

# EUROPEAN ORGANISATION FOR RARE DISEASES FINANCIAL REPORT 2011



#### **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, 2011

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Year ended December 31, 2011

In compliance with the assignment entrusted to us by the Members' meeting, we hereby report to you, for the year ended December 31, 2011, 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, 2011 and the results of its operations for the year then ended in accordance with French accounting regulations.

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Without qualifying the above opinion, we draw your attention to the note to the financial statements presented on page 6 describing the change in method used to record the deferral of the annual grants and the donations, which had no impact on the comparability of the 2011 and 2010 financial statements.

#### 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.

With the exception of the impact of the matters described in the first part of this report, 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, May 2, 2012

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.



### **Eurordis financial reporting** (Assets and Liabilities)

Ass	sets	2010	2011	Ratio	Difference
FI)	KED ASSETS				
	Intangible assets	2 189	749	-66%	-1 440
	Tangible assets	73 136	86 883	19%	13 747
	Financial assets	532	532	0%	0
TO	TAL	75 857	88 164	16%	12 307
CU	RRENT ASSETS				
	Account receivable due within one year	1 317 292	1 109 002	-16%	-208 290
	Account receivable due after one year		118 000	NA	118 000
	Liquid assets	745 789	904 391	21%	158 602
	Deferred expenses	8 695	113 476	1205%	104 781
ΤO	TAL	2 071 776	2 244 869	8%	173 092
то	TAL ASSETS	2 147 633	2 333 033	9%	185 400

Liabilities	2010	2011	Ratio	Difference
ASSOCIATION FUNDS				
Reserve	375 493	495 042	32%	119 549
Profit & loss for the year	119 549	75 747	-37%	-43 802
Subsidies of investment	965	238	-75%	-726
TOTAL	496 006	571 027	15%	75 021
Provisions for risk and charges	159 202	29 061	-82%	-130 141
Dedicated funds on grants	0	0	NA	0
DEBTS				
Bank loans and overdraft	0	0	NA	0
Trade creditors	297 164	138 636	-53%	-158 528
Tax payable and social liabilities	211 565	191 127	-10%	-20 438
Other debts	29 364	31 307	7%	1 943
Deferred income within one year	954 332	1 253 875	31%	299 543
Deferred income after one year		118 000	NA	118 000
TOTAL	1 651 627	1 762 006	7%	110 379
TOTAL LIABILITIES	2 147 633	2 333 033	9%	185 400



#### **2011 Financial Status** vs. 2010 Financial Status (Profit and Loss including in kind contributions)

Revenue	2010 Fin.	2011 Fin.	Ratio
Reveilue	Status	Status	Katio
Patient Organisations	884 124	893 246	29%
AFM Telethon Grants	650 000	630 000	20%
In kind contributions (AFM)	193 202	229 848	7%
Membership fees and grants	40 922	33 398	1%
Volunteers	375 990	419 002	14%
Representative and task forces	334 302	402 450	13%
Project, office and translators	41 688	16 552	1%
European Commission	1 379 775	814 521	26%
DG Research	143 369	38 660	1%
DG Health and consumers	1 180 687	719 897	23%
EMA in kind contributions	55 720	55 964	2%
National authorities	95 184	72 046	2%
Secunded Staff (INSERM)	94 921	65 514	2%
National officials in EC projects	263	2 102	0%
Grants from National authorities	0	4 430	0%
Corporate funding	546 811	690 583	22%
Pharma. and Biotech Cie	541 360	690 583	22%
Other corporate funding	5 451		
Foundations and NPOs	130 517	143 758	5%
Pharma. and Biotech Found.	130 517	143 758	5%
Other Found. and NPOs			
Miscellaneous	140 708	60 464	2%
Fees	79 055	22 870	1%
In kind contributions (Others)	22 500	2 175	0%
Reimbursment	25 938	17 733	1%
Others	13 215	17 686	1%
Sub-total	3 553 109	3 093 620	100%
Recovery of provisions	51 757	133 059	4%
Report of non-used income	33 500		
Total Revenue	3 638 366	3 226 678	104%

