

EURORDIS
FINANCIAL
REPORT 2016



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, 2016

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STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2016

In compliance with the assignment entrusted to us by the Members' meeting, we hereby report to you, for the year ended December 31, 2016, 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, 2016 and the results of its operations for the year then ended, in accordance with French accounting regulations.

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 17, 2017

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.



EURORDIS 2016 Financial Report

(Assets and Liabilities)

Assets	2015	2016	Ratio	Difference
FIXED ASSETS				
Intangible assets	2 461	1 440	-41%	-1 021
Tangible assets	60 529	60 485	0%	-45
Financial assets	14 649	18 649	27%	4 000
TOTAL	77 639	80 574	4%	2 934
CURRENT ASSETS				
Account receivable due within one year	1 900 152	1 386 056	-27%	-514 096
Account receivable due after one year	567 049	543 494	-4%	-23 555
Liquid assets	1 285 153	1 183 079	-8%	-102 074
Prepaid expenses	93 612	104 944	12%	11 332
TOTAL	3 845 967	3 217 574	-16%	-628 393
TOTAL ASSETS	3 923 606	3 298 148	-16%	-625 458

Liabilities	2015	2016	Ratio	Difference
ASSOCIATION FUNDS				
Reserve	825 571	878 740	6%	53 169
Profit & loss for the year	53 169	-89 417	-268%	-142 586
Subsidies of investment	0	0	NA	0
TOTAL	878 740	789 323	-10%	-89 417
Provisions for risk and charges	34 535	159 969	363%	125 434
Dedicated funds on grants	0	0	NA	0
DEBTS				
Bank loans and overdraft	0	0	NA	0
Trade creditors	140 739	155 653	11%	14 913
Tax payable and social liabilities	276 248	262 276	-5%	-13 972
Other debts	0	0	NA	0
Deferred income within one year	1 989 318	1 361 391	-32%	-627 928
Deferred income after one year	604 026	569 537	-6%	-34 489
TOTAL	3 044 866	2 508 825	-18%	-536 041
TOTAL LIABILITIES	3 923 606	3 298 148	-16%	-625 458

2016 Financial Status vs. 2015 Financial Status

(P Profit and Loss including in kind contributions)

Revenue	2015	2016	Ratio	Δ in euros	Δ in %
Patient Organisations	855 856	950 467	15%	94 611	11%
Financial contributions	635 400	689 446	11%		
AFM Telethon	634 500	634 500	10%		
Other Members	900	54 946	1%	54 046	6005%
In kind contributions (AFM)	172 746	212 746	3%	40 000	23%
Membership fees	47 710	48 275	1%	565	1%
Individuals	997 913	1 126 296	18%	128 383	13%
Volunteers	986 216	1 113 885	18%	127 670	13%
Donations	11 697	12 411	0%	714	6%
European Commission	1 504 585	1 768 718	28%	264 134	18%
DG Research	408 958	421 710	7%	12 751	3%
DG Health and food safety	1 004 106	1 078 738	17%	74 632	7%
DG Employment	25 135	199 985	3%	174 850	696%
EMA contributions (*)	66 385	68 285	1%	1 900	3%
National authorities	10 979	37 268	1%	26 289	239%
Grants from National authorities	10 979	37 268	1%	26 289	239%
Corporates	1 408 296	1 743 574	28%	335 278	24%
Pharma. and Biotech Companies	1 213 005	1 443 631	23%	230 626	19%
Other Health Sector Corporates	43 000	90 812	1%	47 812	111%
Outside Health Sector Corporates	152 291	209 131	3%	56 840	37%
Not for Profit Organisations	97 848	137 780	2%	39 932	41%
Pharma. and Biotech Found.					
Other Health Sector NPOs	97 848	132 780	2%	34 932	36%
Outside Health Sector NPOs		5 000	0%	5 000	
Event Fees	47 375	252 316	4%	204 941	433%
Miscellaneous	176 534	295 765	5%	119 231	68%
Reimbursements	22 697	244 732	4%	222 034	978%
Others	153 836	51 033	1%	-102 803	-67%
Sub-total	5 099 384	6 312 183	100%	1 212 799	24%
Recovery of provisions	3 272			-3 272	
Report of unused income					
Total Revenue	5 102 656	6 312 183		1 209 527	24%

