

EUROPEAN ORGANISATION FOR RARE DISEASES

Financial Report $\rightarrow 2009$









Paris, March 2010





Foreword by the Treasurer



In 2009, the European Commission's Directorate General for Health and Consumers (DG SANCO), introduced a new financial instrument, the Operating Grant. The 2009 EURORDIS Operating Grant has been used to co-fund recurrent activities such as Networking, Services to Patients, Therapeutic Development and Communications. This new contract has enabled us to increase our budget by $0.4~\mathrm{M}\odot$ for a total of $2.9~\mathrm{M}\odot$ the maximum amount ever reached by EURORDIS.

These new developments have been possible thanks to the continued financial support of the French Muscular Dystrophy Association (Association Française contre les Myopathies, AFM-Téléthon). Currently, for each euro donated by the French Telethon, EURORDIS is able to raise almost three euros from the European Commission, volunteers and private sources. To allow us to be totally independent from any stakeholders other than patient organisations, the AFM covers 100% of our office and staff costs in Brussels dedicated to our advocacy and public affairs activities.

The contribution of volunteers to EURORDIS activities also reached a peak. More volunteers represented EURORDIS at meetings, conferences, workshops as well as in several committees at the European Medicine Agency (EMA). Notwithstanding the economic value of their time and experience, the knowledge and dedication of a large number of these volunteers is vital for the maintenance of EURORDIS activities and contacts. They now represent 4 full-time equivalents or 15% of our expenses.

For the year 2010, we expect three major financial events: (i) renewal of the three-year collaborative agreement with AFM for the period 2010-2012 and its consolidation, (ii) the 2010 EURORDIS Operating Grant has been awarded for 733 388 € and the contract has been signed with the Executive Agency for Health and Consumers; in addition, two further applications will be submitted for 2011 (in March 2010) and 2012 (in December 2010). Finally, (iii) a Communications and Development Director will be hired to develop the funding from the private sector. Our goal is to establish by 2015 an equilibrium for funding with one-third from patient organisations and volunteers, one-third from the public sector and one-third from the private sector (both from corporations and not-for-profit organisations).

Jean Elie Treasurer



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EURORDIS

Association governed by the French law of 1901

102, rue Didot 75014 PARIS Deloitte.



Statutory auditor's report on the financial statements 2009

year ended December 31, 2009

In compliance with the assignment entrusted to us by the Members' meeting, we hereby report to you, for the year ended December 31, 2009, 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, 2009 and the results of its operations for the year then ended in accordance with French accounting regulations.

Société anonyme au capital de 1 723 040 € Société d'Expertise Comptable inscrite au Tableau de l'Ordre du Conseil Régional de Paris / Ile-de-France Société de Commissaires aux Comptes, membre de la Compagnie régionale de Versailles 572 028 041 RCS Nanterre TVA: FR 02 572 028 041

Member of Deloitte Touche Tohmatsu

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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, April 23, 2010

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.

2009 Eurordis financial Statement as of December 31st

(Assets and Liabilities)

Assets	2008	2009	Ratio	Difference
FIXED ASSETS				
Intangible assets	1 996	475	-76%	-1 521
Tangible assets	41 412	49 622	20%	8 211
Financial assets	532	532	0%	0
TOTAL	43 940	50 629	15%	6 689
CURRENT ASSETS				
Account receivable due within one year	508 503	807 169	59%	298 666
Account receivable due after one year	810 753	349 610	-57%	-461 143
Liquid assets	824 638	674 216	-18%	-150 421
Deferred expenses	1 977	16 399	729%	14 422
TOTAL	2 145 871	1 847 394	-14%	-298 476
TOTAL ASSETS	2 189 810	1 898 024	-13%	-291 787

Liabilities	2008	2009	Ratio	Difference		
ASSOCIATION FUNDS						
Reserve	316 360	347 484	10%	31 125		
Profit & loss for the year	31 124	28 008	-10%	-3 116		
Subsidies of investment	2 417	1 691	-30%	-726		
TOTAL	349 901	377 184	8%	27 283		
Provisions for risk and charges	26 606	108 526	308%	81 920		
Dedicated funds on grants	14 916	33 500	125%	18 584		
DEBTS						
Bank loans and overdraft	0	0	NA	0		
Trade creditors	147 457	167 984	14%	20 527		
Tax payable and social liabilities	147 356	170 023	15%	22 667		
Other debts	48 759	0	-100%	-48 759		
Deferred income within one year	630 067	714 774	13%	84 707		
Deferred income after one year	824 748	326 033	-60%	-498 715		
TOTAL	1 839 909	1 520 840	-17%	-319 069		
TOTAL LIABILITIES	2 189 810	1 898 024	-13%	-291 787		