Δ in	Δ in %
euros	
9 122	1%
-20 000	-3%
36 646	19%
-7 524	-18%
43 012	11%
68 148	20%
-25 136	-60%
-565 255	-41%
-104 709	-73%
-460 790	-39%
244	0%
-23 138	-24%
-29 407	-31%
1 839	700%
4 430	
143 772	26%
149 223	28%
-5 451	
13 241	10%
13 241	10%
00.044	
-80 244	-57%
-56 186	-71%
-20 325	-90%
-8 205	-32%
4 471	34%
-459 489 81 302	-13% 157%
-33 500	15/%
-33 500	-11%
-411 08/	-11%

France	2010 Fin.	2011 Fin.	Datia
Expenses	Status	Status	Ratio
Staff	1 551 659	1 578 839	50%
Wages and charges	1 406 740	1 475 278	47%
Paid staff	1 219 773	1 320 154	42%
Secunded staff	186 967	155 124	5%
Other salaries	112 130	78 137	2%
Training and other costs	32 789	25 424	1%
Volunteers	375 990	419 002	13%
Representative and task forces	334 302	402 450	13%
Project, office and translators	41 688	16 552	1%
Travel and subsistence	378 186	320 892	10%
Travels	322 466	262 752	8%
In kind contribution	55 720	58 139	2%
Services	998 214	687 485	22%
Fees	429 385	291 250	9%
Event logistics and catering	277 790	92 358	3%
EC projects partners	17 857	9 262	0%
Telecom and post	38 486	45 462	1%
Rent	117 543	152 964	5%
Other services	117 152	96 189	3%
Purchase	106 357	135 144	4%
Office furniture	29 843	24 704	1%
Amortization	30 111	27 131	1%
Publications	28 485	76 769	2%
Other purchases	17 917	6 540	0%
Financial and insurance expenses	5 978	6 651	0%
Sub-total	3 416 384	3 148 014	100%
Contingency and loss provisions	102 433	2 917	0%
Commitment on assigned income			
Total Expenses	3 518 817	3 150 931	100%
Result	119 549	75 747	

∆ in	Δ in %
euros	
27 180	2%
68 538	5%
100 381	8%
-31 843	-17%
-33 993	-30%
-7 365	-22%
43 012	11%
68 148	20%
-25 136	-60%
-57 294	-15%
-59 713	-19%
2 420	4%
-310 729	-31%
-138 135	-32%
-185 432	-67%
-8 595	-48%
6 976	18%
35 421	30%
-20 963	-18%
28 787	27%
-5 139	-17%
-2 980	-10%
48 284	170%
-11 377	-64%
673	11%
-268 370	-8%
-99 516	-97%
-367 885	-10%

#### Introduction

2011 has been a transitional year, where major EC projects ended (Polka, Europlan, Treat-NMD), with no European Conference on Rare Diseases (ECRD) and where, at the same time, the Operating Grant decreased from EUR 733 388 to EUR 580 000 while its percentage of co-funding was decreased by 5 points (from 60% to 55%). For these reasons, both revenue and expenses decreased: EC funds decreased by 41% and Services by 31%. The EC fund reduction was compensated by increase of corporate funds, but not sufficiently to cover all expenses. A recovery of provisions amounting to EUR 133 059 resulted in a net surplus of EUR 75 747 which we suggest to allocate to the reserve.

The <u>assets and liabilities</u> table shows a slight increase (+9%). This is because of the deferred income of EURORDIS Gala Dinner and signature of a pluriannual grant with DG SANCO "European Platform for Rare Diseases Registries" (Epirare).

#### 1. Assets and Liabilities

#### 1.1. Assets

Current assets increased from 2 072 k€ to 2 242 k€.

