

Rare Diseases Europe



FINANCIAL REPORT

2010

Amsterdam, May 2011



www.eurordis.org

EURORDIS

Association governed by the French law of 1901

96, rue Didot
75014 PARIS

STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2010

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Association governed by the French law of 1901

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75014 PARIS

STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2010

In compliance with the assignment entrusted to us by the Members' meeting, we hereby report to you, for the year ended December 31, 2010, 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 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, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements give a true and fair view of the EURORDIS Association financial position and its assets and liabilities, as of December 31, 2010 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 inform you that the assessments to which we proceeded related to 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 enable us to express an unqualified opinion 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 financial report and in the documents addressed to the members with respect to the financial position and the financial statements.

Neuilly-sur-Seine, May 09, 2011

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 with, and construed in accordance with, French law and professional auditing standards applicable in France.



Eurordis financial reporting
(Assets and Liabilities)

Assets	2009	2010	Ratio	Difference
FIXED ASSETS				
Intangible assets	475	2 189	361%	1 714
Tangible assets	49 622	73 136	47%	23 514
Financial assets	532	532	0%	0
TOTAL	50 629	75 857	50%	25 228
CURRENT ASSETS				
Account receivable due within one year	807 169	1 317 292	63%	510 123
Account receivable due after one year	349 610	0	-100%	-349 610
Liquid assets	674 216	745 789	11%	71 573
Deferred expenses	16 399	8 695	-47%	-7 704
TOTAL	1 847 394	2 071 776	12%	224 382
TOTAL ASSETS	1 898 023	2 147 633	13%	249 610

Liabilities	2009	2010	Ratio	Difference
ASSOCIATION FUNDS				
Reserve	347 484	375 493	8%	28 008
Profit & loss for the year	28 008	119 549	327%	91 540
Subsidies of investment	1 691	965	-43%	-726
TOTAL	377 184	496 006	32%	118 823
Provisions for risk and charges	108 526	159 202	47%	50 676
Dedicated funds on grants	33 500	0	-100%	-33 500
DEBTS				
Bank loans and overdraft	0	0	NA	0
Trade creditors	167 984	297 164	77%	129 180
Tax payable and social liabilities	170 023	211 565	24%	41 542
Other debts	0	29 364	NA	29 364
Deferred income within one year	714 774	954 332	34%	239 558
Deferred income after one year	326 033	0	-100%	-326 033
TOTAL	1 520 840	1 651 627	9%	130 787
TOTAL LIABILITIES	1 898 023	2 147 633	13%	249 610

2010 Financial statement as of 31/12/2010

(Profit and Loss including in kind contributions)

Revenue	2009	2010	Ratio	Δ in euros	Δ in %
Patient Organisations	879 633	884 874	24%	5 241	1%
AFM Telethon Grants	622 000	650 000	18%	28 000	5%
In kind contributions (AFM)	165 936	193 202	5%	27 266	16%
Membership fees and grants	81 784	41 422	1%	-40 362	-49%
Donations from individuals	9 913	250	0%	-9 663	-97%
Volunteers (*)	406 622	375 990	10%	-30 632	-8%
Representative and task forces	369 702	334 302	9%	-35 400	-10%
Project, office and translators	36 920	41 688	1%	4 768	13%
European Commission	767 802	1 379 775	38%	611 973	80%
DG Research	50 934	143 369	4%	92 435	181%
DG Health and consumers	675 657	1 180 687	32%	505 030	75%
EMA in kind contributions	41 211	55 720	2%	14 508	35%
National authorities	97 642	95 184	3%	-2 458	-3%
Corporate funding	478 141	546 811	15%	68 669	14%
Pharma. and Biotech Cie	478 141	541 360	15%	63 219	13%
Other corporate funding		5 451	0%	5 451	
Foundations and NPOs	154 129	130 517	4%	-23 612	-15%
Pharma. and Biotech Found.	154 129	130 517	4%	-23 612	-15%
Miscellaneous	78 108	139 958	4%	61 850	79%
Fees	26 581	78 555	2%	51 975	196%
In kind contributions (Others)	32 216	22 500	1%	-9 716	-30%
Reimbursement	9 692	25 938	1%	16 246	168%
Others	9 620	12 965	0%	3 345	35%
Sub-total	2 862 078	3 553 109	98%	691 031	24%
Recovery of provisions	15 263	51 757	1%	36 494	239%
Report of non-used income	14 916	33 500	1%	18 584	125%
Total Revenue	2 892 256	3 638 366	100%	746 109	26%

