NPOs	50 694	97 848	2%	47 154	93%
Outside Health Sector NPOs					
Event Fees	216 429	47 375	1%	-169 054	-78%
Miscellaneous	71 222	176 534	3%	105 312	148%
Reimbursement	22 534	22 697	0%	163	1%
Others	48 688	153 836	3%	105 149	216%
Exceptional income	26 561	100 797	2%	74 236	279%
Honoraries	1 774			-1 774	
Others fees	571	30 603	1%	30 032	5255%
Financial assets	19 782	22 436	0%	2 655	13%
Sub-total	4 635 242	5 099 384	100%	464 142	10%
Recovery of provisions	116 956	3 272		-113 684	-97%
Report of non-used income					
Total Revenue	4 752 198	5 102 656		350 458	7%

Expenses	2014 Fin. Status	2015 Fin. Status	Ratio	Δ in euros	Δ in %
Staff	2 006 444	2 286 542	45%	280 098	14%
Wages and charges	1 933 063	2 051 528	41%	118 465	6%
Other salaries	64 229	208 355	94%	144 126	224%
Training and other costs	9 153	26 660	1%	17 507	191%
Volunteers	823 876	986 216	20%	162 340	20%
Representative and task forces	674 395	800 601	16%	126 206	19%
Project, office and translators	149 482	185 615	4%	36 134	24%
Travel and subsistence	424 575	557 718	11%	133 143	31%
Travels	355 713	466 536	9%	110 824	31%
In kind contribution (*)	68 862	91 182	2%	22 320	32%
Services	1 181 964	1 109 722	22%	-72 242	-6%
Fees	437 134	509 812	10%	72 679	17%
Event logistics and catering	365 963	201 946	4%	-164 017	-45%
Telecom and post	45 457	38 905	1%	-6 553	-14%
Other services	112 302	126 735	3%	14 433	13%
Purchase	92 910	92 580	2%	-330	0%
Office furniture	19 500	22 731	0%	3 231	17%
Amortisation	21 459	24 315	0%	2 856	13%
Communications, Publications	31 840	35 413	1%	3 573	11%
Other purchases	20 111	10 121	0%	-9 990	-50%
Miscellaneous	9 601	16 708	0%	7 107	74%
Financial expenses, Insurance, Tax	9 601	16 708	0%	7 107	74%
Exceptional expenses					
Sub-total	4 539 370	5 049 487	100%	510 117	11%
Contingency and loss provisions	12 993			-12 993	
Commitment on assigned income					
Total Expenses	4 552 363	5 049 487		497 124	11%
Result	199 835	53 169			

* covering travel/accommodation costs for EMA meetings

2015 Financial report comments

1. Assets and Liabilities

1.1. Assets

Current assets increased from 2 503 k€ to 3 846 k€.

	2014	2015	Difference	
Accounts receivable	1 647 949	2 467 201	819 252	50%
Liquid assets	806 268	1 285 153	478 886	59%
Prepaid expenses	48 420	93 612	45 192	93%
Total	2 502 637	3 845 967	1 343 329	54%

This 1 343 k€ increase comes from two factors:

- i. Operating Grant calendar: Usually, the Operating Grant from DG Health and Food Safety (DG SANTE) is signed and the first instalment is transferred before the end of the year preceding the start of the contract. In 2014, DG SANTE changed its processes and because of IT issues on the European Commission (EC) side, the signature and pre-financing of the 2015 grant (amounting to 770k€) was postponed to the start of 2015 hence the low amounts of “Accounts receivable” and “Liquid assets” in 2014.
In 2015, the signature and payment of the first instalment of the 2016 grant (amounting to 792k€) was processed in December 2015.
- ii. In 2015 EURORDIS signed two pluri-annual contracts, RD-ACTION and InnovCare.

As a general conclusion, the Assets increase is not caused by a structural change in EURORDIS' funding scheme but by the resolution of an IT issue at the European Commission. This position can be considered as back to normal.

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 (2 283 k€, 95%).

1.1.2. Liquid assets

Liquid assets are cash in the bank. The increase is roughly equivalent to the amount of the first instalment of the Operating Grant which was absent in 2014.