	2010	2011	Differ	ence
Accounts receivable	1 317	1 224	-93	-7%
Liquid assets	746	904	159	+21%
Prepaid expenses	9	113	105	+1205%
Total current assets	2 072	2 242	170	+8%

All figures in thousand of euro

#### 1.1.1. Account receivables

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

These include the European Commission (845 k€, 69%), co-funders (211 k€, 17%) of project such as the 30 months project with DG SANCO "European Platform for Rare Diseases Registries" (Epirare) and funders of the Gala 2012 (75 k€, 5%).

#### 1.1.2. Liquid assets

The increase of liquid assets mainly comes from the collection of 2011 transfers in the context of the Gala 2012 (and thus for expenses that will occur in 2012).

#### 1.1.3. Prepaid expenses

Advance payments were made for the booking of ECRD2012 and Gala Dinner venues.

#### 1.2. Liabilities

#### 1.2.1. Association funds

The overall association funds increased from 496  $k \in$  to 571  $k \in$ , signifying a 15% rise. The dedicated reserves constituted in 2010 for EuroBioBank (EUR 8000) and Europlan (EUR 16 335) have been consumed and the corresponding amounts are transferred to the main reserve.

#### 1.2.2. Provisions

As usual, we have been very cautious to take into account all risks when interpretation of the project contract could be ambiguous, i.e. when we don't have a formal response from the funder, we record a provision for risk and if we have a response we recover the risk.

Hopefully, almost all provisions could be recovered during the year.

			2011	
	2010	Recoveries	New	Balance
			provisions	
Provisions on ongoing contracts	140 609	-114 466	2 917	29 060
Forecasted loss on EUROPLAN	18 593	-18 593	0	0
Provisions for risk and charges	159 202	-133 059	2 917	29 060

All figures in euro

#### 1.2.3. Trade creditors

2010	297 k€	14%
2011	139 k€	6%
difference	- 158 k€	-53%

Trade creditors are monies to be paid to suppliers for invoices that have been received (or to be received) and not paid yet. The level of 2010 was higher because of several invoices received at the end of the year and for which the payments were made in 2011. The situation at the end of 2011 is average.

#### 1.2.4. Deferred income

2010	954 k€	44%
2011	1 372 k€	59%
difference	+ 418 k€	+31%

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

In 2011, this is mainly composed of EC projects (754  $k \in$ , 55%), funds from the Gala 2012 (301  $k \in$ , 22%) and co-funding of projects (205  $k \in$ , 15%).

#### 2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions as well as report of unused incomes, amounted to 3 094 k€. This represents a decrease of 13% compared to 2010.

The bulk of this decrease is due to the European Commission

- end of POLKA (-260 k€) and Europlan (-60 k€) in 2011
- decrease of the 3<sup>rd</sup> DG Sanco Operating Grant (- 153 k€; total 580 k€ to be compared to 2<sup>nd</sup> Operating Grant in 2010 of 733 k€)
- decrease of other costs (no ECRD fees in 2011)

and was compensated by the increase of donations from Pharmaceutical companies  $(+149 \text{ k}\mathbb{C})$ .

The breakdown of EURORDIS' revenue by sources is as follows (amounts are in thousands of euros, recovery of provisions are excluded<sup>1</sup>)

Source of funding
AFM
Membership fees and grants
Volunteers
Patient Org. and Volunteers
European Commission
National authorities
Pharmaceutical companies
Foundations and NPOs
Others
Total

2010		
843	24%	
41	1%	
<i>376</i>	11%	
1 260	35%	
1 380	39%	
95	3%	
541	15%	
131	4%	
146	4%	
3 553	100%	

2011		
860	28%	
33	1%	
419	14%	
1 312	42%	
815	26%	
72	2%	
691	22%	
144	5%	
60	2%	
3 094	100%	

Difference		
17	+2%	
-8	-18%	
43	+11%	
52	+4%	
-565	-41%	
-23	-24%	
149	+28%	
13	+10%	
-86	-59%	
-459	-13%	

All figures in thousand of euro

Overall: 42% of resources are contributed by our members and volunteers, 28% by European and national public authorities, 22% by pharmaceutical companies and 7% from other private resources.