2009 Financial Statement as of December 31th

(Profit and Loss including in kind contributions)

Revenue	2008	2009	Ratio
Patient Organisations	792 070	879 633	31%
AFM Telethon Grants	588 720	622 000	22%
In kind contributions (AFM)	179 166	165 936	6%
Membership fees and grants	23 919	81 784	3%
Donations from individuals	265	9 913	0%
Volunteers	262 935	406 622	14%
Representative and task forces	225 113	369 702	13%
Project, office and translators	37 823	36 920	1%
European Commission	243 942	767 802	27%
DG Research	108 940	50 934	2%
DG Health and consumers	119 835	675 657	24%
EMA in kind contributions	15 167	41 211	1%
National authorities	87 259	97 642	3%
Corporate funding	492 000	478 141	17 %
Pharma. and Biotech Cie	492 000	478 141	17%
Foundations and NPOs	186 154	154 129	5%
Pharma. and Biotech Found.	176 154	154 129	5%
Other Found. and NPOs	10 000	0	0%
Miscellaneous	42 410	78 108	3%
Fees	3 206	26 581	1%
In kind contributions (Others)	9 935	32 216	1%
Reimbursment	11 352	9 692	0%
Others	17 916	9 620	0%
Sub-total	2 106 769	2 862 078	100%
Recovery of provisions	46 375	15 263	- <u> </u>
Report of non-used income	40 000	14 916	-
TOTAL REVENUE	2 193 144	2 892 256	-

Δ in euros	Δin %
87 563	11%
33 280	6%
-13 230	-7%
57 865	242%
9 648	3641%
143 686	55%
144 590	64%
-903	-2%
523 861	215%
-58 006	-53%
555 822	464%
26 044	172%
10 383	12%
-13 859	-3%
-13 859	-3%
-32 024	-17%
-22 024	-13%
-10 000	-100%
35 699	84%
23 374	729%
22 281	224%
-1 660	-15%
-8 296	-46%
755 309	36%
-31 112	-67%
-25 084	-63%
699 112	32%

Expenses	2008	2009	Ratio
Staff	1 151 065	1 297 471	47%
Wages and charges	1 046 704	1 141 831	42%
Other salaries	101 934	139 495	5%
Training and other costs	2 428	16 145	1%
Volunteers	262 935	406 622	15%
Representative and task forces	225 113	369 702	14%
Project, office and translators	37 823	36 920	1%
Travel and Subsistence	155 951	277 835	10%
Travel and Subsistence	140 784	233 766	9%
In kind contribution	15 167	44 069	2%
Services	470 769	649 654	24%
Fees	230 754	351 437	13%
Event logistics and catering	51 655	81 806	3%
EC projects partners	9 137	9 769	0%
Telecom and post	45 089	53 625	2%
Rent	96 749	104 079	4%
Other services	37 384	48 937	2%
Purchase	81 498	96 683	4%
Office furniture	22 310	28 282	1%
Amortization	14 715	21 458	1%
Publications	27 571	39 102	1%
Other purchases	16 902	7 841	0%
Financial and insurance expenses	4 580	5 302	0%
Sub-total	2 126 797	2 733 565	100%
Contingency and loss provisions	20 306	97 183	-
Commitment on assigned income	14 916	33 500	-
TOTAL EXPENSES	2 162 019	2 864 248	-
SURPLUS	31 126	28 008	_

Δ in euros	Δ in %
146 406	13%
95 127	9%
37 561	37%
13 717	565%
143 686	55%
144 590	64%
-903	-2%
121 884	78%
92 982	66%
28 902	191%
178 885	38%
120 683	52%
30 150	58%
632	7%
8 536	19%
7 330	8%
11 553	31%
15 185	19%
5 972	27%
6 743	46%
11 531	42%
-9 061	-54%
722	16%
606 768	29%
76 877	379%
18 584	125%
702 230	32%