Expenses	2015	2016	Ratio	Δ in euros	Δ in %
Staff	2 286 542	2 647 385	42%	360 842	16%
Wages and charges	2 051 528	2 421 686	39%	370 158	18%
Other salaries	208 355	207 742	3%	-612	0%
Training and other costs	26 660	17 957	0%	-8 703	-33%
Volunteers	986 216	1 113 885	18%	127 670	13%
Representatives and task forces	800 601	900 427	14%	99 827	12%
Project, office and translators	185 615	213 458	3%	27 843	15%
Travel and subsistence	557 718	697 905	11%	140 187	25%
Travels	466 536	615 190	10%	148 654	32%
In kind contributions (*)	91 182	82 715	1%	-8 467	-9%
Services	1 109 722	1 682 567	27%	572 844	52%
Fees	509 812	631 475	10%	121 663	24%
Event logistics and catering	201 946	594 025	9%	392 078	194%
Telecom and post	38 905	33 954	1%	-4 950	-13%
Rent	232 324	268 126	4%	35 802	15%
Other services	126 735	154 987	2%	28 251	22%
Purchases	92 580	96 300	2%	3 720	4%
Office furniture	22 731	25 264	0%	2 534	11%
Depreciation	24 315	29 136	0%	4 821	20%
Communications, Publications	35 413	29 022	0%	-6 391	-18%
Other purchases	10 121	12 878	0%	2 756	27%
Miscellaneous	16 708	38 125	1%	21 417	128%
Financial expenses, Insurance, Tax	16 708	38 125	1%	21 417	128%
Exceptional expenses					
Sub-total	5 049 487	6 276 167	100%	1 226 680	24%
Contingency and loss provisions		125 434	2%	125 434	
Commitment on assigned income					
Total Expenses	5 049 487	6 401 601		1 352 114	27%
Result	53 169	-89 417			

(*) covering travel/accommodation costs for EMA meetings

2016 Financial report comments

Introduction

EURORDIS revenues in 2016 amounted to 6 312 k€ including in-kind contributions, an increase of 1 213 k€ (+19% compared to 2015) which was needed in order to cover the organic growth of our activities and the European Conference on Rare Diseases in Edinburgh. However we fell short by 89 417 € to break even.

This is our first deficit since 2001. The Non-Profit sector budget challenges and the risk of a possible deficit were presented at the Annual General Assembly of 2016. These risks were mitigated during the year, notably by reducing the exposure of EURORDIS to long-term programmes.

The initiative for the European Year for Rare Diseases 2019 has been cancelled and efforts concentrated on policy actions. The RareConnect platform is being transferred to SickKids Hospital in Toronto, Canada. Our partnership with SickKids will enable RareConnect to reach more undiagnosed patients and access new public funds.

After the allocation of the 89 k€ deficit to the reserves, they will then amount to 789 k€, representing less than 20% of one-year operations. These reserves are now at a low level compared to our annual budget. Therefore, we need to minimize the risk of another deficit and seek to increase our reserves through positive results.

The budget 2017 is more conservative in order to have a balanced budget: expenses have been reduced by 446 k€ and the challenge on the Non-Profit sector has been significantly lessened.

1. Assets and Liabilities

1.1. Assets

Current assets decreased from 3 846 k€ to 3 218 k€.

	2015	2016	Difference	
Accounts receivable	2 467 201	1 929 550	-537 651	-22%
Liquid assets	1 285 153	1 183 079	-102 074	-8%
Prepaid expenses	93 612	104 944	11 332	12%
Total	3 845 967	3 217 574	-628 393	-16%

This 628 k€ decrease mainly comes from the fact that we had no significant pluri-annual project signed in 2016. The pluri-annual contract which compensated the consumption of the existing projects (INNOVCare, EUPATI, RD-ACTION = 624 k€ at the end of 2016) was the Joint Action on Rare Cancers (which account receivables amounted to 42 k€ at the end of 2016).

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 (1 701 k€, 90%).

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 reserve which is the sum of all surplus / deficit since the creation of EURORDIS. At the end of 2015, the reserve amounted to 879k€. The reserve decreased from 879 k€ to 789 k€, signifying an 8% decrease.

1.2.2. Provisions

	2015	2016		
		Recoveries	New provisions	Balance
Provisions for charges	0	0	24 350	24 350
Provisions for risks	0	0	92 000	92 000
Provision for retirement benefits	34 535	0	9 084	43 619
Provisions for risks and charges	34 535	0	125 434	159 969

We have made

- a provision for charges related to employee departures in 2017,
- a provision for risks related to employee departures in 2016,
- a provision for retirement benefits

1.2.3. Trade creditors

2015	141 k€	4%
2016	156 k€	5%
difference	+ 15 k€	+ 11%

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 2016 was average compared to previous years.