This repartition of funding fully complies with our Policy on Financial Support by Commercial Companies $^2$ : the level of revenues from Pharmaceutical companies represents 22% and is contributed by 38 different pharmaceutical companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (42%).

<sup>&</sup>lt;sup>1</sup> Recovery of provisions are 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.

<sup>&</sup>lt;sup>2</sup> for more details on policy and financial structure, see www.eurordis.org

#### More details on revenues:

#### 2.1. Patient Organisations and Volunteers

2010	1 261 k€	35%
2011	1 312 k€	42%
difference	+52 k€	+4%

This increase is mainly due to our volunteers who increased their participation to advocacy activities. It is also the full time impact of our move to new office space kindly offered by AFM-Téléthon.

#### 2.1.1. Association Française contre les Myopathies (AFM - Téléthon)

2010	843 k€	24%
2011	860 k€	28%
difference	+ 17 k€	+ 2%

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 revenues.

This grant is in the framework of the 2010-2013 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.

Unfortunately, it decreased by 20 k€ in 2011, from 650 k€ to 630 k€.

In addition to the money granted, the AFM provides us with in-kind contribution: one senior staff member, Fabrizia Bignami PhD, Therapeutic Development Director and the office space for the staff in Paris on the Rare Disease Platform.

In 2010, the Rare Diseases Platform moved to a larger more functional and pleasant space. The full time effect, in 2011, has an impact of 39  $k \in$  and compensates the diminution of the grant.

#### 2.1.2. Volunteers

2010	376 k€	11%
2011	419 k€	14%
Difference	+43 k€	+11%

We are impressed by the growing dedication of our volunteers. Altogether, their participation was equivalent to 4 full time equivalent (fte), which means that EURORDIS would have had to recruit 4 full time position right from the start of 2011 to keep the same level of representation at EU level.

But moreover, volunteers are an irreplaceable way to communicate our enthusiasm, thanks to their diversity of experience, skills and background.

They mainly work on Public Affairs issues (2,1 fte) and Orphan Drugs (1,4 fte).

Time spent by volunteers is validated by the volunteer him/herself (98.4%) or estimated by project managers. The overall process is validated by our auditors.

#### 2.2. European Commission

2010	1 380 k€	39%
2011	815 k€	26%
Difference	-565 k€	-41%

The severe reduction of the Operating Grant (from 733 to 580 k€), the end of POLKA: Patients' Consensus on Preferred Policy Scenarii, Europlan: European Project for Rare Diseases National Plans Development and Treat-NMD: Neuromuscular Network caused this 41% diminution.

Since April 1<sup>st</sup> 2011, EURORDIS is involved in a new project coordinated by the Istituto Superiore di Sanità (ISS) and co-financed by the Health and Consumer Protection Directorate-General of EC (DG Sanco). This European Platform for Rare Diseases Registries (Epirare) started on April 1<sup>st</sup> 2011 and will last until October 31<sup>st</sup> 2013. It authorised us the creation of one full time position to enhance our capacities on Registries. It is an excellent opportunity for Patients to contribute to the elaboration of good practices on that very crucial matter.

The co-funding of this project (40%) is covered by Pharmaceutical Companies for the entire period.

In 2012, EURORDIS will be also involved in the EUCERD Joint Action (EJA) for the continuation of the European Project for Rare Diseases National Plans Development (EUROPLAN) and the creation of a new position to work on Social Policy and Specialised Social Services. This new position is in continuation of The Rare Disease Patient Solidarity project (Rapsody) and will allow us to bring Patient's added value on Therapeutic Recreation Programs (TRP), Respite Care Services (RCS) and Adapted Housing.