Expenses	2009	2010	Ratio	Δ in euros	Δ in %
Staff	1 297 471	1 551 659	44%	254 189	20%
Wages and charges	1 141 831	1 406 740	40%	264 909	23%
Other salaries	139 495	112 130	3%	-27 365	-20%
Training and other costs	16 145	32 789	1%	16 644	103%
Volunteers (*)	406 622	375 990	11%	-30 632	-8%
Representative and task forces	369 702	334 302	10%	-35 400	-10%
Project, office and translators	36 920	41 688	1%	4 768	13%
Travel and subsistence	277 835	378 186	11%	100 351	36%
Travels	233 766	322 466	9%	88 700	38%
In kind contribution	44 069	55 720	2%	11 650	26%
Services	649 654	998 214	28%	348 560	54%
Fees	351 437	429 385	12%	77 948	22%
Event logistics and catering	81 806	277 790	8%	195 984	240%
EC projects partners	9 769	17 857	1%	8 088	83%
Telecom and post	53 625	38 486	1%	-15 140	-28%
Rent	104 079	117 543	3%	13 464	13%
Other services	48 937	117 152	3%	68 215	139%
Purchase	96 683	106 357	3%	9 674	10%
Office furniture	28 282	29 843	1%	1 562	6%
Amortization	21 458	30 111	1%	8 653	40%
Publications	39 102	28 485	1%	-10 617	-27%
Other purchases	7 841	17 917	1%	10 076	128%
Financial and insurance expenses	5 302	5 978	0%	677	13%
Sub-total	2 733 565	3 416 384	97%	682 818	25%
Contingency and loss provisions	97 183	102 433	3%	5 250	5%
Commitment on assigned income	33 500			-33 500	
Total Expenses	2 864 248	3 518 817	100%	654 569	23%
Result	28 008	119 549			

Introduction

The profit and loss figures have increased by 24%¹, the main reasons being i) the European Conference on Rare Diseases in Krakow (ECRD2010) which was the largest ECRD organised so far, ii) the significant increase (+55% compared to 2009) of the Operating Grant with DG Sanco (EUR 733 388).

Despite the absence of new pluriannual contract in 2010, the assets and liabilities table shows a slight increase (+13%). This is because the first instalment of the Operating Grant 2011 (EURORDIS FY2011) was transferred in 2010.

1. Assets and Liabilities

1.1. Assets

Current assets increased from 1 847 k€ to 2 072 k€.

	2009	2010	Difference	
Accounts receivable	1 157	1 317	161	+14%
Liquid assets	674	746	72	+11%
Prepaid expenses	16	9	-8	-47%
Total current assets	1 847	2 072	224	+12%

All figures in thousand of euro

1.1.1. Account receivables

Accounts receivable are monies to be received from funders with whom an agreement has been signed.

These include the European Commission (1 069 k€, 81%), co-funders (150 k€, 11%) of the three-year project with DG SANCO "*Patients' consensus on preferred policy scenarii for rare diseases*" (POLKA) and funders of the Gala 2012 (50 k€, 4%).

1.1.2. Liquid assets

In December 2010, we received the first instalment of the Operating Grant 2011, hence the increase of liquid assets (the first instalment of the 2010 grant was received in early 2010).

1.2. Liabilities

1.2.1. Association funds

The overall association funds increased from 377 k€ to 496 k€, signifying a 32% rise.

