



EURORDIS
Rare Diseases Europe

European
Organisation
for Rare Diseases

FINANCIAL REPORT 2013

|| 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, 2013

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STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2013

In compliance with the assignment entrusted to us by the Members' meeting, we hereby report to you, for the year ended December 31, 2013, 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, 2013 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, April 24, 2014

The Statutory Auditor

Deloitte & Associés

Philippe GUAY

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.

Forewords of the Treasurer

Patients' involvement in public affairs has seen an annual intensification at both national and international levels. The financial impact of this involvement can be measured on the "Volunteers" budget line which has steadily increased over the past 4 years. During this period, the "Volunteers" line has almost doubled, with an increase of 83%.

The growth in patient involvement is also visible through a greater participation in EU funded projects: EURORDIS is currently leading or participating in seven projects with three different EU bodies (DG Sanco; DG Research; IMI-JU).

The widening of EURORDIS' membership base (with currently 624 members in 58 countries), the increase in the number of countries participating in Rare Disease Day (up to 84 countries in 2014), as well as the rise in EURORDIS' patient representatives appointed to expert committees both at the regulatory and political levels, are all elements demonstrating the organic growth of the organisation and reflect the positive resonance that EURORDIS' activities have within the Rare Disease community. Up to now, this growth has been sustained through a good level of liquidities and accounts receivable. However, it is also increasingly challenging to balance the budget.

We hope that in 2014, EURORDIS will still be able to accommodate the expansion of its activities with the overarching goal to help addressing the increasing needs of the rare disease patients' community, the growing complexity and heterogeneity of patients' legitimate expectations to be covered within financially challenged European societies.

Assets	2012	2013	Ratio	Difference
FIXED ASSETS				
Intangible assets	725	206	-72%	-519
Tangible assets	70 415	59 800	-15%	-10 615
Financial assets	4 249	4 249	0%	0
TOTAL	75 389	64 255	-15%	-11 134
CURRENT ASSETS				
Account receivable due within one year	1 081 098	1 273 897	18%	192 799
Account receivable due after one year	867 050	638 328	NA	-228 722
Liquid assets	1 388 594	1 433 419	3%	44 825
Prepaid expenses	108 000	58 940	-45%	-49 061
TOTAL	3 444 742	3 404 584	-1%	-40 158
TOTAL ASSETS	3 520 132	3 468 839	-1%	-51 293

Liabilities	2012	2013	Ratio	Difference
ASSOCIATION FUNDS				
Reserve	570 789	633 193	11%	62 404
Profit & loss for the year	62 404	17 357	-72%	-45 047
Subsidies of investment	0	0	NA	0
TOTAL	633 193	650 550	3%	17 357
Provisions for risk and charges	161 929	116 956	-28%	-44 973
Dedicated funds on grants	0	0	NA	0
DEBTS				
Bank loans and overdraft	0	0	NA	0
Trade creditors	120 452	155 045	29%	34 593
Tax payable and social liabilities	187 090	269 154	44%	82 064
Other debts	56 307	29 364	-48%	-26 943
Deferred income within one year	1 311 531	1 419 428	8%	107 896
Deferred income after one year	1 049 630	828 343	-21%	-221 287
TOTAL	2 886 939	2 818 289	-2%	-68 650
TOTAL LIABILITIES	3 520 132	3 468 839	-1%	-51 293

2013 Financial Status vs.

2012 Financial Status

(Profit and Loss including in kind contributions)