1.2. Liabilities

1.2.1. Association Funds

Association funds are the reserve which is the sum of all surplus / deficit since the creation of EURORDIS. At the end of 2014, the reserve amounted to 826k€. The reserve increased from 826 k€ to 879 k€, signifying a 6% increase.

1.2.2. Provisions

There was no need for provisions except the provision for retirement benefits which slightly varied in comparison to 2015.

1.2.3. Trade creditors

2014	173 k€	7%
2015	141 k€	4%
difference	- 32 k€	-2%

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 2015 was average compared to previous years.

1.2.4. Deferred income

2014	1 223 k€	48%
2015	2 593 k€	66%
difference	1 370 k€	+ 112%

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 was back to standard level (please see explanations 1.1.i.).

It is mainly composed of the pluri-annual EC projects (2 387 k€, 93%).

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 5 099 k€. This represents an increase of 464 k€ (+ 9%) compared to 2014.

This increase is due to a combination of several factors such as:

- Volunteers
- European Commission (EUPATI, InnovCare, PACE-ERN, WebRadr, etc.)
- Corporates (Rare Diseases International, RareConnect, ERTC)

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

	2014 Fin. Status		2015 Fin. Status		Difference	
<i>AFM</i>	807	17%	807	16%	0	0%
<i>Membership fees and grants</i>	83	2%	49	1%	-34	-70%
<i>Individuals(incl. Volunteers)</i>	830	18%	998	20%	168	17%
Patient Org. and Individuals	1 720	37%	1 854	36%	134	7%
European Commission	1 358	29%	1 505	30%	147	10%
National authorities	23	0%	11	0%	-12	-109%
<i>Pharma. and Biotech Companies</i>	1 073	23%	1 213	24%	140	12%
<i>Other Health Sector Corporates</i>	30	1%	43	1%	13	29%
Health Sector Corporates	1 104	24%	1 256	25%	152	12%
Other Corporates	92	2%	152	3%	60	39%
Foundations and NPOs	51	1%	98	2%	47	48%
Event fees	216	5%	47	1%	-169	-357%
Others	71	2%	177	3%	105	60%
Total	4 635	100%	5 099	100%	464	9%

Overall: 36% of resources are contributed by our members and individuals, 30% from European Commission and Member States, 25% by Health Sector Corporates, which is very stable compared to 2014.

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 25% and is contributed by 56 different companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (36%).

More details on revenues:

2.1. Patient Organisations and Individuals

2014	1 720 k€	37%
2015	1 854 k€	36%
difference	+ 134 k€	+ 7%

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

The Patient Organisations and Individuals section is our largest source of resources covering more than a third of our expenses. The larger part of it is in kind (volunteer contributions; office space kindly offered by AFM) and the rest mainly comes from the annual AFM-Téléthon grant.

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

2014	807 k€	17%
2015	807 k€	16%
Difference	0 k€	0%

The AFM-Téléthon grant enables us to maintain the independence of EURORDIS for its core activities while using this financial support as leverage to develop and diversify our sources of revenue.

In the framework of the 2014-2017 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, it is our best guarantee of independence with respect to public institutions and commercial companies.

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 addition to the money granted, the AFM-Téléthon provides us with office space for our Paris-based staff at the Rare Disease Platform. The valorisation of this in-kind contribution is based on current property prices that are updated every third year.

2.1.2. Individuals

2014	830 k€	18%
2015	998 k€	20%
Difference	+ 168 k€	+ 17%

We had some donations from individuals in 2015 but our main source of revenue from individuals remains in kind (volunteers).

The dedication of our volunteers continues to grow and diversify. In 2015, their work represented 8.8 full time equivalents (fte), a total amount of almost 15,000 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 and rich diversification of skills, background and expertise is something money cannot buy.

In 2015, they mainly worked on matters pertaining to public affairs (4 fte), orphan medicinal products (1.9 fte) and moderation of the rareconnect.org website (2.1 fte).

2.2. European Commission

2014	1 358 k€	29%
2015	1 505 k€	30%
Difference	+ 147 k€	+ 10%

In 2015, EURORDIS ran ten different EC grants from DG SANTE, DG RESEARCH, DG EMPLOYMENT and IMI-JU³.

