



EUROPEAN ORGANISATION FOR RARE DISEASES

FINANCIAL REPORT 2012

**THE VOICE OF
RARE DISEASE
PATIENTS IN EUROPE**

EURORDIS.ORG



EURORDIS
Rare Diseases Europe

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, 2012

EURORDIS

Association governed by the French law of July 1, 1901

96, Rue Didot
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STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2012

In compliance with the assignment entrusted to us by the Members' meeting, we hereby report to you, for the year ended December 31, 2012, 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, 2012 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' management report and in the documents addressed to the Members with respect to the financial position and the financial statements.

Neuilly-sur-Seine, March 15, 2013

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.

Assets	2011	2012	Ratio	Difference
FIXED ASSETS				
Intangible assets	749	725	-3%	-24
Tangible assets	86 883	70 415	-19%	-16 468
Financial assets	532	4 249	699%	3 717
TOTAL	88 164	75 389	-14%	-12 774
CURRENT ASSETS				
Account receivable due within one year	1 109 002	1 081 098	-3%	-27 903
Account receivable due after one year	118 000	867 050	635%	749 050
Liquid assets	904 391	1 388 594	54%	484 203
Prepaid expenses	113 476	108 000	-5%	-5 476
TOTAL	2 244 869	3 444 742	53%	1 199 874
TOTAL ASSETS	2 333 033	3 520 132	51%	1 187 099

Liabilities	2011	2012	Ratio	Difference
ASSOCIATION FUNDS				
Reserve	495 042	570 789	15%	75 747
Profit & loss for the year	75 747	62 404	-18%	-13 343
Subsidies of investment	238	0	-100%	-238
TOTAL	571 027	633 193	11%	62 166
Provisions for risk and charges	29 061	161 929	457%	132 868
Dedicated funds on grants	0	0	NA	0
DEBTS				
Bank loans and overdraft	0	0	NA	0
Trade creditors	138 636	120 452	-13%	-18 185
Tax payable and social liabilities	191 127	187 090	-2%	-4 037
Other debts	31 307	56 307	80%	25 000
Deferred income within one year	1 253 875	1 311 531	5%	57 656
Deferred income after one year	118 000	1 049 630	790%	931 630
TOTAL	1 762 006	2 886 939	64%	1 124 933
TOTAL LIABILITIES	2 333 033	3 520 132	51%	1 187 099

Revenue	2011 Fin. Status	2012 Fin. Status	Ratio	Δ in euros	Δ in %
Patient Organisations	893 246	919 776	23%	26 530	3%
AFM Telethon Grants	630 000	705 000	17%	75 000	12%
In kind contributions (AFM)	229 848	181 886	5%	-47 962	-21%
Membership fees and grants	33 398	32 890	1%	-508	-2%
Volunteers	419 002	588 629	15%	169 627	40%
Representative and task forces	402 450	525 444	13%	122 994	31%
Project, office and translators	16 552	63 185	2%	46 633	282%
European Commission	814 521	926 760	23%	112 239	14%
DG Research	38 660	34 502	1%	-4 158	-11%
DG Health and consumers	719 897	848 867	21%	128 970	18%
EMA in kind contributions (1)	55 964	43 391	1%	-12 573	-22%
National authorities	72 046	27 117	1%	-44 929	-62%
Secured Staff (INSERM)	65 514			-65 514	
National officials in EC projects	2 102			-2 102	
Grants from National authorities	4 430	27 117	1%	22 687	512%
Corporates	690 583	1 078 447	27%	387 864	56%
Pharma. and Biotech Companies	690 583	987 390	24%	296 807	43%
Other Health Sector Corporates		22 500	1%	22 500	
Outside Health Sector Corporates		68 557	2%	68 557	
Not for Profit Organisations	143 758	175 675	4%	31 917	22%
Pharma. and Biotech Found.					
Other Health Sector NPOs	143 758	175 675	4%	31 917	22%
Outside Health Sector NPOs					
Event fees	22 870	277 562	7%	254 693	1114%
Miscellaneous	37 595	44 095	1%	6 501	17%
In kind contributions (Others)	2 175			-2 175	
Reimbursement	17 733	21 914	1%	4 181	24%
Others	17 686	22 181	1%	4 495	25%
Sub-total	3 093 620	4 038 061	100%	944 441	31%
Recovery of provisions	133 059	2 917	0%	-130 141	-98%
Report of non-used income					
Total Revenue	3 226 678	4 040 978	100%	814 300	25%