Revenue	2012 Fin. Status	2013 Fin. Status	Ratio	Δ in euros	Δ in %
Patient Organisations	919 776	839 604	21%	-80 173	-9%
AFM Telethon Grants	705 000	634 500	16%	-70 500	-10%
In kind contributions (AFM)	181 886	172 746	4%	-9 140	-5%
Membership fees and grants	32 890	32 358	1%	-533	-2%
Volunteers	588 629	691 697	17%	103 068	18%
Representative and task forces	525 444	567 091	14%	41 647	8%
Project, office and translators	63 185	124 606	3%	61 421	97%
European Commission	926 760	1 101 444	28%	174 684	19%
DG Research	34 502	221 422	6%	186 921	542%
DG Health and consumers	848 867	831 576	21%	-17 291	-2%
EMA in kind contributions (*)	43 391	48 445	1%	5 054	12%
National authorities	27 117	16 061	0%	-11 056	-41%
Secunded Staff (INSERM)				-11 056	-41%
National officials in EC projects				-1 748	0%
Grants from National authorities	27 117	16 061	0%	19 797	2%
Corporates	1 078 447	1 076 699	27%	-2 748	0%
Pharma. and Biotech Companies	987 390	1 007 187	25%	-2 748	0%
Other Health Sector Corporates	22 500	18 000	0%	-4 500	-20%
Outside Health Sector Corporates	68 557	51 512	1%	-17 045	-25%
Not for Profit Organisations	175 675	183 823	5%	8 148	5%
Pharma. and Biotech Found.				-26 852	-15%
Other Health Sector NPOs	175 675	148 823	4%	35 000	
Outside Health Sector NPOs		35 000	1%	-5 372	-25%
Event Fees	277 562	34 104	1%	-243 458	-88%
Miscellaneous	44 095	51 859	1%	7 764	18%
Reimbursement	21 914	16 542	0%	-5 372	-25%
Others	22 181	35 317	1%	13 136	59%
Sub-total	4 038 061	3 995 290	100%	-42 771	-1%
Recovery of provisions	2 917	44 973		42 056	1442%
Total Revenue	4 040 978	4 040 263		-715	0%

Expenses	2012 Fin. Status	2013 Fin. Status	Ratio	Δ in euros	Δ in %
Staff	1 709 395	1 984 262	49%	274 867	16%
Wages and charges	1 598 147	1 906 260	47%	308 113	19%
Other salaries	63 616	64 243	2%	627	1%
Training and other costs	47 631	13 759	0%	-33 873	-71%
Volunteers	588 629	691 697	17%	103 068	18%
Representative and task forces	525 444	567 091	14%	41 647	8%
Project, office and translators	63 185	124 606	3%	61 421	97%
Travel and subsistence	402 980	443 631	11%	40 650	10%
Travels	357 414	395 185	10%	37 771	11%
In kind contribution (*)	45 566	48 445	1%	2 879	6%
Services	1 026 148	807 936	20%	-218 212	-21%
Fees	323 479	275 691	7%	-47 788	-15%
Event logistics and catering	273 657	179 721	4%	-93 937	-34%
Projects' partners	59 093			-59 093	
Telecom and post	46 118	44 777	1%	-1 341	-3%
Rent	213 174	218 702	5%	5 528	3%
Other services	110 627	89 045	2%	-21 581	-20%
Purchase	100 857	83 936	2%	-16 921	-17%
Office furniture	19 404	13 785	0%	-5 619	-29%
Amortization	27 064	23 290	1%	-3 774	-14%
Communications, Publications	51 806	39 641	1%	-12 165	-23%
Other purchases	2 583	7 219	0%	4 636	179%
Miscellaneous	14 780	11 445	0%	-3 335	-23%
Financial expenses, Insurance, Tax	14 697	11 445	0%	-3 253	-22%
Exceptional expenses	82			-82	
Sub-total	3 842 788	4 022 906	100%	180 118	5%
Contingency and loss provisions	135 786			-135 786	
Commitment on assigned income					
Total Expenses	3 978 574	4 022 906		44 332	1%
Result	62 404	17 357			

* covering travel/accommodation costs for EMA meetings

2013 Financial report comments

1. Assets and Liabilities

1.1. Assets

Current assets decreased from 3 445 k€ to 3 405 k€.

	2012	2013	Difference	
Accounts receivable	1 948	1 912	-36	-2%
Liquid assets	1 389	1 433	45	+3%
Prepaid expenses	108	59	-49	-45%
Total current assets	3 445	3 405	-40	-1%

All figures in thousand of euro

1.1.1. Accounts receivable

Accounts receivable are monies to be received from 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 (1 774 k€, 93%) and co-funders (98 k€, 5%) of EC projects.

1.1.2. Liquid assets

Liquid assets are cash at bank. The increase of cash mainly comes from the first instalment of the Operating Grant 2014 which is greater than the Operating Grant 2013. The first instalment of an Operating Grant is transferred in December of the year before the start of the contract, hence the impact of the growth of the Operating Grant 2014 on the level of cash at the end of 2013.