In addition to

- the DG SANTE Operating Grant (which has been renewed every year since 2009);
- the DG SANTE, DG RESEARCH and IMI-JU Grants started in 2013 (EUCERD Joint Action, ECRIN, RD-CONNECT, EUPATI);
- the DG RESEARCH Grant started in 2014, RARE-Bestpractices;
- the IMI-JU Web-Radr project started in 2014,

EURORDIS has started collaboration with the following grants in 2015:

- the DG RESEARCH Grant Genetic Clinic of the Future,
- the DG SANTE Joint Action RD-ACTION,
- the IMI-JU2 Grant Adapt-Smart,
- the DG EMPLOYMENT Grant InnovCare.

EURORDIS also piloted the completion of a DG SANTE call for tender called PACE-ERN.

The DG SANTE Operating Grant is now embedded in a Framework Partnership Agreement which will last from 2015 to 2017. It means that the concept of a support of recurrent activities is guaranteed over those three years, however, the amount needs to be revaluated every year.

It was 770 k€ in 2015 and will be 792 k€ in 2016 which puts us on the safe side on that level for 2016.

2.3. National authorities

2014	23 k€	0%
2015	11 k€	0%
Difference	- 12 k€	- 109%

This line is a part of the co-funding of the EUCERD Joint Action by the “Caisse Nationale de Solidarité pour l’Autonomie” (25 k€ per year for 3 years). It funds 21% of the costs incurred in the context of the Work Package 6 “Specialised Social Services”, hence the variation of the amounts from one year to another.

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 (82%) is recorded under chapter “DG Research” and the contribution from EFPIA companies through a “cash pot” collected and redistributed by the coordinator (European Patient Forum - EPF) under the chapter “Other Health Sector NPOs”.

2.4. Health Sector Corporates

2014	1 104 k€	24%
2015	1 256 k€	25%
Difference	152 k€	+ 12%

This line comprises 51 pharmaceutical companies and 5 health sector consulting firms.

The level of contribution from the Health Sector Corporations followed the overall budget increase.

The increase comes from:

- the funding of Rare Diseases International
- more funds on RareConnect
- more members at the EURORDIS Round Table of Companies

Funds raised in the context of the EURORDIS Membership Meeting and the EURORDIS Black Pearl Event remained constant.

The five largest donors are, in descending order: 1st SHIRE, 2nd CELGENE, 3rd PFIZER, 4th GSK, 5th BIOMARIN, GENZYME and NOVARTIS.

The percentage of each of the 56 companies in the overall budget comprises between 0.04% and 1.9%.

The two guarantees of our independence with this sector are (1) the limitation of the overall amount compared to income of Patient Organisation provenance and (2) the diversity and limited impact of each single donor.

2.5. Other Corporates

2014	92 k€	2%
2015	152 k€	3%
difference	+ 60 k€	+39%

This funding has been proceeded through in kind services from

- DLA Piper UK LLP for legal services,
- Burson-Marsteller and Multiburo, two companies based in Brussels,
- Publicis Lifebrand, Media Planet and Enfin Bref Productions

as well as a contribution from Ares Life Sciences, an investment partnership.

2.6. Foundations and Not for Profit Organisations (NPOs)

2014	51 k€	1%
2015	98 k€	2%
difference	+ 47 k€	+ 48%

Grants came from Health Sector organisations:

- the Russian organisation AIPM (Association of International Pharmaceutical Manufacturers),
- the US based organisation “Everylife Foundation for Rare Diseases”

- the European Federation of Pharmaceutical Industries and Associations (EFPIA) in the context of the EUPATI project co-funding.

2.7. Event Fees

2014	216 k€	5%
2015	47 k€	1%
difference	-159 k€	- 357%

In absence of ECRD, Event fees consist of EURORDIS Black Pearl Gala Dinner seats and EURORDIS Membership Meeting registration fees in Madrid.

3. Expenses

Operating expenses, including in-kind contributions and excluding provisions, amounted to 5 049 k€, which shows an increase of 10% compared to 2014.