Expenses	2011 Fin. Status	2012 Fin. Status	Ratio	Δ in euros	Δ in %
Staff	1 578 839	1 709 395	44%	130 555	8%
Wages and charges	1 475 278	1 598 147	42%	122 869	8%
Other salaries	78 137	63 616	2%	-14 521	-19%
Training and other costs	25 424	47 631	1%	22 207	87%
Volunteers	419 002	588 629	15%	169 627	40%
Representative and task forces	402 450	525 444	14%	122 994	31%
Project, office and translators	16 552	63 185	2%	46 633	282%
Travel and subsistence	320 892	402 980	10%	82 089	26%
Travels	262 752	357 414	9%	94 662	36%
In kind contribution	58 139	45 566	1%	-12 573	-22%
Services	687 485	1 026 148	27%	338 663	49%
Fees	291 250	323 479	8%	32 229	11%
Event logistics and catering	92 358	273 657	7%	181 299	196%
EC projects partners	9 262	59 093	2%	49 832	538%
Telecom and post	45 462	46 118	1%	656	1%
Rent	152 964	213 174	6%	60 209	39%
Other services	96 189	110 627	3%	14 437	15%
Purchase	135 144	100 857	3%	-34 288	-25%
Office furniture	24 704	19 404	1%	-5 300	-21%
Amortization	27 131	27 064	1%	-68	0%
Publications	76 769	51 806	1%	-24 963	-33%
Other purchases	6 540	2 583	0%	-3 957	-61%
Financial and insurance expenses	6 651	14 780	0%	8 128	122%
Sub-total	3 148 014	3 842 788	100%	694 774	22%
Contingency and loss provisions	2 917	135 786	4%	132 868	4554%
Commitment on assigned income					
Total Expenses	3 150 931	3 978 574	104%	827 643	26%
Result	75 747	62 404			

(1) covering travel/accommodation costs for EMA meetings

Introduction

In 2012, two big events – the European Conference on Rare Diseases and the EURORDIS Black Pearl Gala Dinner – in addition to the signature of several pluriannual projects – EUCERD Joint Action, EUPATI, RD-Connect – had a significant impact both on “assets and liabilities” (+51%) and “revenue and expenses” (+25%) accounts.

The funding scheme of these two events was totally new for EURORDIS and the risk was properly managed. It resulted in a growth of the reserves by 11% - a net surplus of EUR 62 404 after provisions that we propose to allocate to the reserves.

A contract loss accrual was constituted to cover the loss on the continuation of the EUROPLAN project where no co-funding could be raised.

1. Assets and Liabilities

1.1. Assets

Current assets increased from 2 245 k€ to 3 445 k€.

	2011	2012	Difference	
Accounts receivable	1 227	1 948	721	+59%
Liquid assets	904	1 389	484	+54%
Prepaid expenses	113	108	-5	-5%
Total current assets	2 245	3 445	1 200	+53%

All figures in thousand of euro

1.1.1. Account receivables

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

Four new EC pluri-annual projects were signed in 2012, hence the increase of this line:

- EUCERD Joint Action: Working for Rare Diseases, 42 months
- EUPATI European Patient's Academy on Therapeutic Innovation, 60 months
- ECRIN IA European Clinical Research Infrastructure Network, 48 months
- RD-CONNECT An integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research, 72 months

The bulk of this line comes from the European Commission (1 721 k€, 88%) and co-funders (175 k€, 9%) of EC project.

1.1.2. Liquid assets

The increase of liquid assets mainly comes from the first instalment of the above mentioned projects.