1.1.3. Prepaid expenses

The decrease is due to the absence of advance payment for the booking of the venue for EMM2014 / ECRD 2014 Berlin, whereas there had been an advance payment end of 2012 for EMM 2013 Dubrovnik.

1.2. Liabilities

1.2.1. Association funds

Association funds are the reserve which is the addition of all surplus / deficit since the creation of EURORDIS. In 2013, the surplus amounted to 17 k€, the reserve increased from 633 k€ to 651 k€, signifying a 3% increase.

1.2.2. Provisions

Provisions on ongoing contracts

In 2009, the Executive Agency for Health and Consumers (EAHC) mandated a private company to audit the RAPSODY project that ended in 2008. The auditor had reported that EURORDIS may have to refund up to EUR 26 144 to the EAHC of which a definite amount of EUR 5 175 would have to be refunded. Some salary provisions were refused even though they are accurate from an accounting point of view. At the end of 2012, EURORDIS was audited again at the request of the EAHC for the two Operating Grants of 2010 and 2011. This external audit covered a total grant amount of 1 313 k€ corresponding to a total amount of expenses of 2 287 k€.

The decision of EAHC after this second audit was “to close the audit file without any further request to your organisation” (EURORDIS), which means that the audit results were 100% satisfactory. Although we could not hope for a better “quality label” for our administrative processes, we will continue to improve them.

Forecasted loss on EUCERD Joint Action

In 2013, the main risk still lay in the completion of the funding of activities in the context of the EUCERD Joint Action. The forecasted loss is a resource allocation of our funds in order to completely cover the action up to the end of the contract (August 2015) which is a very conservative approach.

	2012	2013		
		Recoveries	New provisions	Balance
Provisions on ongoing contracts	26 144	-20 969	0	5 175
Forecasted loss on EUCERD Joint Action	135 786	-24 004	0	111 782
Provisions for risks and charges	161 930	-44 973	0	116 957

All figures in euro

1.2.3. Trade creditors

2012	120 k€	2%
2013	155 k€	4%
difference	+ 35 k€	29%

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 2013 was average compared to previous years.

1.2.4. Deferred income

2012	2 361 k€	67%
2013	2 248 k€	65%
difference	- 113 k€	-5%

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 account 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 (2 248 k€) is greater than accounts receivable (1 912 k€). It means that we have a cash advance which explains the satisfactory level of liquidities.

In 2013, this was mainly composed of the pluri-annual EC projects (2 059 k€, 92%) and correlated co-funding (75 k€, 3%).

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 3 995 k€. This represents a decrease of 1% compared to 2012.

This slight decrease is the average resulting from decreasing and increasing revenues compared to 2012

- the absence of European Conference on Rare Diseases in 2013 (-243 k€)
- the decrease of the grant from AFM - Téléthon (-80 k€)

compensated by

- the increase of Grants from the European Commission (+175 k€)
- the increase of volunteers' work (+103 k€)

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

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

AFM - Téléthon	887	22%	807	20%	-80	-10%
Membership fees and grants	33	1%	32	1%	-1	-2%
Volunteers	589	15%	692	17%	103	15%
Patient Org. and Volunteers	1 508	37%	1 531	38%	23	1%
European Commission	927	23%	1 101	27%	175	16%
National authorities	27	1%	16	1%	-11	-69%
Pharma. and Biotech Companies	987	24%	1 007	25%	20	2%
Other Health Sector Corporates	23	1%	18	0%	-5	-25%
Health Sector Corporates	1 010	25%	1 025	26%	15	1%
Other Corporates	69	2%	52	1%	-27	-65%
Foundations and NPOs	176	4%	184	5%	8	4%
Event fees	278	7%	34	1%	-243	-714%
Others	44	1%	52	1%	8	15%
Total	4 038	100%	3 995	100%	-43	-1%

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.

Overall: 38% of resources are contributed by our members and volunteers, 28% from European Commission and Member States, 26% by Health Sector Corporates, 5% from Foundations & NPOs and 3% from other private resources.