The increase is due to the development of:

- Rare Disease Day (new website, +53% events registered, +85% stories on the 5 continents in more than 80 countries with 10 new countries participating)

and the start of:

- Rare Diseases International
- Rare Barometer
- Web-Radr
- EUPATI training sessions

The breakdown of EURORDIS expenses is as follows
(in thousands of euros, provisions excluded⁴)

Expenses	2014 Fin. Status		2015 Fin. Status		Difference	
Staff costs	2 006	44%	2 287	45%	280	12%
Volunteers	824	18%	986	20%	162	16%
Travel and subsistence	425	9%	558	11%	133	24%
Services	1 182	26%	1 110	22%	-72	-7%
Others	103	2%	109	2%	7	6%
Total	4 539	100%	5 049	100%	510	10%

⁴ 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

2014	2 006 k€	44%
2015	2 287 k€	45%
difference	+ 280 k€	+ 12%

The number of FTE⁵ was 32 in 2015.

10 new positions were created in 2015 (in order of appearance):

- Online Community Manager dedicated to WebRadr, Carmen Lasheras, Barcelona
- Rare Barometer (surveys) Leader, Sandra Courbier, Paris
- Patient Engagement Manager, Elisa Ferrer, Barcelona
- Public Affairs Junior Manager, Jennifer Steele, Brussels
- Research Infrastructures Project Manager, Virginie Bros-Facer, Paris
- Web Technology Manager, Laura Amorini, Barcelona
- Rare Connect Manager, Outreach, Tihana Khreso, Zagreb
- Rare Connect Manager, Web Content, Dubravka Franz, Zagreb
- Rare Connect Manager, Outreach, Sandra Pavlovich, Belgrade
- Rare Connect Manager, Web Content, Igor Ban, Belgrade

Altogether, at the end of the year, we were 41 staff members in 7 countries comprising:

Paris: 24 permanent employees, one office volunteer;

Brussels: 3 permanent employees, one limited contract;

Barcelona: 6 permanent employees;

Geneva: 1 permanent employee;

Zagreb: 2 permanent employees;

Belgrade: 2 permanent employees;

London: one staff seconded to the European Medicines Agency.

3.2. Travel and subsistence

2014	425 k€	9%
2015	558 k€	11%
difference	133 k€	24%

The increase of travel and subsistence costs mainly incurred in the context of:

- EUPATI project, 2 face to face sessions
- More fellowships (EURORDIS membership meeting, European Federations)
- More travels in the context of RareConnect and several other projects

⁵ 1 full time equivalent = 1 people on a full time position during one year

3.3. Services

2014	1 182 k€	26%
2015	1 110 k€	22%
Difference	- 72 k€	- 7%

As expected, we had less costs on the “Services” section because of the absence of ECRD in 2015, hence a minus 164 k€ on “Event logistics and catering”. It was partially counterbalanced by an increase of the in kind contribution donations in the context of the Rare Disease Day.