Lastly, EURORDIS will contribute to the European Clinical Research Infrastructure Network (ECRIN) and European Patients' Academy on Therapeutic Innovation (EUPATI). ECRIN is 100% financed by the Research Directorate-General of EC (DG Research) and EUPATI is co-financed by DG Research (80%) and the European Federation of Pharmaceutical Industries and Associations (EFPIA, 20%). The collaboration with these two networks required the creation of a full time position on training matters, more specifically on the Clinical Trials and Pharmacovigilance areas. This position will be recruited in 2012.

#### 2.3. National authorities

2010	95 k€	3%
2011	72 k€	2%
Difference	- 23 k€	- 24%

The contribution of the National authorities is principally the secondment of François Faurisson, Clinical Research Advisor, from INSERM. François had to leave EURORDIS on August 31<sup>st</sup> 2011, after nine years of secondment. The duration of this secondment is a record and we are very grateful to INSERM for its generosity but still, we would have been happy to be able to keep François Faurisson in the team for another 3 year period.

#### 2.4. Pharmaceutical companies

2010	541 k€	15%
2011	691 k€	22%
Difference	149 k€	+ 28%

Despite the international economic crisis, our Round Table of Companies is constantly increasing: it increased from 290 k $\in$  in 2010 to 315 k $\in$  in 2011 (+25 k $\in$ ).

Other pharmaceutical companies' support consist in co-funding projects (Epirare), supporting the EURORDIS Membership Meeting, the Rare Connect project (Online Patient Communities) and the Gala Dinner.

The 691 k€ are contributed by 38 different companies, the five largest donors being CSL BEHRING, NOVARTIS, SIGMA TAU, GSK and SHIRE. The part of each company in the overall budget is comprised between 0.02% and 2.71%.

The two guarantees of our independence are (1) the limitation of overall amount compared to income of Patient Organisation provenance and (2) the diversity of donors. In 2011, the number of companies increased from 32 to 38.

#### 2.5. Others

2010	145 k€	4%
2011	60 k€	2%
difference	-85 k€	-59%

Other revenue includes conference fees, reimbursements, financial revenue, etc.

The difference between 2011 and 2010 is mainly explained by the registration fees of ECRD 2010 Krakow that amounted to 71 k€.

#### 3. Expenses

The operating expenses, including in-kind contributions and excluding provisions, amounted to 3 148 k€, which shows a decrease of 8% compared to 2010.

The breakdown of EURORDIS' expenses is as follows (in thousands of euros, provisions excluded<sup>3</sup>)

Expenses		
Staff costs		
Volunteers		
Travel and subsistence		
Services		
Purchase		
Financial and insurance expenses		
Total		

2010		
1 552	45%	
376	11%	
378	11%	
998	29%	
106	3%	
6	0%	
3 416	100%	

2011			
1 579	50%		
419	13%		
321	10%		
687	22%		
135	4%		
7	0%		
3 148	100%		

Difference		
27	+2%	
43	+11%	
-57	-15%	
-311	-31%	
29	+27%	
1	+11%	
-268	-8%	

All figures in thousand of euro

The decrease is due to the absence of ECRD in 2011 compared to 2010 (ECRD2010 – Krakow).

#### More details on expenses:

#### 3.1. Staff costs

2010	1 552 k€	45%
2011	1 579 k€	50%
difference	+ 27 k€	+ 2%

The number of FTE<sup>4</sup> was 22.9 in 2011, thus an increase of 1 FTE (+ 4%).

This increase results from plus and minus: On the one hand we have, in 2011, the full time impact of 4 positions created in 2010 (1. Event Manager, 2. Volunteers and NGO Partners Coordinator, 3. Online Patient Coordinator, 4. Communications and Development Director) and the creation of a position in 2011 (Registry Project Manager); On the other hand, we had some departures in 2011 that were not replaced.