The proportion of funding by source fully complies with our Policy on Financial Support by Commercial Companies²: the level of revenues from Health Sector Corporates represents 26% and is contributed by 42 different companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (38%).

More details on revenues:

2.1. Patient Organisations and Volunteers

2012	1 508 k€	37%
2013	1 531 k€	38%
difference	+ 23 k€	+ 1%

Since EURORDIS creation up to 2012, AFM-Téléthon was EURORDIS' largest donor. In 2013, the addition of all grants from the DG Sanco of the European Commission (through EAHC) amounted to 832 k€ compared to 807 k€ from AFM-Téléthon.

Hopefully, the increase of participation of volunteers compensated this loss and even more. Altogether, the ratio from the Patient Organisation's sector remains the highest.

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

2012	887 k€	22%
2013	807 k€	20%
Difference	- 80 k€	- 10%

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 2011-2013 AFM/EURORDIS agreement, the purpose of this grant is focused on core operations (governance, membership, advocacy, therapeutic development, management). It is our best guarantee of independence with respect to public institutions and commercial companies.

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

In 2013, it amounted to 635 k€ which means a loss of 71 k€ compared to 2012 (-10%). This decrease – applied to almost all AFM grants – is the direct repercussion of the Téléthon's revenue decrease in 2012. After a decrease in 2012 compared to 2011, the Téléthon of 2013 did not follow the same pattern: it was stable compared to 2012 which is reassuring. We take this opportunity to thank all donors to the AFM-Téléthon: 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 the public institutions.

In addition to the money granted, the AFM provides us with the office space for the staff in Paris in the Rare Disease Platform. Its amount is based on statistics. Its decrease amounted to 9 k€ in 2013, hence a total difference amounting to 80 k€.

2.1.2. Volunteers

2012	589 k€	15%
2013	692 k€	17%
Difference	+ 103 k€	+ 15%

The growing dedication of our volunteers is recurrent; we could almost become used to it. But we are not. We are simply impressed by the dedication of our volunteers whose participation was almost that of 7 (!) full time equivalents (fte), which means that EURORDIS would have had to recruit 7 full time positions from the start of 2013 to keep the same level of representation at EU level.

Moreover, volunteers are an irreplaceable way of communicating our enthusiasm, thanks to their diversity of experience, skills and background.

They mainly work on matters pertaining to Public Affairs (3.2 fte), Orphan Drugs (1.7 fte) and moderation of the rareconnect.org website (1.5 fte).

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.

2.2. European Commission

2012	927 k€	23%
2013	1 101 k€	27%
Difference	+ 175 k€	+ 16%

EURORDIS currently runs seven different grants from both DG Sanco, DG Research and IMI-JU.

In addition to

- the DG Sanco Operating Grant (which has been renewed since 2009 but can always be stopped from one year to another);

- the DG Sanco, DG Research and IMI-JU³ Grants started in 2012 (EUCERD Joint Action, ECRIN, RD-CONNECT, EUPATI);

EURORDIS started yet another grant with DG Research in 2013, coordinated by the Instituto Superiore de Sanità, RARE-Bestpractices.

This 4 years DG Research project will work at promoting communication on the management of rare diseases by disseminating trustworthy guidelines ranging from diagnostic tests and treatments to the organisation of care, to help professionals, patients, policy makers with the best and most up to date information. EURORDIS is the interface between patient organisations and academics. This project allowed us to recruit one dedicated staff member.

2.3. National authorities

2012	27 k€	1%
2013	16 k€	1%
Difference	- 11 k€	- 69%

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.

2.4. Health Sector Corporates

2012	1 010 k€	25%
2013	1 025 k€	26%
Difference	15 k€	+ 1%

This heading comprises 40 pharmaceutical companies and two health sector consulting firms.

The level of contribution from the Health Sector Corporations remains stable. The slight increase comes from the EURORDIS Round Table of Companies (ERTC) which has been constantly increasing since 2008 despite the unfavourable economic environment.

Other pharmaceutical companies' support consists of co-funding of projects (Epirare), supporting the EURORDIS Membership Meeting, the RareConnect project (Online Patient Communities) and the EURORDIS Black Pearl Gala Dinner.

The five largest donors are, in decreasing amount order, CELGENE, SIGMA TAU, GSK, SHIRE and GENZYME.