The revenue and expense figures have increased significantly, despite the absence of any major event such as the European Conference on Rare Diseases (ECRD): the total revenue before recovery of provisions increased by 36%1. This growth is due to i) the signing of the first Operating Grant (OPERA) with DG SANCO (EUR 473 075) and ii) the increased implication of our volunteers in Public Affairs and the Task Forces related to represen-

tation of EURORDIS representatives in the scientific committees and working parties at the European Medicine Agency (EMA). The overall increase of volunteers is estimated to be EUR 143 686.

In contrast, as EURORDIS did not sign any new pluriannual contract in 2009, the assets and liabilities table shows a slight decrease (-13%).



1.Assets and Liabilities

1.1 Assets

Current assets decreased from 2 146 k€ to 1 847 k€.

	2008	2009	Difference	
Accounts receivable	1 319	1 157	-162	-12%
Liquid assets	825	674	-150	-18%
Prepaid expenses	2	16	14	+729%
Total current assets	2 146	1 847	-298	-14%

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 (758 k€, 66%) and co-funders of the three-year project with DG SANCO "Patients' consensus on preferred policy scenarii for rare diseases" (POLKA, 300 k€, 26%).

1.1.2 Liquid assets

Liquid assets are consistent with figures for 2009 while those for 2008 were particularly high because of a payment received in December 2008.

1.2 Liabilities

1.2.1 Association funds

The overall association funds increased from 350 k€ to 377 k€, signifying an 8% rise.

1.2.2 Provisions

	2008	2009	Difference	
Provisions for risk and charges	27	109	82	+304%
Dedicated funds on grants	15	33	18	+120%
Total current assets	42	142	100	+238%

All figures in thousand of euro

As usual, we have been very cautious to take into account all risks when interpretation of the 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.

	2000	2009			
	2008	Recoveries	New provisions	Balance	
Provisions on completed contracts	26 622	-15 278	0	11 344	
Provisions on ongoing contracts	0	0	40 084	40 084	
Forecasted loss on EUROPLAN	0	0	57 099	57 099	
Provisions for risk and charges	26 622	-15 278	97 183	108 527	
nEUroped co-funding (AFM)	4 201	-4 201	0	0	
Polka co-funding	10 715	-10 715	33500	33500	
Dedicated funds on grants	14 916	-14 916	33 500	33 500	

Provisions amounted to 109 k€ in 2009, which comprises

- risk in the framework of completed or ongoing contracts (52 k€)
- a forecasted loss on EUROPLAN (57 k€)²

Dedicated funds were totally consumed for nEUroped in

For Polka co-funding, we have recorded 33 k€. As the costs on Polka will mainly occur in 2010 because of the ECRD2010 event, we can forecast that they will indeed be consumed in 2010.

1.2.3 Trade creditors

2008	147 k€	7%
2009	168 k€	9%
Difference	+21 k€	14%

Trade creditors are monies to be paid to suppliers for invoices received or to be received. The level is higher than in 2008 because of several invoices received at the end of the year and for which the payments were made in 2010.

1.2.4 Deferred income

2008	1 455 k€	66%
2009	1 041 k€	55%
Difference	- 414 k€	-28%

Deferred income is the part of the 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 2009, this is mainly composed of EC projects (564 k€, 54%) and co-funding of POLKA (300 k€, 29%).





2.Revenue

The revenue including in-kind contributions and excluding recovery of provisions as well as report of non-used incomes, amounted to $2\,862\,k$. It shows a growth of 36% compared to 2008.

The majority of this increase is due to the signing of the Operating Grant from DG SANCO (+ 473 $k \in$) and the increased participation of volunteers (+ 144 $k \in$).

This repartition of funding fully complies with our Policy on Financial Support by Commercial Companies³: the level of Pharmaceutical companies (17%) does not exceed the amount from Patient Organisations and volunteers (45%).