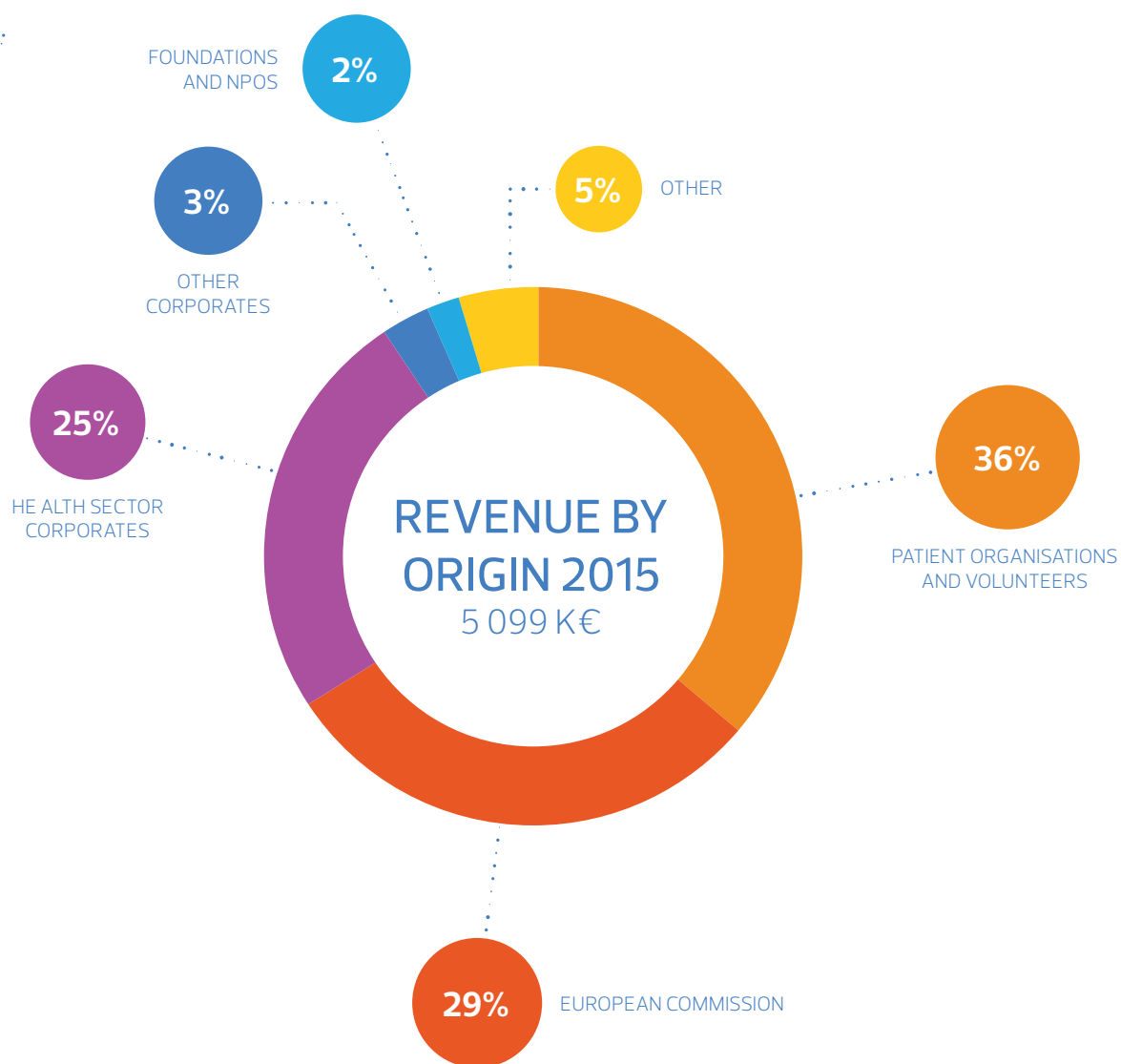
4. Result

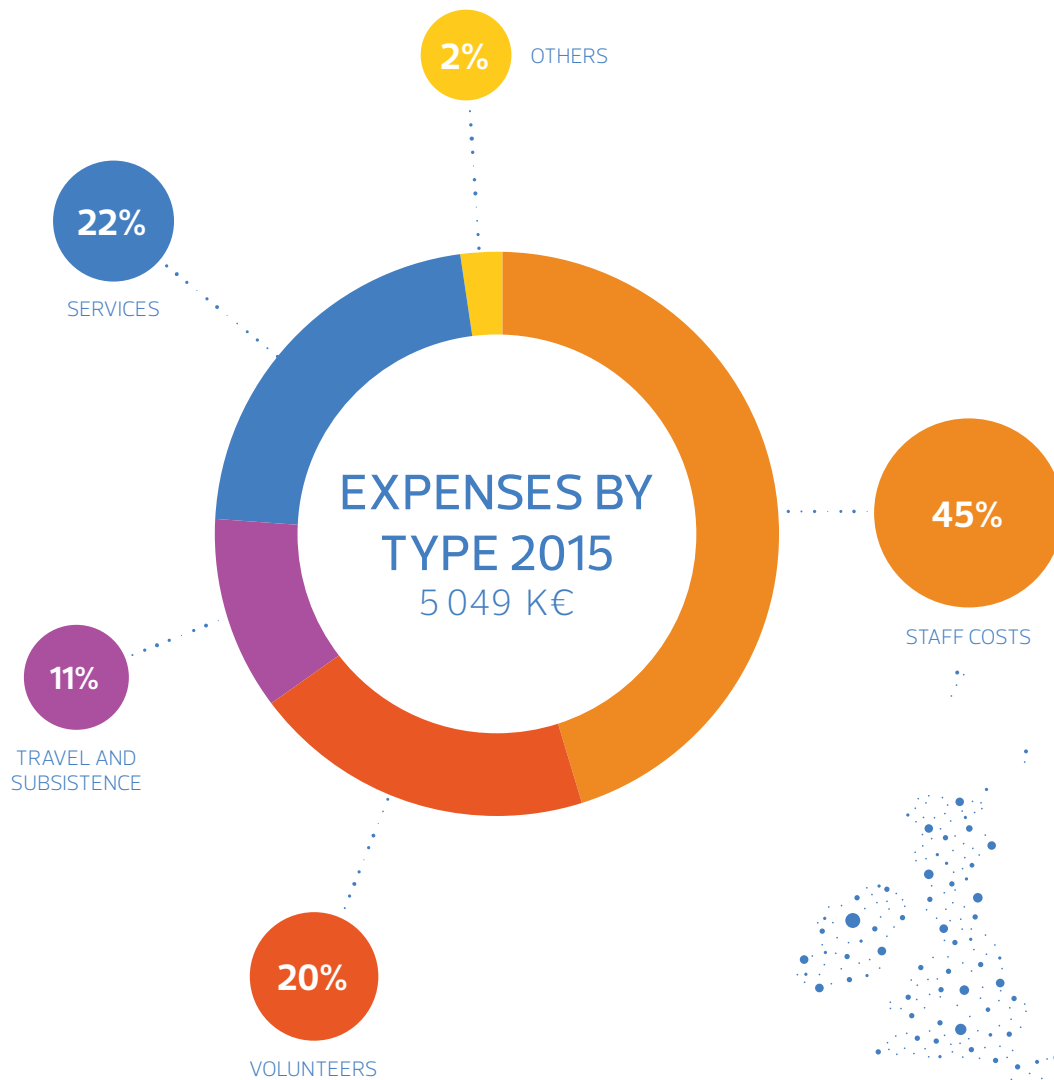
The surplus amounted to 53 169 euros, we suggest to allocate it to the reserve which will amount to 878 740 euros.