¹ Total revenue before recovery of provisions

1.2.2. Provisions

	2009	2010	Difference	
Provisions for risk and charges	109	159	50	+46%
Dedicated funds on grants	33	0	-33	-100%
Total current assets	142	159	17	+12%

All figures in thousand of euro

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.

	2009	2010		
		Recoveries	New provisions	Balance
Provisions on completed contracts	11 344	-11 344	0	0
Provisions on ongoing contracts	40 084	-1 908	102 433	140 609
Forecasted loss on EUROPLAN	57 099	-38 506	0	18 593
Provisions for risk and charges	108 527	-51 758	102 433	159 202
Polka co-funding	33 500	-33 500	0	0
Dedicated funds on grants	33 500	-33 500	0	0

All figures in euro

Provisions amounted to 159 k€ in 2010, which comprises

- risk in the framework of completed or ongoing contracts (141 k€)
- a forecasted loss on EUROPLAN (19 k€)²

Dedicated funds were totally consumed for Polka in 2010.

1.2.3. Trade creditors

2009	168 k€	9%
2010	297 k€	14%
difference	+ 129 k€	77%

Trade creditors are monies to be paid to suppliers for invoices received or to be received. The level is higher than in 2009 because of several invoices received at the end of the year and for which the payments were made in 2011.

² EUROPLAN is a three year (01/04/2008 – 31/03/2011) project in which we are an associated partner. In 2009, after attempts to find co-funding in 2008-2009 failed, we considered it reasonable to record a provision for 2010-2011. It has been updated for the last three months of 2011.

1.2.4. Deferred income

2009	1 041 k€	55%
2010	954 k€	44%
difference	- 86 k€	-8%

Deferred income refers to the part of grants concerning the incoming years. The fact that they are consistent with the accounts receivable means that the cash flow is consistent with budget consumption.

In 2010, this is mainly composed of EC projects (749 k€, 79%), co-funding of POLKA (150 k€, 16%) and co-funding of the Gala 2012 (50 k€, 5%).

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions as well as report of unused incomes, amounted to 3 553 k€. This represents a growth of 24% compared to 2009.

The bulk of this increase is due to the European Commission:

- increase of the 2nd annual Operating Grant from DG SANCO (+ 260 k€), total 733 k€, to be compared to 1st Operating Grant in 2009 of 473 k€
- increase of consumption of POLKA's budget due to the costs of ECRD2010 and Play Decide games concentrated in 2010 (+ 209 k€)

The breakdown of EURORDIS' revenue by sources is as follows (amounts are in thousands of euros, recovery of provisions are excluded³)

Source of funding	2009		2010		Difference	
<i>AFM</i>	788	28%	843	24%	55	+7%
<i>Membership fees and grants</i>	82	3%	41	1%	-41	-50%
<i>Volunteers</i>	407	14%	376	11%	-31	-8%
<i>Individual donations</i>	10	0%	0	0%	-10	-97%
Patient Org. and Volunteers	1 287	45%	1 261	35%	-26	-2%
European Commission	768	27%	1 380	39%	612	+80%
National authorities	98	3%	95	3%	-2	-3%
Pharmaceutical companies	478	17%	541	15%	63	+13%
Foundations and NPOs	154	5%	131	4%	-24	-15%
Others	78	3%	145	4%	68	+87%
Total	2 862	100%	3 553	100%	691	+24%

All figures in thousand of euro

Overall: 35% of resources are contributed by our members and volunteers, 41% by European and national public authorities, 15% by pharmaceutical companies and 8% from other private resources (cf. graphs).

This repartition of funding fully complies with our Policy on Financial Support by Commercial Companies⁴: the level of revenues from Pharmaceutical companies

³ 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.

represents 15% and it contributed by 32 different pharmaceutical companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (35%).

More details on revenues:

2.1. Patient Organisations and Volunteers

2009	1 287 k€	45%
2010	1 261 k€	35%
difference	- 26 k€	- 2%

This decrease, due to several factors (decrease of NORD's grant for the online patient communities project, volunteers allocated on national plans, no individual donations) has been partly compensated by the increase of the grant from AFM-Téléthon.