1.2.4. Deferred income

2015	2 593 k€	66%
2016	1 931 k€	59%
Difference	- 662 k€	- 26%

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 6 312 k€. This represents an increase of 1 213 k€ (+ 19%) compared to 2015.

The bulk of the increase is due to:

- The ECRD 2016 Edinburgh related EC and town grants and event fees (+354 k€);
- Funds from Health Corporates for new activities such as the Multi-Stakeholder Symposium, Rare Diseases International and Rare Barometer (+215 k€);
- More funds from EC in the context of the development of the activity of the project INNOVCare (180 k€);
- Increase of the participation of volunteers (+128 k€).

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

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

	2015		2016		Difference	
<i>AFM</i>	807	16%	847	13%	40	5%
<i>Membership fees and grants</i>	49	1%	103	2%	55	112%
<i>Volunteers</i>	998	20%	1 126	18%	128	13%
Patient Org. and Volunteers	1 854	36%	2 077	33%	223	12%
European Commission	1 505	30%	1 769	28%	264	18%
National authorities	11	0%	37	1%	26	239%
<i>Pharma. and Biotech Companies</i>	1 213	24%	1 444	23%	231	19%
<i>Other Health Sector Corporates</i>	43	1%	91	1%	48	111%
Health Sector Corporates	1 256	25%	1 534	24%	278	22%
Other Corporates	152	3%	209	3%	57	37%
Foundations and NPOs	98	2%	138	2%	40	41%
Event fees	47	1%	252	4%	205	433%
Others	177	3%	296	5%	119	68%
Total	5 099	100%	6 312	100%	1 213	24%

Overall: 33% of revenue are contributed by our members and individuals, 28% from European Commission and Member States, 24% by Health Sector Corporates, which is stable compared to 2015.

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 24% and is contributed by 59 different companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (33%).

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

More details on revenues:

2.1. Patient Organisations and Individuals

2015	1 854 k€	36%
2016	2 077 k€	33%
difference	+ 223 k€	+ 12%

The Patient Organisations and Individuals section is our largest source of revenue covering a third of our expenses. The larger part of it is in kind (volunteer contributions; office space and Rare Disease Day 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)

2015	807 k€	16%
2016	847 k€	13%
Difference	+ 40 k€	+ 5%

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.

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 2015-2017 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.

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 is based on current property prices that are updated every third year. In 2016, AFM-Téléthon also granted us with an in kind Rare Disease Day video, hence the 40k€ difference.

2.1.2. Individuals

2015	998 k€	20%
2016	1 126 k€	18%
Difference	+ 128 k€	+ 13%

We had some donations from individuals in 2016 but our main source of revenue from individuals remains in kind (volunteers).

The dedication of our volunteers continues to grow and diversify. In 2016, their work represented 9.7 full time equivalents (fte), a total amount of 16,700 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 2016, they mainly worked on matters pertaining to public affairs (4 fte), orphan medicinal products (1.7 fte) and moderation of the rareconnect.org website (2.2 fte).

2.2. European Commission

2015	1 505 k€	30%
2016	1 769 k€	28%
Difference	+ 264 k€	+ 18%

In 2016, 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 RESEARCH and IMI-JU Grants started in 2013 (RD-CONNECT, EUPATI);
- the DG RESEARCH Grant started in 2013, RARE-Bestpractices;
- the IMI-JU Web-Radr project started in 2014,
- the projects started in 2016:
 - o the DG RESEARCH Grant Genetic Clinic of the Future,
 - o the DG SANTE Joint Action RD-ACTION,
 - o the IMI-JU2 Grant Adapt-Smart,
 - o the DG EMPLOYMENT Grant INNOVCare.

EURORDIS has been involved in a DG SANTE Joint Action on Rare Cancers.

The DG SANTE Operating Grant is embedded in a Framework Partnership Agreement (FPA) which lasts 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, 792 k€ in 2016 and 2017.

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".

2.3. National authorities

2015	11 k€	0%
2016	37 k€	1%
Difference	+ 26 k€	+ 239%

In 2015, this line was 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). In 2016 it was the grant from the city of Edinburgh in the context of the ECRD 2016, Edinburgh.

2.4. Health Sector Corporates

2015	1 256 k€	25%
2016	1 534 k€	24%
Difference	+ 278 k€	+ 22%

This line comprises 53 pharmaceutical companies and 6 health sector consulting firms.

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

The increase comes from:

- the creation of the Multi-Stakeholder Symposium
- increase of international initiatives such as Rare Diseases International and Rare Barometer
- more support in the context of ECRD 2016, Edinburgh

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

The percentage of each of the 59 companies in the overall budget comprises between 0.03% 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 origin and (2) the diversity and limited impact of each single donor.

