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# **STRATEGIC APPROACH 2007-2010 & WORKPLAN 2009**

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Athens, May 2009

# Contents

## ❖ **Our strategic approach 2007 – 2010**

- Eurordis in 2010
- Strategic orientations
- Priorities 2007 -2010

## ❖ **Our action plan 2009**

- Key priorities
- Key topics

## ❖ **Budget 2009**

## ❖ **Budget comparison 2008 and 2009**

## ❖ **Governance**

## ❖ **Significant European activities**

## Our Strategic Approach 2007 - 2009



### Eurordis in 2010

- ❖ Eurordis is the European movement of rare disease patient groups and **individuals** and their European voice.
- ❖ Eurordis brings added value through advocacy, information, **capacity building and services**
- ❖ Eurordis added value is **perceived** by our members, patients & families and stakeholders
- ❖ Eurordis has a **renewed long term vision and strategy**.

### Strategic orientations

- ❖ Fewer priorities to achieve measurable results
- ❖ More innovative therapies, patient-centred healthcare and patient driven research bridging science & society
- ❖ More integrated approach between EU and national levels, and between Eurordis and national alliances
- ❖ Based more deeply on individual patient and families
- ❖ Develop private funding for resource diversification and for long term financial self-sustainability
- ❖ Promote Eurordis as a brand name in everything we do
- ❖ Web Communications at the centre of what we do: members, volunteers, staff, patient and families as producers of information
- ❖ More international openness and perspective
- ❖ Build a long term and prospective vision

## Priorities 2007 - 2010

### Rare Diseases: a priority visible on the European agenda

- Promote rare diseases as a public health priority at EU and national levels
- Organise the European Rare Disease Conference 2007 Lisbon & 2010 Cracow
- Promote an enhanced EU policy framework with a Commission Communication and a Council Recommendation on Rare Diseases
- Promote national plans on rare diseases in EU Member states
- Focus on key EU public policy issues relevant to People Living With rare Diseases
- Promote rare diseases as global public health priority and international networking
- Raise Rare Disease Awareness through Rare Disease Day 2008 & 2009 & 2010

### To consolidate and empower the rare diseases patient community

- Enhance communication with rare disease groups, members and non members
- Broaden the patient group membership base
- Maintain focus on new and future Member States
- Organise Membership Meetings 2007 Paris & 2008 Copenhagen & 2009 Athens & 2010 Cracow
- Bring up the network of National Rare Disease Alliances to a more active level
- Create the network of European Rare Disease specific Federations
- Create a new version of EURORDIS Website with new structure and functions to enhance information dissemination, experience exchange and networking between rare diseases' patient groups and advocates
- Identify, involve and support volunteers in more activities
- Organise capacity building and training sessions for patient representatives

### To shape the European environment for Better Information, Care and Drug development for Rare Disease Patients and families

- To shift our priorities toward more public health activities and services to patients:
  - Promote access to quality care:
    - Centres of Expertise and European Reference Networks
    - Cross-border healthcare and patient mobility
    - Organ donation & transplantation
    - Blood & Plasma derived products
    - Diagnosis, gene testing and counselling
  - Promote access to quality information and support services:
    - European Network of Help Lines
    - Support service to connect very isolated patients in EU
    - Social networking and support through online patient communities
    - Therapeutic Recreation Programmes
    - Integration at School
    - Respite Care Services
- To focus our therapy activities on development of and access to orphan drugs, paediatric drugs, advanced therapies:
  - Participate in EMEA Scientific Committees – COMP, PDCO, CAT, PCWP
  - Provide patient expertise in drug development
  - Facilitate dialogue between patient groups, experts, companies and regulators
  - Improve patient access to rare disease therapies
  - Address the challenges of Health Technology Assessment in Rare Diseases
  - Inform and involve more members and volunteers in therapeutic activities
- To address bottlenecks towards therapies through patient driven European research infrastructures :
  - Biobanks
  - Patient databases & registries
  - Clinical trials

- To bridge the gap between patient needs and research in biomedicine, public health, social, economy, policy and ethic

**To achieve cross-cutting Priorities**

- To perform EURORDIS Strategic Review 2010-2015 involving all members and relevant stakeholders
- To include Web Communication in all EURORDIS activities
- To develop office support services for better quality work and increased efficiency:
  - Contact Management Database
  - Advanced Financial and Budget Information System
  - Advanced Human Resource Policy
  - Advanced Information Technology as a support for projects management, work with volunteers and virtual office to ease mobility
  - Optimise synergies between websites, project databases, contact management database
- Increase EU support to EURORDIS projects and other rare disease activities
- Reinforce current funding base: AFM, members, health industry
- Develop private funding and partnerships with corporations and foundations outside the health sector, from EU and US
- Develop fund raising events e.g. Gala Dinner 2010 Brussels