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

2009	788 k€	28%
2010	843 k€	24%
difference	+ 55 k€	+ 7%

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.

In 2010, it increased by 28 k€, from 622 k€ in 2009 to 650 k€ in 2010.

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, which is the second reason of this increase.

⁴ for more details on policy and financial structure, see www.eurordis.org

2.1.2. Volunteers

2009	407 k€	14%
2010	376 k€	11%
Difference	- 31 k€	- 8%

2010 was the first year of intense work on national plans across EU. Thus, the volunteers contributing to the European Public Affairs Committee (EPAC) have worked more on a national level, hence the decrease of their implication with EURORDIS, which does not mean a decrease of their implication with rare diseases at large.

This decrease (-65 k€) was partly compensated by the increase on the work with the European Medical Agency (EMA, Task Forces) and some international NGOs such as EPPOSI (+34 k€).

Together, this represents 3.5 full-time equivalents (752 days), with a high level of competence and commitment, as well as a broad range of national cultures and rare diseases represented.

Time spent by volunteers is, in most cases, validated by the volunteer him/her self (94%) or estimated by project managers (6%). The overall process is validated by our auditors. We are grateful to the volunteers who kindly took time to answer our requests for appraisal of the economic value of their time.

2.2. European Commission

2009	768 k€	27%
2010	1 380 k€	39%
difference	+ 612 k€	+ 44%

In 2010, several activities initiated in 2008/2009 reached a peak:

- The Operating Grant, which increased significantly (+ 260 k€)
- Polka, with the ECRD2010 and the PlayDecide games (+ 209 k€)
- EUROPLAN, with 15 conferences organised in 15 different Member States (+ 30 k€)

In addition, we had some formal approval from the Treat-NMD consortium - about funding concerning previous years – that allowed us to record some additional funds in 2010 that had not been recorded previously by precaution (+ 92 k€).

An Operating Grant is a financial instrument that allows us to fund recurrent activities (whereas projects only allow us to fund new activities thus obliging the initiation of new activities without any financial perspective to sustain them).

The main limitation of this financial instrument is that we don't have any formal guarantee of renewal and as it co-funds recurrent activities, the fact that the grant can theoretically end or significantly vary in its amount from one year to another, results in a lack of economic visibility for the robust management of our organisation.

In 2010, we had at the same time an opportunity of a 55% increase compared to 2009 while facing a severe decrease of 21% for 2011. As a consequence, we had to cancel some plans for recruitments such as the Research Policy Manager and put some activities such as the European Network of Help Lines on hold, including discontinuation in the employment of the manager to support this activity.

In addition, as of 2011, the EC contribution will decrease by 5 points each year. It means that the EC Contribution, which was 60% in 2009 and 2010, will be 55% of expenses in 2011, 50% in 2012... and so on.

The implication is that we must be able to secure increasing co-funding from our own resources or co-funding sources while the level of core funding from commercial companies representing a conflict of interest is limited to 20% to ensure financial independence.

In conclusion, our experience of this financial instrument is that it is a great opportunity to develop some activities but it can also severely jeopardises an organisation.

2.3. National authorities

2009	98 k€	3%
2010	95 k€	3%
difference	- 3 k€	- 2%

The contribution of the National authorities is principally the secondment of François Faurisson, Clinical Research Advisor, from INSERM.

2.4. Pharmaceutical companies

2009	478 k€	17%
2010	541 k€	15%
difference	63 k€	+ 12%

Despite the international economic crisis, our Round Table of Companies appears to be very attractive: contributions from pharmaceutical companies increased from 245 k€ in 2009 to 290 k€ in 2010 (+45 k€, 18%).