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, one self-employed unlimited contract and one office volunteer. Hence an overall total of 25 staff members.

<sup>&</sup>lt;sup>3</sup> Recovery of provisions are 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.

<sup>&</sup>lt;sup>4</sup> 1 full time equivalent = 1 people on a full time position during one year

#### 3.2. Volunteers

Together, EURORDIS volunteers represent 4 full-time equivalents. Please see 2.1.2. above.

#### 3.3. Travel and subsistence

2010	378 k€	11%
2011	321 k€	10%
difference	-57 k€	-15%

The absence of major event such as ECRD in 2011 and the stop of Europlan allowed us to reduce travel and subsistence expenses.

#### 3.4. Services

2010	998 k€	29%
2011	687 k€	22%
difference	-311 k€	-31%

The amount of services was 650 k€ in 2009, which is constant with 2011, 2010 being the exception with the organisation of the European Conference on Rare Diseases in Krakow (ECRD 2010, 220 k€) and the conception of the Play Decide Games (90 k€) in partnership with ECSITE, the European Network of Science Museums.

#### 4. Result

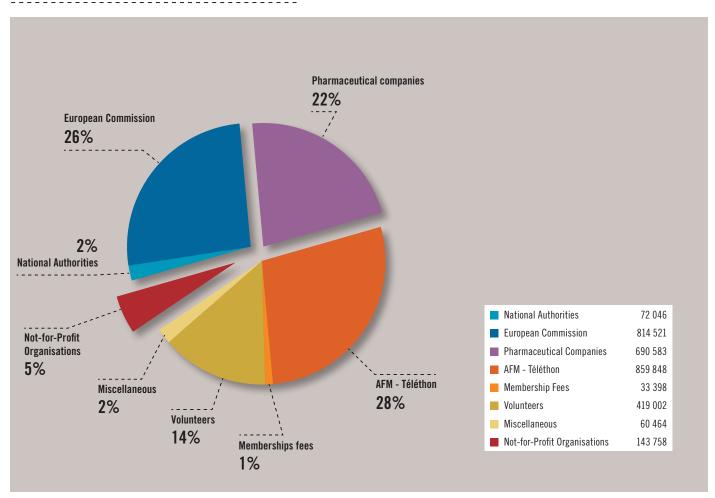
The 2011 surplus amounted to EUR 75 747 and we suggest to allocate it to the reserve.

The reserve fund would then be increased by EUR 75 747 to EUR 571 027, which will represent approximately 4 months of low-level activity.

### **REVENUE** and expenses 2011

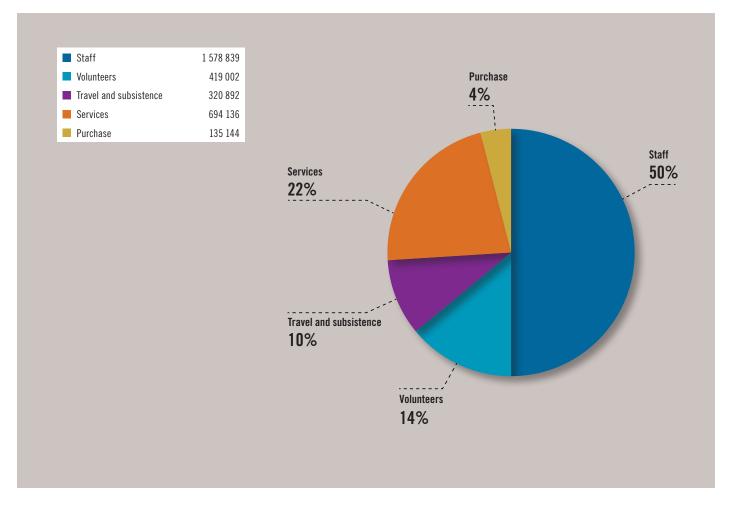
(in euros, provisions excluded)