The breakdown of EURORDIS' revenue by sources is as follows (amounts are in thousands of euros, recovery of provisions are excluded⁴)

Source of funding	20	08	20	09	Diffe	rence
AFM Membership fees and grants Volunteers Individual donations	768 24 263 0	36% 1% 12% 0%	788 82 407 10	28% 3% 14% 0%	20 58 144 10	3% 242% 55% NA
Patient Org. and Volunteers	1 055	50%	1 286	45%	231	22%
European Commission	244	12%	768	27%	524	215%
National authorities	87	4%	98	3%	10	11%
Pharmaceutical companies	492	23%	478	17%	-14	-3%
Foundations and NPOs	186	9%	156	5%	-30	-16%
Others	42	2%	76	3%	33	78%
Total	2 107	100%	2 862	100%	755	36%

All figures in thousand of euro

Overall: 45% of resources are contributed by our members and volunteers, 30% by European and national public authorities, 17% by 31 pharmaceutical companies and 8% from other private resources (cf. graphs).

2.1 Patient Organisations and Volunteers

2008	1 055 k€	50%
2009	1 286 k€	45%
Difference	+231 k€	+22%

This increase arises from two factors:

- a donation of 50 k€ from the National Organization for Rare Disorders (NORD), USA, for the creation of the Online Patient Communities Pilot on the web (www.rarediseasecommunities.org)
- the increasing participation of volunteers (+ 144 k€)

2.1.1 Association Française contre les Myopathies (AFM – Téléthon)

2008	768 k€	36%
2009	788 k€	28%
Difference	+20 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 a leverage to develop and diversify our sources of revenues.

This grant is in the framework of the 2007-2009 AFM/EURORDIS agreement. It specifies that the

³ for more details on policy and financial structure, see www.eurordis.org

^{*}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.

purpose of the grant is focused on core operations (governance, membership, advocacy, therapeutic development) to guarantee our independence with respect to public institutions and commercial companies.

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

The agreement between EURORDIS and the AFM will be renewed for 2010-2012. In addition, the Rare Disease Platform where EURORDIS' office space is located will be moved to a new building totally renovated in 2010 with AFM funds.

2.1.2 Volunteers

2008	263 k€	12%
2009	407 k€	14%
Difference	+144 k€	+55%

The main reason for this increase comes from:

- the strengthening of the Task Forces and the increased level of activities of EURORDIS representatives in the scientific committees and working parties at the European Medicine Agency (EMA, + 98 k€).
- the fact that more volunteers contribute on behalf of Eurordis at the European level, thereby acting as the voice of EURORDIS (+ 46 k€).

Together, this represents 4 full-time equivalents (868 days), with a high level of competence and commitment, as well as a broad range of national cultures and rare diseases.

Time spent by volunteers is, in most cases, validated by the volunteer him/herself (93%) or estimated by project managers (7%). 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 Co<u>mmission</u>

2008	244 k€	12%
2009	768 k€	27%
Difference	+ 524 k€	+ 215%

The majority of this growth is due to the Operating Grant with DG SANCO (+473 k).

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

The Operating Grant was already implemented in several areas of activity by the European Commission (i.e. to support European consumers or environment organisations) and is now extended to European large umbrella patient organisations. We are very satisfied to be able, from 2009, to co-fund our recurrent activities thanks to this DG SANCO financial instrument. Concurrently, we are consolidating the financial support from our members through membership fees and grants, AFM-Telethon and volunteers.

A consequence of the Operating grant is that it obliges EURORDIS to take its accounting and budgeting tools to a higher level of sophistication, and to implement many new processes (i.e. call for tenders) and to double the number of annual audits by including a specific audit for this grant as well as a special report. In addition, DG SANCO never funds an activity at 100%, the ratio of cofunding is 60% maximum, therefore we must be able to quarantee the remaining 40% for these activities.

The other limitation of this new financial instrument is that we don't have any formal guaranty of renewal and as it co-funds recurrent activities, the fact that it can theoretically stop 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.

On the positive side, it has helped us to progress in the administrative treatment of all operations and has thus enhanced the quality of our financial information.

The good news is that our contract has been signed for 2010 with an increased amount of 733 $k \in$ and the application for the Operating Grant 2011 will be submitted in March 2010.

2.3 National authorities

2008	87 k€	4%
2009	98 k€	3%
Difference	+11 k€	+12%

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



2.3 Pharmaceutical companies

2008	492 k€	23%
2009	478 k€	17%
Difference	-14k€	-3%

If the amount of the Pharmaceutical donations remains fairly constant with a slight decrease of 3% as a result of the international economical crisis, the relative part of this source of funding decreases from 23% to 17%.