Other pharmaceutical companies support are co-funding of projects and corporate partnership in support of the European Conference on Rare Diseases

The 541 k€ are contributed by 32 companies, the five largest contributors being SIGMA TAU (2.11%), CSL BEHRING (1.69%), NOVARTIS (1.69%), CELGENE (1.45%), GENZYME (0.93%).

2.5. Others

2009	78 k€	3%
2010	145 k€	4%
difference	+ 68 k€	+ 47%

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

The difference between 2009 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 3 416 k€, which shows a growth of 25% compared to 2009.

The breakdown of EURORDIS' expenses is as follows
(in thousands of euros, provisions excluded⁵)

Expenses	2009		2010		Difference	
Staff costs	1 297	47%	1 552	45%	254	+20%
Volunteers	407	15%	376	11%	-31	-8%
Travel and subsistence	278	10%	378	11%	100	+36%
Services	650	24%	998	29%	349	+54%
Purchase	97	4%	106	3%	10	+10%
Financial and insurance expenses	5	0%	6	0%	1	+13%
Total	2 734	100%	3 416	100%	683	+25%

All figures in thousand of euro

Half expenses growth are due to an increase of Services (+ 349 k€) and the rest is spread on the Staff costs (+ 254 k€) and Travel and subsistence lines (+ 100 k€).

More details on expenses:

3.1. Staff costs

2009	1 297 k€	47%
2010	1 552 k€	45%
difference	+ 254 k€	+ 16%

The number of FTE⁶ was 21.9 in 2010, thus an increase of 2.8 FTE (+ 18%), comparable to the staff increase of 2009 (+ 2 FTE).

⁵ 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.

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

Of these 2.8 fte, 2.5 are from the creation of four new full time positions:

- an Events Manager responsible for the organisation of several events such as the Membership Meeting, the Summer School, ECRD and the Gala Diner (0.9 fte)
- a Volunteers and NGO Partners Coordinator (0.9 fte)
- an Online Patient Communities Coordinator (0.33 fte)
- a Communications and Development Director (0.33 fte)

In addition to these new positions, there have been some limited contracts and trainees that partially compensated for the non-replacement of the Help Lines Coordinator.

3.2. Volunteers

Together, EURORDIS volunteers represent 3.5 full-time equivalents. Please see 2.1.2. above.

3.3. Travel and subsistence

2009	278 k€	10%
2010	378 k€	11%
difference	+ 100 k€	+ 27%

The first reason for this decrease is the ECRD2010 as we cover costs of travel and subsistence for speakers, staff, etc.

In addition, thanks to the increase of the Operating Grant and to private sponsors, we had the opportunity to propose fellowships for patients' representatives to attend the conference.

The growing volume of activity of Europlan, the Rare Disease Day event in Brussels and the organisation of several workshops are also responsible for this increase.

3.4. Services

2009	650 k€	24%
2010	998 k€	29%
difference	+ 349 k€	+ 35%

This increase is due to 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

In 2011, 2 activities will not be funded:

1. the EuroBioBank annual meeting: usually, the Treat-NMD project covers 100% of these costs but, as 2011 is the last year of this project, they do not have enough budget to cover all costs and have refused to cover the costs of travel and subsistence allowances of this meeting for 2011. We evaluate these costs to EUR 8 000.
2. the Europlan project ends on March 31st 2011. However, this does not mean that the animation of the national plans does not need to continue. It should be funded again right from the start of 2012 in the context of the Joint Action on Rare Diseases (co-funded by DG Sanco) but in the meantime, we will have EUR 16 335 of costs that are not covered by a grant.