2.5. Other Corporates

2015	152 k€	3%
2016	209 k€	3%
difference	+ 57 k€	+ 37%

This funding comes from in kind services:

- DLA Piper UK LLP for legal services,
- Burson Marsteller, Media Planet, Publicis Lifebrand and Redmond Consulting on Communications,
- Google, Interactius, Trommons, Translators without borders and Individual volunteer translators on RareConnect

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

2.6. Foundations and Not for Profit Organisations (NPOs)

2015	98 k€	2%
2016	138 k€	2%
difference	+ 40 k€	+ 41%

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,
- Kindness for Kids, a German based foundation which aims at increasing the quality of life of children with rare diseases.

2.7. Event Fees

2015	47 k€	1%
2016	252 k€	4%
difference	+ 205 k€	+ 433%

The bulk of this increase comes from ECRD2106, Edinburgh (172 k€) and the Multi-Stakeholders Symposium (33 k€).

3. Expenses

Operating expenses, including in-kind contributions and excluding provisions, amounted to 6 276 k€, which shows an increase of 24% compared to 2015.

The increase is due to the development of:

- ECRD2016, Edinburgh (+ 338 k€),
- RareConnect (Google AdWords, recruitments, developments, + 247 k€),
- INNOVCare, a project working on the social aspects of the Rare Disease condition (+ 204 k€),
- Rare Diseases International (more staff and travels, + 119 k€),
- European Reference Networks (more staff and volunteers, + 105 k€),
- The Multi-Stakeholder Symposium (+ 103 k€)

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

Expenses	2 015		2 016		Difference	
Staff costs	2 287	45%	2 647	42%	361	16%
Volunteers	986	20%	1 114	18%	128	13%
Travel and subsistence	558	11%	698	11%	140	25%
Services	1 110	22%	1 683	27%	573	52%
Others	109	2%	134	2%	25	23%
Total	5 049	100%	6 276	100%	1 227	24%

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

2015	2 287 k€	45%
2016	2 647 k€	42%
difference	+ 361 k€	+ 16%

The number of FTE⁵ was 40 in 2016.

As of end of year, the team was composed by 41 staff members dispatched in 8 countries.

The main office is in France (25), followed by Spain (6), Belgium (4), Serbia (2), Switzerland (1), Germany (1), Croatia (1) and the United Kingdom of Great Britain and Northern Ireland (1).

4 new positions were created in 2016 (in order of appearance):

- Patient Advocacy Groups Manager, Lenja Wiehe, Paris
- Social Policy Senior Advisor, Annette Dumas, Brussels
- Junior Events Manager, Emilie Zingg, Paris
- Research Executive Rare Barometer, Erwan Berjonneau, Paris

3 positions were stopped

- Online Patient Community Manager, Carmen Lasheras, Barcelona
- Online Patient Community Manager, Dubravka Franz, Zagreb
- Fundraising Manager, Lenja Wiehe, Paris

And we hired Clara Hervas to replace Jennifer Steele in the Public Affairs Junior Manager position in Brussels.

Also, in Barcelona, Iolanda Arbiol from the “Plataforma Malalties Minoritàries” was hired. In this context EURORDIS acts as an administrative shelter as it does for Maria Mavris who actually works for the European Medicine Agency but is still on our payroll. Iolanda and Maria’s salaries are counted in the Financial Report’s figures but are not part of the staff counted in FTE and in year-end counting.

3.2. Travel and subsistence

2015	558 k€	11%
2016	698 k€	11%
difference	+ 140 k€	+ 25%

- ECRD 2016, Edinburgh (+ 68 k€),
- Rare Diseases International (+ 40 k€),
- INNOVCare (+ 37 k€),
- Multi-Stakeholder Symposium (+ 22 k€)