### Revenue by origin 2011 = 3,094 k€





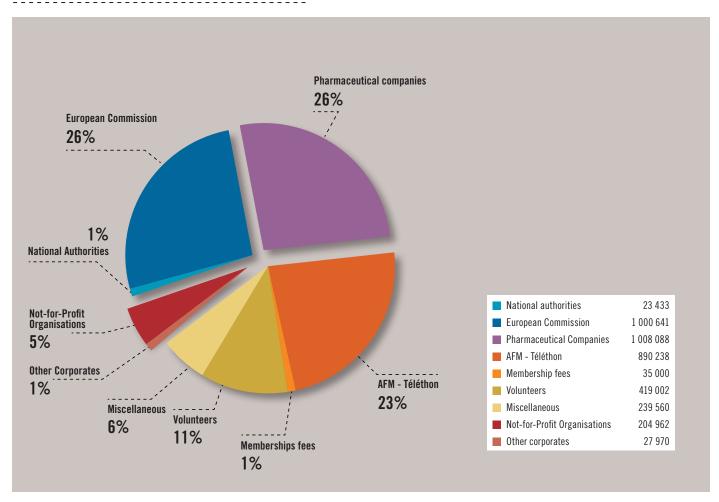
# Expenses by Type 2011 = 3,148 k€



### **BUDGET** 2012

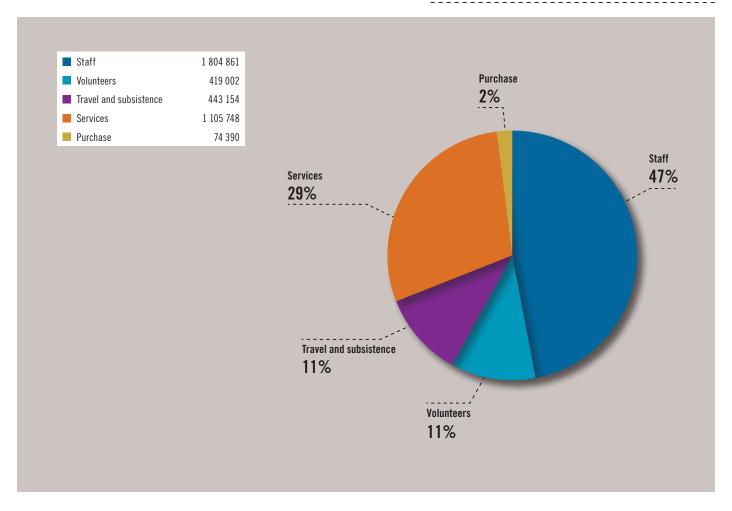
(in euros, provisions excluded)

### Revenue by origin 2012 = 3,849 k€





## Expenses by Type 2012 = 3,847 k€



#### 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:

- Polka (Patients' consensus on preferred policy scenarii for rare diseases),
  - o from 01-Sep-08 to 31-Aug-11
  - EURORDIS is main beneficiary
- Europlan (European Project for Rare Diseases National Plans Development)
  - o from 01-Apr-08 to 31-Mar-11
  - EURORDIS is co-beneficiary
- EURORDIS FY2011 (2011 Operating Grant)
  - o from 01-Jan-11 to 31-Dec-11
- Epirare (European Platform for Rare Diseases Registries),
  - o from 01-Apr-11 to 31-Oct-13
  - EURORDIS is co-beneficiary

*DG Research:* Research Directorate-General of EC Ongoing Projects:

- Treat-NMD (Translational Research in Europe Assessment and Treatment of Neuromuscular Diseases)
  - o from 01-Jan-07 to 31-Dec-2011
  - EURORDIS as co-beneficiary

ECRD: European Conference on Rare Diseases.

5 of them already occurred

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 sixth will occur in May 2012 in Brussels.

EMA: European Medicine Agency

EUCERD: European Union Committee of Experts on Rare Diseases



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