The 2010 surplus amounted to EUR 119 549 and we suggest to allocate it as follows:

- EUR 8 000 to the EuroBioBank related activities
- EUR 16 335 to the Europlan related activities
- EUR 95 214 to the main reserve

The reserve fund would then be increased by EUR 95 214 to EUR 470 707, which will then represent approximately 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:

- *Polka* (Patients' consensus on preferred policy scenarii for rare diseases),
 - o from 01-Sep-08 to 31-Aug-11
 - o EURORDIS is main beneficiary
- *Euoplan* (European Project for Rare Diseases National Plans Development)
 - o from 01-Apr-08 to 31-Mar-11
 - o EURORDIS is co-beneficiary
- *EURORDIS FY2010* (2010 Operating Grant)
 - o from 01-Jan-10 to 31-Dec-10

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
 - o 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)

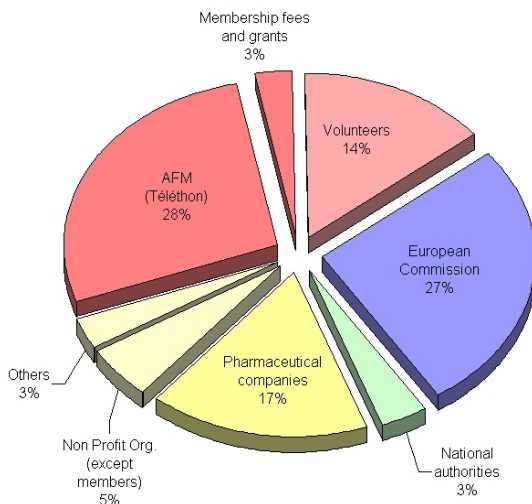
ECRD2003, in Evry (France, organised by Alliance Maladies Rares)

ECRD2001, in Copenhagen (organised by Rare Disorders Denmark)

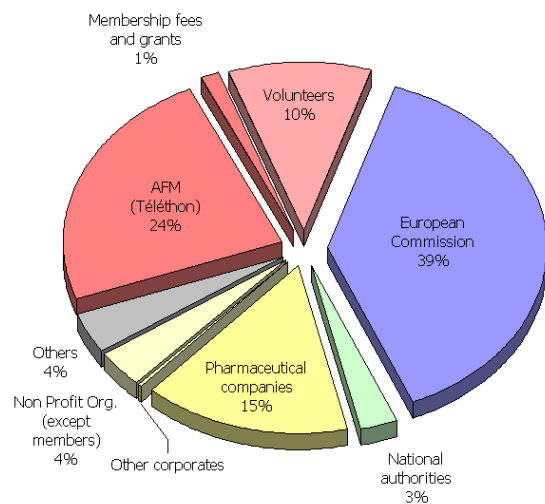
The sixth will occur in May 2012 in Amsterdam.

EMA: European Medicine Agency

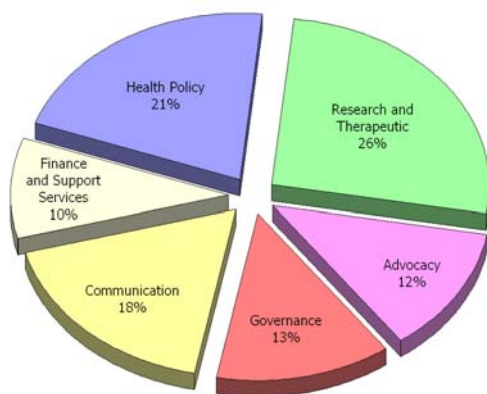
Revenue and expenses 2009 - 2010
(in thousand of euros, provisions excluded)



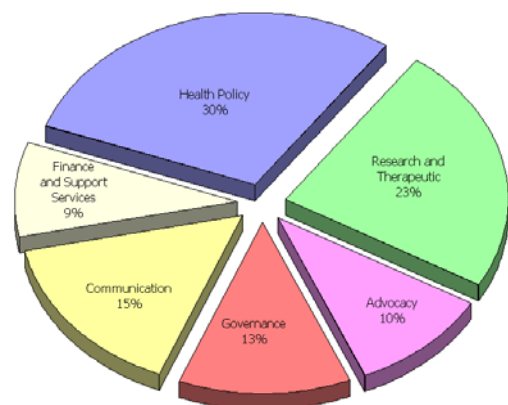
Revenue 2009 = 2,862



Revenue 2010 = 3,553



Expenses 2009 = 2,733



Expenses 2010 = 3,519