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

3.3. Services

2015	1 110 k€	22%
2016	1 683 k€	27%
Difference	+ 573 k€	+ 52%

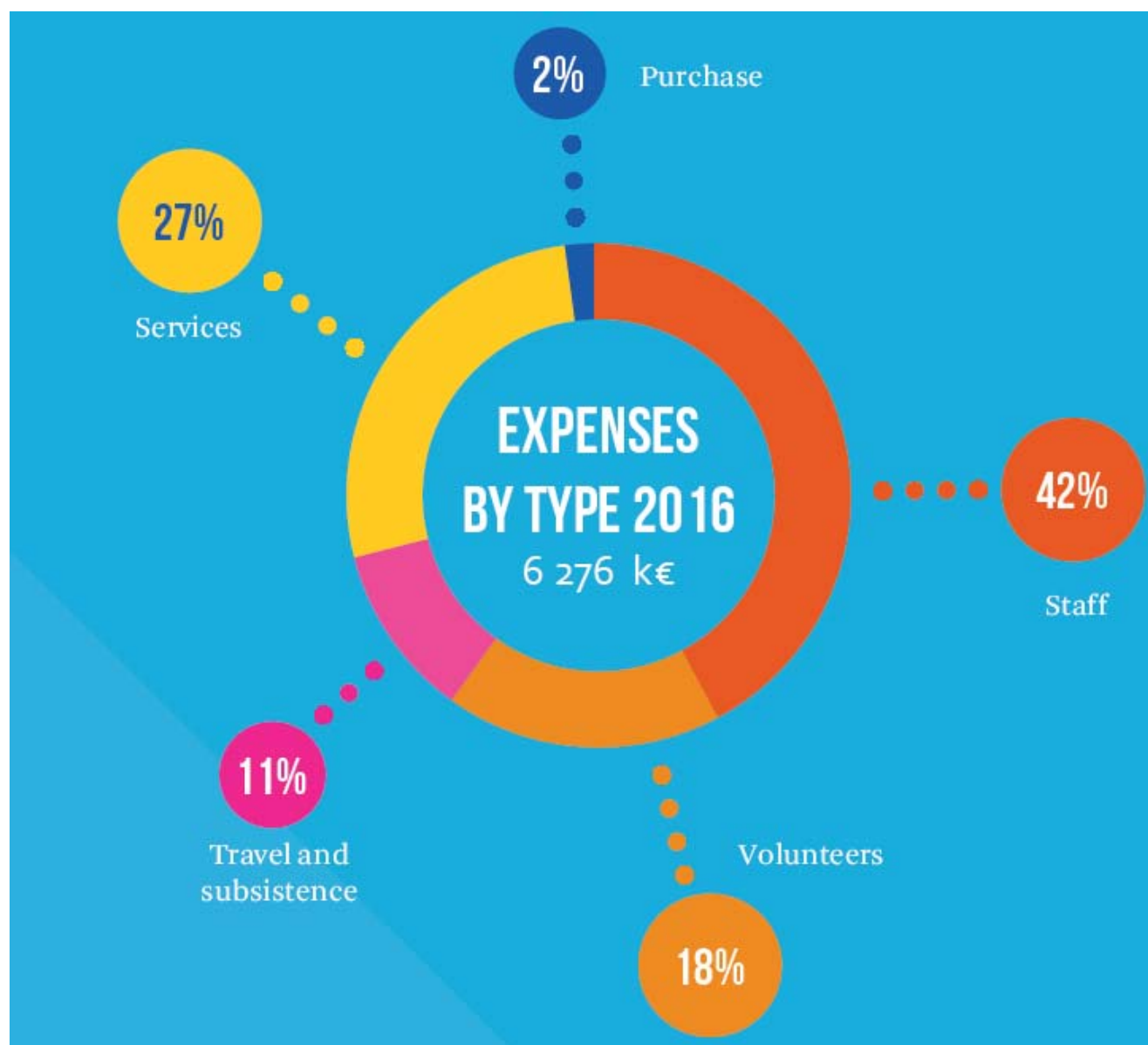
- ECRD2016, Edinburgh (+ 270 k€),
- RareConnect (+ 136 k€ out of which 109 k€ from Google AdWords)
- Multi-Stakeholder Symposium (+ 76 k€)

4. Result

The deficit amounted to 89 417 euros, we suggest allocating it to the reserve which will amount to 789 323 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 not safe enough. EURORDIS would need to have a higher level of reserve.





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 FY2016** (2016 Operating Grant)
 - o from 01-Jan-16 to 31-Dec-16
 - 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
- *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.

8 of them have already taken place

ECRD 2016, in Edinburgh (co-organised by EURORDIS and DIA)

ECRD 2014, in Berlin (co-organised by EURORDIS and DIA)

ECRD 2012, in Brussels (co-organised by EURORDIS and DIA)

ECRD 2010, in Krakow (organised by EURORDIS and partners)

ECRD 2007, in Lisbon (organised by EURORDIS and partners)

ECRD 2005, in Luxembourg (organised EURORDIS and partners)

ECRD 2003, in Evry (France, organised by Alliance Maladies Rares)

ECRD 2001, in Copenhagen (organised by Rare Disorders Denmark)

The ninth will take place in May 2018 in Vienna.

EMA: European Medicines Agency



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