The percentage of each of the 42 companies in the overall budget comprises between 0.13% and 2.13%.

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” (18%).

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

2012	69 k€	2%
2013	52 k€	1%
difference	- 17 k€	-25%

It is the second year that EURORDIS succeeds in raising funds from one corporate that is not exclusively dedicated to the health sector. This funding has been proceeded through in kind services from Burson-Marsteller and Multiburo, two companies based in Brussels, as well as a contribution from Ares Life Sciences, an investment partnership.

2.6. Foundations and Not for Profit Organisations (NPOs)

2012	176 k€	4%
2013	184 k€	5%
difference	8 k€	4%

All NPOs that provide funds to EURORDIS come from the Health Sector but they are not Pharmaceutical Companies' foundations.

They comprise Pharmaceutical Syndicates such as the LeeM (French), AIPM (Russian) and EFPIA (European); one medical devices foundation, the Medtronic foundation and one family foundation, EveryLife Foundation which belongs to Mr Kakkis, MD, PhD, CEO and President of Ultragenyx pharmaceutical.

NPOs also include one non-profit company devoted to the development of new therapies and diagnostics in the field of rare diseases, RarePartners.

Also, the Fundació Doctor Robert kindly provided us with the office space in Barcelona in the same way that the AFM does in Paris, for an estimated amount of 12 k€.

2.7. Event fees

2012	278 k€	7%
2013	34 k€	1%
difference	- 243 k€	- 714%

In 2012, to be able to organise a 6th European Conference on Rare Diseases (ECRD) with a contribution of the European Commission constricted at 100 k€, EURORDIS partnered with the Drug Information Association (DIA). This partnership allowed us to attract more participants from the for-profit sector and thus increase the participation fees to 235 k€.

In 2013, in absence of an ECRD, Event fees consist of EURORDIS Black Pearl Gala Dinner seats and EURORDIS Membership Meeting in Dubrovnik.

3. Expenses

The operating expenses, including in-kind contributions and excluding provisions, amounted to 4 023 k€, which shows an increase of 5% compared to 2012. It is the first time that a year without European Conference on Rare Diseases (ECRD) incurs more expenses than a year with a ECRD.

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

Expenses	2012	Fin. Status	2013	Fin. Status	Difference
Staff costs	1 709	44%	1 984	49%	275
Volunteers	589	15%	692	17%	103
Travel and subsistence	403	10%	444	11%	41
Services	1 026	27%	808	20%	-218
Purchase and miscellaneous	116	3%	95	2%	-20
Total	3 843	100%	4 023	100%	180
					4%

The increase is due to more staff, either employees or volunteers.

More details on expenses:

3.1. Staff costs

2012	1 709 k€	45%
2013	1 984 k€	49%
difference	+ 275 k€	+ 14%

The number of FTE⁵ was 26 in 2013, thus an increase of 2.3 FTE (+ 9%).

This increase results from the start of new projects in 2012 (EUCERD Joint Action, EUPATI, RD-Connect) and in 2013 (RARE-Bestpractices), as well as the creation of a new position to manage projects transversally (in order of contractual start):

1. Registry & Biobank Projects Manager, RD-Connect, Anna Kole
2. Health Research Projects Manager, RARE-Bestpractices, Juliette Sénécat
3. Operations and Projects Manager, Mathieu Boudes

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.

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

Altogether, at the end of the year, we were 21 employees, one trainee and one office volunteer in France, one employee in Belgium, one full time consultant in Belgium, three full time employees and one trainee in Spain. Hence an overall total of 29 staff members.

3.2. Travel and subsistence

2012	403 k€	10%
2013	444 k€	10%
difference	+41 k€	+9%

Despite the absence of a European Conference on Rare Diseases, Travel and Subsistence costs increased because of the organisation of capacity building sessions in the context of the EpiRare and RD-Connect projects, as well as the preparation of the 25 conferences on National Plans in the context of the EUCERD Joint Action.

Out of these 444 k€, 144 k€ have been allocated on travel of staff members, the rest (68%) have been allocated to travel of volunteers and invitees in order to attend, amongst many activities,

- the EURORDIS Summer School in Barcelona,
- the 25 European Conferences in the context of the EUCERD Joint Action WP4 (continuation of the EUROPLAN project),
- the capacity building sessions in the context of the EPIRARE project,
- the EUCERD WP6 Social Specialised Services,
- etc.