These 478 k€ are contributed by 31 companies, the five largest contributors being SIGMA TAU (2.62%), NOVARTIS (2.62%), CSL BEHRING (2.27%), CELGENE (1.22%), SHIRE (0.82%).

2.4 Others		
2008	42 k€	2%
2009	78 k€	3%
Difference	+36 k€	+84%

Other revenue includes conference fees, reimbursements, financial revenue, etc.
The difference between 2008 and 2009 is mainly explained by in-kind contributions for our membership meeting in Athens.



3.Expenses

The operating expenses, including in-kind contributions, amounted to 2 734 $k \in$, which shows a growth of 29% compared to 2008.

The increase is equally spread over Staff, Volunteers, Travel and Subsistence and Services.

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

Expenses	20	08	20	09	Diffe	rence
Staff costs	1 151	54%	1 297	47%	146	13%
Volunteers	263	12%	407	15%	144	55%
Travel and subsistence	156	7%	278	10%	122	78%
Services	471	22%	650	24%	179	38%
Purchases	81	4%	97	4%	15	18%
Financial and insurance expenses	5	0%	5	0%	1	22%
Total	2 127	100%	2 734	100%	607	29%

All figures in thousand of euro

3.1 Staff costs

2008	1 151 k€	54%
2009	1 297 k€	47%
Difference	+ 146 k€	+ 13%

In 2008, the Brussels' office staff costs and the contracting of a replacement for a staff member on parental leave were recorded under the line "Services – fees" because for administrative reasons, they are not on EURORDIS' payroll. For a more realistic view of our staff costs, we have included all staff pertaining to the organisational chart under the budget line "Staff costs" even if they don't have an employment or secondment contract with EURORDIS.

The number of fte6 was 17.1 in 2008. An increase of 2 fte brings the 2009 fte level to 19.1.

Out of these 2 fte, 1.3 are from the creation of four new positions at EURORDIS:

- a Web Communications Officer (0.67 fte) responsible for revamping of EURORDIS and Rare Disease Day websites; creation of our new web platforms such as Online Patient Communities or International Blog; animation of accounts on Facebook, Twitter, YouTube
- an Administrative Secretary Trainee and an IT Manager (0.64 fte)

The remainder are from variations due to the returns from maternity leaves and the increasing workload on the EUROPLAN project.

3.2 Volunteers

Together, EURORDIS volunteers represent 4 full-time equivalents.

Please see 2.1.2. above.

3.3 Travel and subsistence

2008	156 k€	7%
2009	278 k€	10%
Difference	+122 k€	+78%

Now that the pluriannual projects settled in 2008 have started, they have reached their normal level of activities, hence the increase.

In addition, the Operating Grant allowed us to invite more patient representatives to our workshops, capacitybuilding sessions or meetings such as the Summer School, the Council of European Federations (CEF), etc. Altogether, 60% of this budget was allocated to non-staff or board members. Our low-cost policy on travels made us spend only 233 euros by flight or train ticket for the staff in the framework of the Operating Grant.

3.4 Services

2008	471 k€	22%
2009	650 k€	24%
Difference	+179 k€	+38%

2009 was the year of the creation of a web 2.0 platform (107 k€) and the start of the Play-Decide project (20 k€). These two activities represent the majority of this increase.



4.Surplus

The 2009 surplus amounted to EUR 28 008. We suggest allocating this amount to the reserve fund, thereby increasing it to EUR 375 492, 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: European Commission's Directorate General for Health and Consumers Ongoing Projects:

- Polka (Patients' consensus on preferred policy scenarii for rare diseases).
 - → from 01-Sep-08 to 31-Aug-11
 - → EURORDIS is main beneficiary
- nEUroped (European Network of Reference for Rare Pediatric Neurological Diseases)
 - → from 24-Apr-08 to 23-Apr-11
 - → EURORDIS is co-beneficiary
- Europlan (European Project for Rare Diseases National Plans Development)
 - → from 01-Apr-08 to 31-Mar-11
 - → EURORDIS is co-beneficiary
- Opera (2009 Operating Grant)
- → from 01-Jan-09 to 31-Dec-09

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

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

ECRD: European Conference on Rare Diseases.