1.1.3. Prepaid expenses

Advance payments were made for the booking of the EURORDIS Membership Meeting 2013 Dubrovnik and the EURORDIS Black Pearl Gala Dinner 2013 venue.

1.2. Liabilities

1.2.1. Association funds

The overall association funds increased from 571 k€ to 633 k€, signifying an 11% rise.

1.2.2. Provisions

In 2012, the main risk lies in the completion of the funding of activities around national plans in the context of the EUCERD Joint Action WP4.

This work package is the continuation of the EUROPLAN project, held in 2009, and for which we did not succeed in finding donors to co-fund the action. At the closing of 2012's accounts, we have not succeeded in co-funding its continuation in the context of EUCERD Joint Action.

We still hope we will succeed in co-funding this activity but in order to be cautious, we have provisioned a contract loss accrual.

	2011	2012		
		Recoveries	New provisions	Balance
Provisions on ongoing contracts	29 061	-2 917	0	26 144
Forecasted loss on EUCERD Joint Action	0	0	135 786	135 786
Provisions for risk and charges	29 061	-2 917	135 786	161 930

All figures in euro

1.2.3. Trade creditors

2011	139 k€	6%
2012	120 k€	3%
difference	- 19 k€	-2%

Trade creditors are monies to be paid to suppliers for invoices that have been received (or to be received) and not paid yet. The situation at the end of 2012 is average.

1.2.4. Deferred income

2011	1 372 k€	59%
2012	2 361 k€	67%
difference	+ 989 k€	+72%

Deferred income refers to the part of grants concerning the incoming years (the part of the grant that has not been consumed yet).

In 2012, this is mainly composed of the above mentioned pluri-annual EC projects (2 140 k€, 91%) and correlated co-funding (108 k€, 5%).

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 4 038 k€. This represents an increase of 31% compared to 2011.

This increase comes from different factors

- the creation of the Gala Dinner (+319 k€ - Corporates line)
- the organisation of ECRD2012 (+235 k€ on event fees)
- the increase of volunteers' work (+170 k€)

The breakdown of EURORDIS' revenue by sources is as follows

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

Source of funding	2011		2012		Difference	
<i>AFM</i>	860	28%	887	22%	27	3%
<i>Membership fees and grants</i>	33	1%	33	1%	-1	-2%
<i>Volunteers</i>	419	14%	589	15%	170	40%
Patient Org. and Volunteers	1 312	42%	1 508	37%	196	15%
European Commission	815	26%	927	23%	112	14%
National authorities	72	2%	27	1%	-45	-62%
<i>Pharma. and Biotech Companies</i>	691	22%	987	24%	297	43%
<i>Other Health Sector Corporates</i>	0	0%	23	1%	23	N/A
Health Sector Corporates	691	22%	1 010	25%	319	46%
Other Corporates	0	0%	69	2%	69	N/A
Foundations and NPOs	144	5%	176	4%	32	22%
Event fees	21	1%	275	7%	262	N/A
Others	40	1%	46	1%	-1	-3%
Total	3 094	100%	4 038	100%	944	31%

Overall: 37% of resources are contributed by our members and volunteers, 25% by Health Sector Corporates, 24% from European Commission and Member States, 7% from event fees and 7% 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 25% and is contributed by 40 different companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (37%).

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 Volunteers

2011	1 312 k€	42%
2012	1 508 k€	37%
difference	+196 k€	+15%

This increase is mainly due to our volunteers who increased their participation in advocacy activities. Also, the financial evaluation of our new office space kindly offered by AFM-Téléthon has been recalculated to take into account a proportional fraction of the space shared by the 6 entities of the platform.

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

2011	860 k€	28%
2012	887 k€	22%
difference	+ 27 k€	+ 3%

AFM-Téléthon is EURORDIS' largest donor. Thanks to this grant, we are able 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.

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

In 2012, the grant amounted to 705 k€ to partially compensate the departure of our seconded staff member, Fabrizia Bignami, PhD.

In addition to the money granted, the AFM provides us with the office space for the staff in Paris in the Rare Disease Platform.