Part of this amount was also allocated to support European Federations and provide attendees to the EURORDIS Membership Meeting with some fellowships.

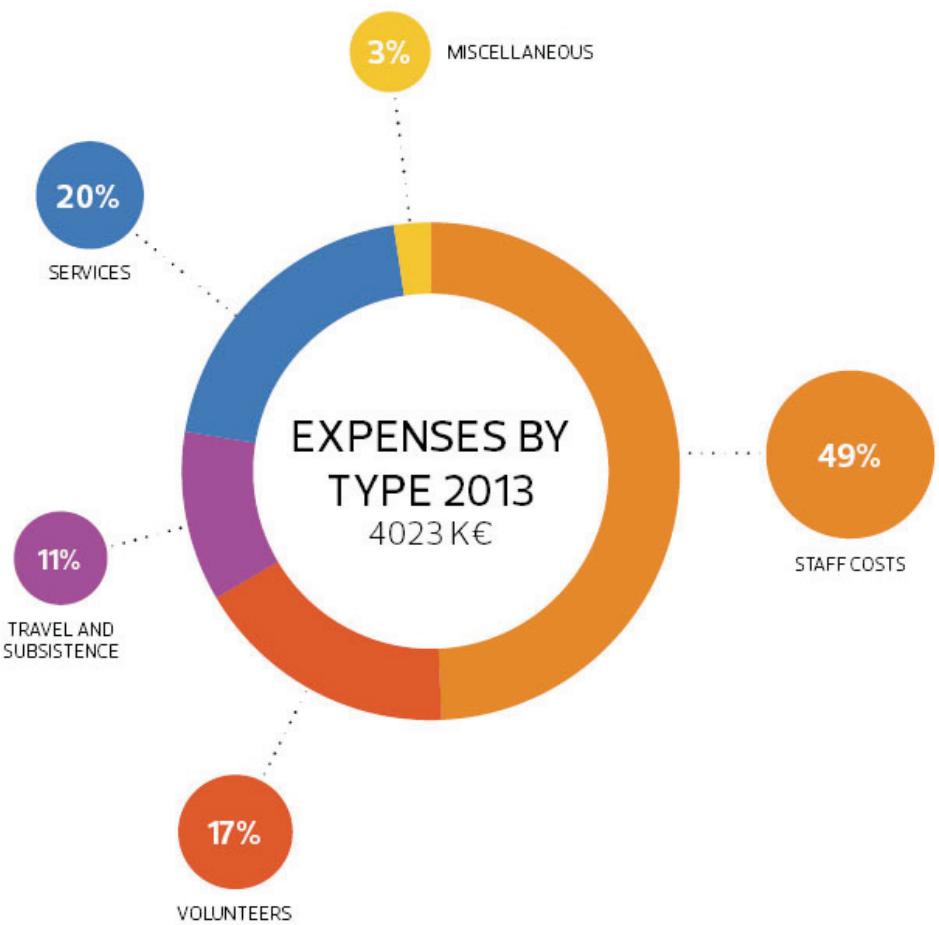
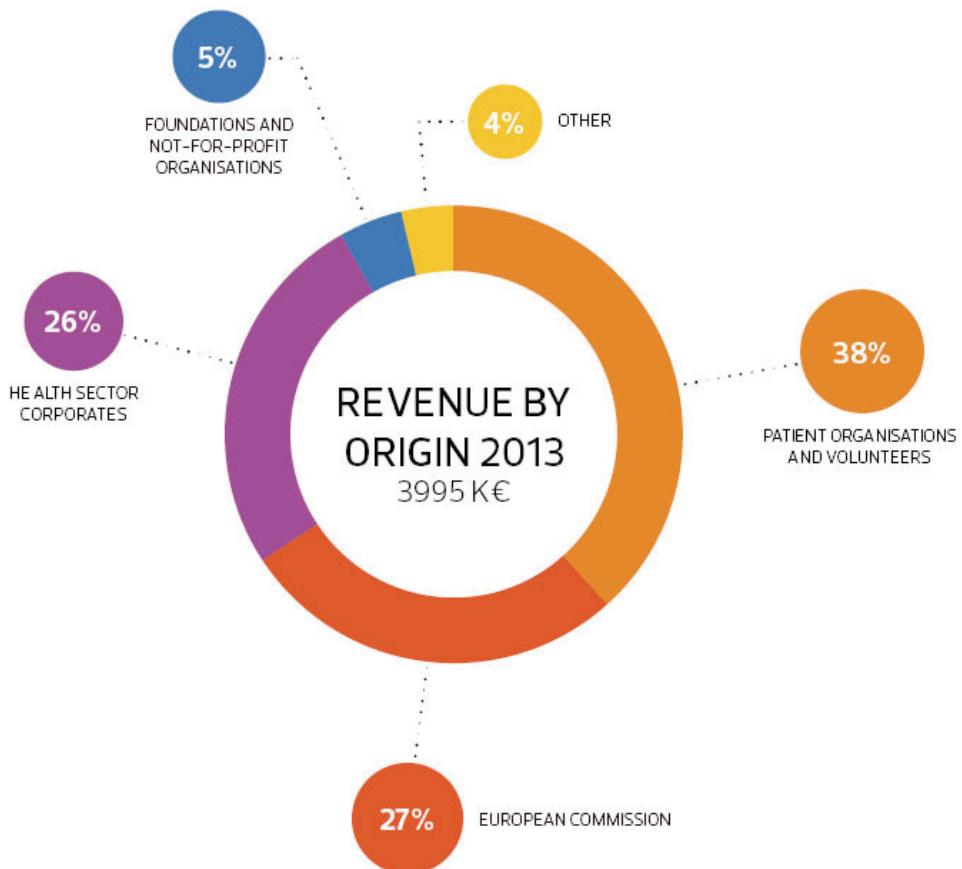
3.3. Services