4 of them already occurred

ECRD2007, in Lisbon (organised by Eurordis and partners) ECRD2005, in Luxembourg (organised Eurordis and

ECRD2003, in Evry France (organised by Alliance Maladies Rares) ECRD2001, in Copenhagen (organised by Rare Disorders

The fifth will occur in May 2010 in Krakow.

EMA: European Medicine Agency



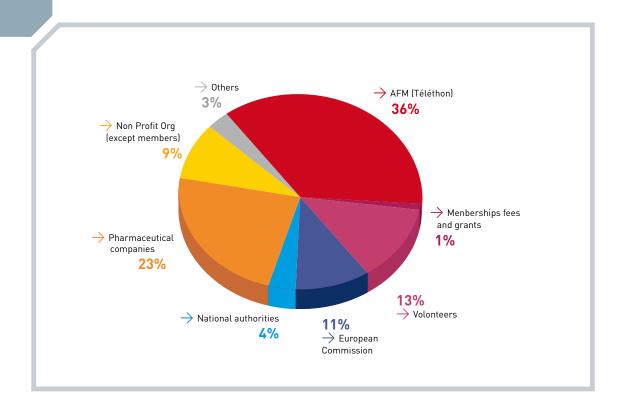
Revenue and Expenses 2008-2009

(in thousand of euros, provisions excluded)

→ Menberships fees

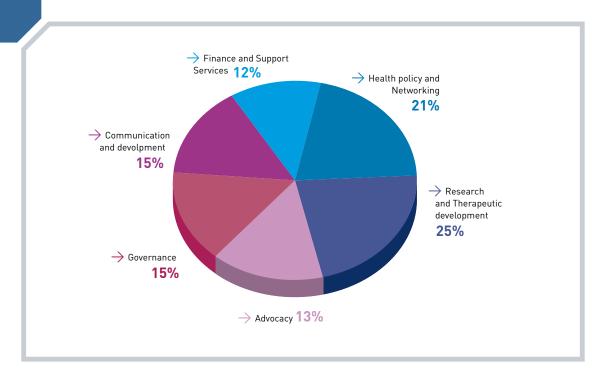
→ Revenue 2008

= 2,107

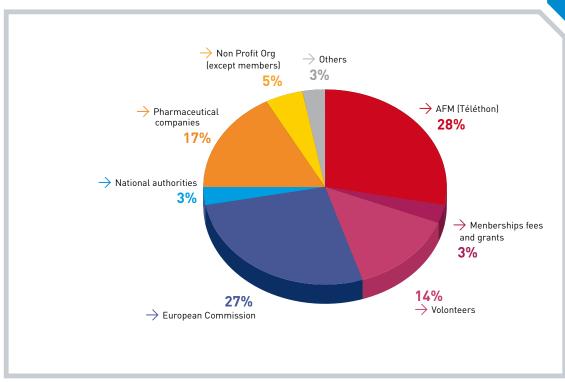


Expenses 2008

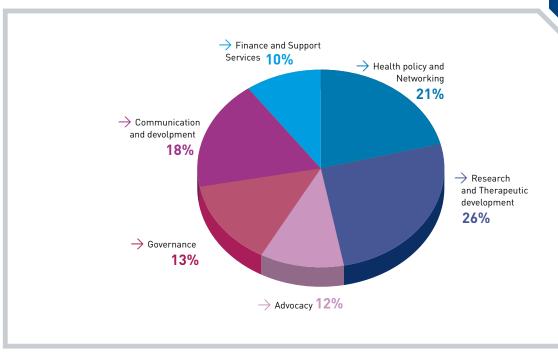
= 2,127



> Revenue 2009 = **2,862**









Comité éditorial Eurordis Conception et réalisation Agence Galilée, tél. : 01 43 63 74 04, www.agencegalilee.com



EURORDIS

Plateforme Maladies Rares 102, Rue Didot, 75014 Paris - France

Tel + 33 1 56 53 52 10 Fax + 33 1 56 53 52 15 Brussels office: Tel/fax + 32 2 733 81 10 EURORDIS@EURORDIS.org