2.1.2. Volunteers

2011	419 k€	14%
2012	589 k€	15%
Difference	+170 k€	+40%

The growing dedication of our volunteers is recurrent and even more impressive than last year. Altogether, their participation was greater than 5 full time equivalents (fte), which means that EURORDIS would have had to recruit 5.7 full time positions from the start of 2012 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 (2.8 fte) and Orphan Drugs (1.6 fte).

Time spent by volunteers is validated by the volunteer him/herself (92.8%) or estimated by project managers. The overall process is validated by our auditors.

2.2. European Commission

2011	815 k€	26%
2012	927 k€	23%
Difference	+112 k€	+14%

In addition to the new EC Grants already described in 2011's financial report (EUCERD Joint Action, EUPATI, ECRIN), EURORDIS started a new project in 2012: RD-Connect. This 6 years DG Research project will work at improving the connection between the different clinical datasets such as registries, biobanks, -omics, etc. EURORDIS will be the interface between patient organisations and academics. This project allowed us to recruit one dedicated staff member.

2.3. National authorities

2011	72 k€	2%
2012	27 k€	1%
Difference	- 45 k€	- 62%

Now that François Faurisson, MD, Clinical Research Advisor, from INSERM has left, this line is mainly focused on co-funding of the EUCERD Joint Action by the "Caisse Nationale de Solidarité pour l'Autonomie" (25 k€ per year for 3 years).

2.4. Health Sector Corporates

2011	691 k€	22%
2012	1 010 k€	25%
Difference	319 k€	+ 46%

This heading comprises 38 pharmaceutical companies and two health sector consulting firms.

The bulk of the increase comes from the Gala Dinner. Also, our Round Table of Companies is regularly increasing: it increased from 315 k€ in 2011 to 340 k€ in 2012 (+25 k€).

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

The five largest donors are GSK, CELGENE, ALEXION, BAYER and PFIZER. The percentage of each company in the overall budget comprises between 0.06% and 2.39%.

The two guarantees of our independence 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

2011	0 k€	0%
2012	69 k€	2%
difference	69 k€	NA

For the first time, in 2012, EURORDIS succeeded in raising funds from one corporate that is not exclusively dedicated to the health sector and also had the positive surprise of receiving two wonderful videos for Rare Disease Day 2012 and 2013. These gifts amounted to 50 k€.

In addition, we received a very advantageous price for the renting of our office space in Brussels because Multiburo wanted to support EURORDIS' mission. This special price allowed us to save 6 k€ in 2012.

2.6. Foundations and Not for Profit Organisations (NPOs)

2011	144 k€	5%
2012	176 k€	4%
difference	32 k€	22%

All NPOs that provided 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) – EFPIA contributed through the EUPATI project which is a Joint Undertaking between DG Research and EFPIA; 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.

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 8 k€.

2.7. Event's fees

2011	21 k€	1%
2012	275 k€	7%
difference	254 k€	N/A

To be able to organise a 6th European Conference on Rare Diseases with a contribution of the European Commission constricted at 100 k€, EURORDIS partnered with the Drug Information Association (DIA). This partnership allowed us to increase the participation fees to 235 k€.

The rest mainly consists of EURORDIS Black Pearl Gala Dinner seats (34 k€).

3. Expenses

The operating expenses, including in-kind contributions and excluding provisions, amounted to 3 843 k€, which shows an increase of 22% compared to 2011.

The breakdown of EURORDIS' expenses is as follows
(in thousands of euros, provisions excluded³)

Expenses	2011		2012		Difference	
Staff costs	1 579	50%	1 709	44%	131	+8%
Volunteers	419	13%	589	15%	170	+40%
Travel and subsistence	321	10%	403	10%	82	+26%
Services	687	22%	1 026	27%	339	+49%
Purchase	135	4%	101	3%	-34	-25%
Financial and insurance expenses	7	0%	15	0%	8	+122%
Total	3 148	100%	3 843	100%	695	+22%

All figures in thousand of euro

The increase is due to

- ECRD2012 related costs
- Increase of volunteers
- Start of new projects

More details on expenses:

3.1. Staff costs

2011	1 579 k€	50%
2012	1 709 k€	44%
difference	+ 131 k€	+ 8%

The number of FTE⁴ was 23.7 in 2012, thus an increase of 0.8 FTE (+ 4%).