2012	1 026 k€	27%
2013	808 k€	20%
difference	- 218 k€	- 27%

The absence of an ECRD is the main cause of this decrease.

4. Result

The 2013 surplus amounted to EUR 17 357 and we suggest to allocate it to the reserve. The reserve fund would then be increased by EUR 17 357 to EUR 650 550, which will represent less than 3 months of low-level activity.



Glossary

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

EC: European Commission

DG Sanco: Health and Consumer Protection Directorate-General of EC

Ongoing Projects:

- *EURORDIS FY2013* (2013 Operating Grant)
 - o from 01-Jan-13 to 31-Dec-13
- Epirare (European Platform for Rare Diseases Registries),
 - o from 16-Apr-11 to 15-Apr-14
 - o EURORDIS is co-beneficiary
- EUCLERD Joint Action,
 - o from 01-Mar-12 to 31-Aug-15
 - o EURORDIS is co-beneficiary

DG Research: Research Directorate-General of EC

Ongoing Projects:

- *ECRIN IA* (European Clinical Research Infrastructures Network)
 - o from 01-Jan-12 to 31-Dec-15
 - o EURORDIS as 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 as 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 as 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 as co-beneficiary

ECRD: European Conference on Rare Diseases.

6 of them already taken place

ECRD2012, in Brussels (co-organised by EURORDIS and DIA)

ECRD2010, in Krakow (organised by EURORDIS and partners)

ECRD2007, in Lisbon (organised by EURORDIS and partners)

ECRD2005, in Luxembourg (organised EURORDIS and partners)

ECRD2003, in Evry (France, organised by Alliance Maladies Rares)

ECRD2001, in Copenhagen (organised by Rare Disorders Denmark)

The seventh will take place in May 2014 in Berlin.

EMA: European Medicine Agency

EUCERD: European Union Committee of Experts on Rare Diseases



EURORDIS
Rare Diseases Europe

European
Organisation
for Rare Diseases

FINANCIAL REPORT 2013

PARIS OFFICE

EURORDIS – Plateforme Maladies Rares
96, rue Didot
75014 Paris
France
Tel: +33 (0) 156 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

c/o Fundació Dr. Robert
UAB Casa Convalescència
St. Antoni Maria Claret, 171
08041 Barcelona
Spain

eurordis.org