If we refer to EURORDIS’ policy, which is to have reserves representing from 3 to 6 months of low-level activity, the situation is safe enough. However, EURORDIS would benefit from a higher level of reserve.

REVENUE & EXPENSES

2015





Glossary

AFM-Téléthon: Association Française contre les Myopathies. Created and organises the French Téléthon.

EC: European Commission

DG SANTE: Health and Food Safety Directorate-General of EC

Ongoing Projects:

- *EURORDIS FY2015* (2015 Operating Grant)
 - o from 01-Jan-15 to 31-Dec-15
 - o EURORDIS sole beneficiary
- *EJA* (EUCERD Joint Action: Working for Rare Diseases)
 - o from 01-Mar-12 to 31-Aug-15
 - o EURORDIS co-beneficiary
- *RD-ACTION* (Data and Policies for Rare Diseases)
 - o from 01-Jun-15 to 31-May-18
 - o EURORDIS co-beneficiary

DG RESEARCH: Research and Innovation Directorate-General of EC

Ongoing Projects:

- *ECRIN IA* (European Clinical Research Infrastructures Network)
 - o from 01-Jan-12 to 31-Dec-15
 - o EURORDIS co-beneficiary
- *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
- *RARE-Bestpractices* (A platform for sharing best practices for the management of rare diseases)
 - o from 01-Jan-13 to 31-Dec-16
 - 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

- *EUPATI* (European Patients' Academy on Therapeutic Innovation)
 - o from 01-Jan-12 to 31-Dec-16
 - o EURORDIS co-beneficiary
- *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.

7 of them already taken place

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 eighth will take place in May 2016 in Edinburgh.

EMA: European Medicines Agency

EUCERD: European Union Committee of Experts on Rare Diseases (now known as Commission Expert Group on Rare Diseases)



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Plateforme Maladies Rares
96, rue Didot
75014 Paris
France
Tel: +33 (0) 1 56 53 52 10
eurordis@eurordis.org

BRUSSELS OFFICE | EURORDIS

Avenue Louise 149/24
1050 Brussels
Belgium
Tel: + 32 (0) 2 535 75 26

BARCELONA OFFICE | EURORDIS

Recinte Modernista Sant Pau
Pabellón de Santa Apolonia
Calle Sant Antoni M^a Claret 167
08041 Barcelona, Spain



eurordis.org