This increase results from plus and minus: On the one hand we have, in 2012, the departure of two seconded staff members (Fabrizia Bignami, PhD from AFM and François Faurisson, MD from Inserm) and the creation of five new positions (in order of contractual start):

1. Social Policy & Specialised Social Services Manager, Raquel Castro
2. Deputy to the Chief Executive Officer, Zoe Alahouzu
3. Training Manager, Nancy Hamilton
4. RareConnect™ Junior Manager, Marta Campabadal
5. Resource Development Director, Jill Bonjean (replaced by Minna Granger)

Altogether, at the end of the year, we were 21 staff members in France, one staff member in Belgium, one full time consultant in Belgium, three full time staff members in Spain and one office volunteer. Hence an overall total of 27 staff members.

³ 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.

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

3.2. Travel and subsistence

2011	321 k€	10%
2012	403 k€	10%
difference	+82 k€	+26%

ECRD2012, including fellowships, and the start of the EUCERD Joint Action with its workshops, are the cause of this increase.

3.3. Services

2011	687 k€	22%
2012	1 026 k€	27%
difference	+339 k€	+49%

Our two major events – ECRD2012 (+245 k€) and the Gala Diner (+49 k€) – are, together with the creation of two in kind videos in the context of Rare Disease Day 2012 and 2013 (+50 k€), the cause of this increase.

4. Result

The 2012 surplus amounted to EUR 62 404 and we suggest to allocate it to the reserve.

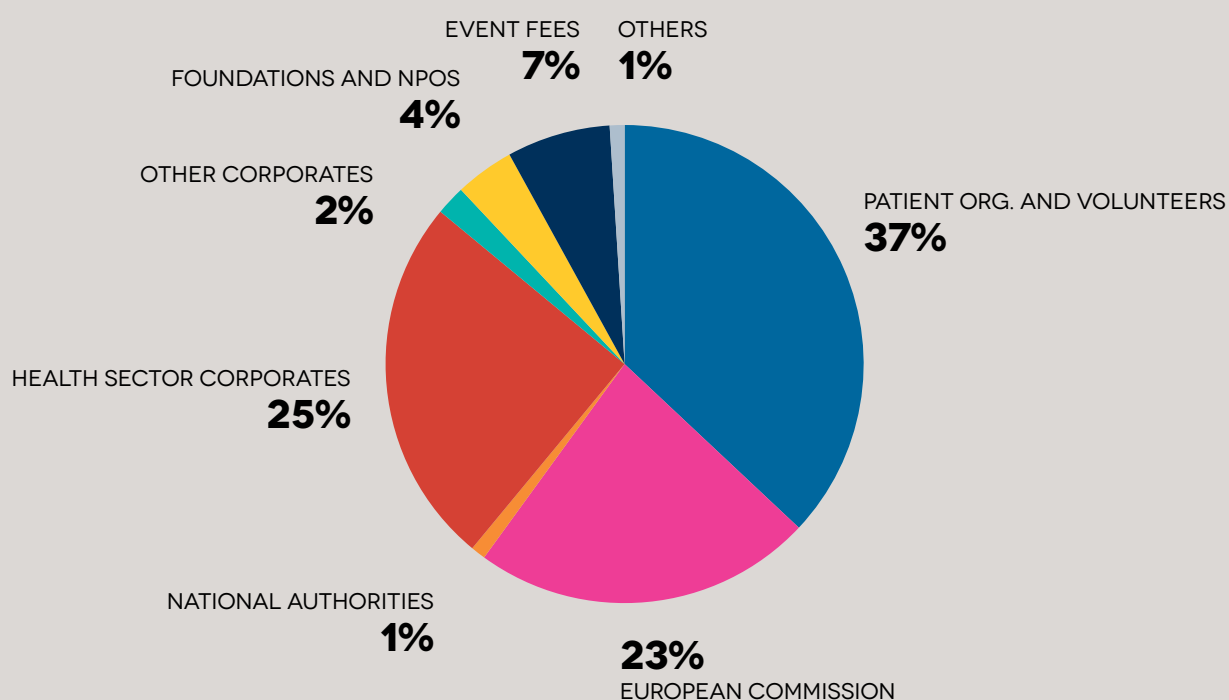
The reserve fund would then be increased by EUR 62 404 to EUR 633 193, which will represent approximately 3 months of low-level activity.

REVENUE AND EXPENSES

2012 (IN EUROS, PROVISIONS EXCLUDED)

REVENUE BY ORIGIN 2012 = 4,038 Ke

- Patient Organisations and Volunteers
- European Commission
- National Authorities
- Health Sector Corporates
- Other Corporates
- Foundations and Not-for-Profit Organisations
- Event fees
- Others

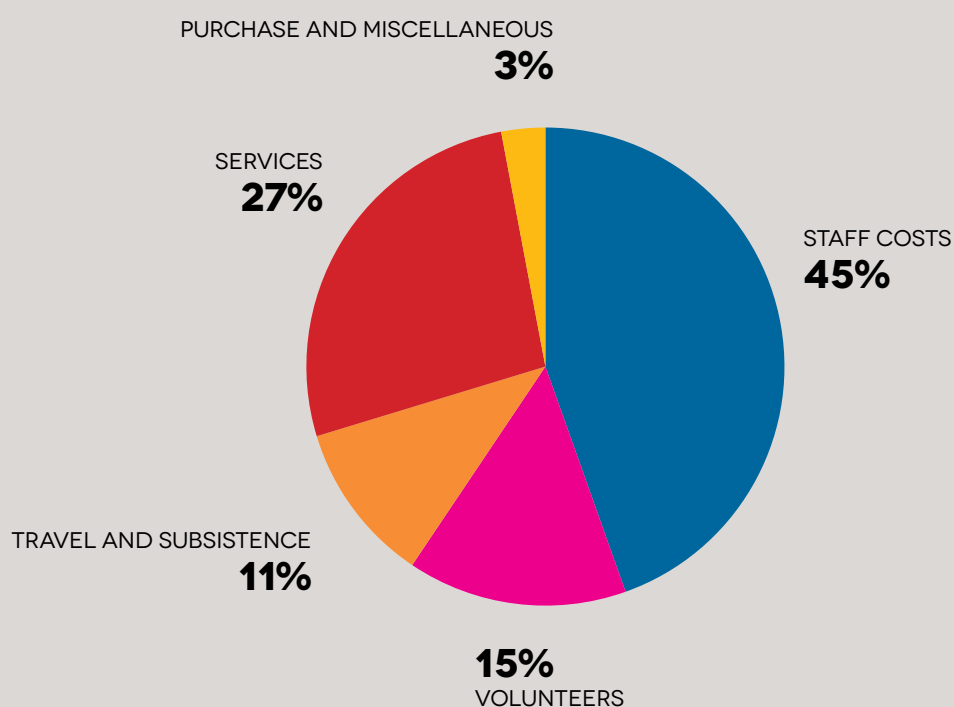




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- Staff costs
- Volunteers
- Travel and subsistence
- Services
- Purchase and miscellaneous

EXPENSES BY TYPE 2012 = 3,828 Ke



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 FY2012* (2012 Operating Grant)
 - o from 01-Jan-12 to 31-Dec-12
- *Epirare* (European Platform for Rare Diseases Registries),
 - o from 01-Apr-11 to 31-Oct-13
 - o EURORDIS is co-beneficiary
- *EUCERD 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-2015
 - 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-2018
 - 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-2016
 - 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

FINANCIAL REPORT 2012

2013 WORKPLAN 2013

THE VOICE OF RARE DISEASE PATIENTS IN EUROPE

EUROPEAN ORGANISATION FOR RARE DISEASES



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