## Our action plan 2009



### Key priorities

- ❖ Adoption of Council Recommendations on Rare Diseases
- ❖ Start implementation of Commission Communication on Rare Diseases
- ❖ Promote National Strategies & Action Plans on Rare Diseases
- ❖ Promote policy on Centres of Expertise & European Reference Networks
- ❖ Build capacities of National Alliances and European Federations
- ❖ Membership Meeting 2009 Athens “Rare Diseases: No Policy Without Patients!” & empowerment of rare disease patient groups through help lines and Web tools
- ❖ Bring the European network of rare disease Help Lines to a new step
- ❖ EURORDIS Web 2.0 Portal: Web Platform, Website V4, On line Communities
- ❖ Publication of the Book “The Voice of 12 000 Patients” and dissemination
- ❖ Promote awareness: Rare Disease Day 2009: “Patient Care: a Public Affair!”
- ❖ Expand activities on drug development, information and access:
  - Orphan Drugs & Paediatric Drugs & Advanced Therapies
  - Improve access to orphan drugs: public European information, Common Assessment of Clinical Added Value of Orphan Drugs, Conditional Pricing
  - Capacity building of our volunteers: Call for Volunteers & Develop Task Forces & Eurordis Summer School 2009
  - Empowerment of our members through information and participation
- ❖ European Conference Rare Diseases: ECRD 2010 Cracow
- ❖ Strategic review of EURORDIS 2010-2015
- ❖ Strategy & plan on private funding (2nd step – start implementation: In Kind, Private Foundations, plan Dinner Gala 2010)
- ❖ Strategy & plan on volunteers (2nd step – expand and further the strategic community organisation of Eurordis)

## Key Topics

### European Public Policy Priorities :

- Rare Diseases as a Public Health Priority in Commission programmes and in Member states
- European Commission Communication on Rare Diseases (2007-2009)
- Council Recommendations on National Strategies & Actions Plans on Rare Diseases (2007-2009)
- Rare diseases: an international public health priority (2009-2010)
  - Draft reference paper within ICORD
  - Coordinated by EURORDIS and involving NORD, NZORD, CORD, Geizer
- Organ Donation and Transplant (ODT) for rare disease patients
  - Contribute to the drafting of the Directive on organ donation safety and quality, and to Commission Action plan on Organ Donation and Transplantation
  - Create EURORDIS Ad Hoc Working Group of volunteers on ODT
- Blood and plasma derived products
- Pharmaceutical Legislation review
- Improvement of the European Pharmacovigilance system
- Directive on information to patients concerning pharmaceuticals (including direct to patient information)
- Medical devices

### Background work on future priorities:

- Diseases are rare, patients are many': a quantitative analysis of rare disease numbers (2009/2010)
- Genetic Discrimination: background work toward an EU legislation to prevent discrimination based genetic information from accessing school, university, work, loans and insurance

### Members and patient groups :

- Membership Meeting 2009 Athens May 8th-9th "Rare Diseases: No Policy without patients!"
- Increase interaction and recognition: favour direct contacts; send more information; ask for opinion; call for volunteers; involve people in projects, workshops, conferences; training sessions
- Priority recruitment of members in new and future EU Member States
- Capacity Building of national alliances:
  - 2 European Workshops of National Alliances<sup>1</sup> :8<sup>th</sup> Workshop on 7<sup>th</sup> May in Athens & 9<sup>th</sup> Workshop in November or December in Paris. Focus on: (a) national plan on rare diseases, national conferences on rare diseases (b) Rare Disease Day<sup>2</sup>
  - Support the development of recent & new national alliances<sup>3</sup>
- Country visits and support (2009-2010): Baltic States, Czech Republic, Greece, Poland, Hungary, Romania<sup>4</sup>

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<sup>1</sup> Supported by Operating Grant

<sup>2</sup> Supported by Operating Grant

<sup>3</sup> Supported by Operating Grant

<sup>4</sup> Supported by Operating Grant

- Capacity Building of European Rare Disease Specific Federations & Networks:
  - Implement the capacity building project Rare! Together to monitor 2 new networks and promote good practices<sup>5</sup>
  - 1<sup>st</sup> European Workshop of European Rare Disease Federations & Networks<sup>6</sup> on 7<sup>th</sup> May in Athens
- Rare Cancers
  - More recruitment of rare cancer patient groups as members and as volunteers
  - Pilot a Eurordis' "rare cancers online community" for patient advocates from rare cancer groups for discussion on transversal themes of interest to all rare cancers, sharing experience and building a common advocacy platform
  - Organise a European workshop (possibly with EPPOSI) on rare cancers
  - Public Policy paper on rare cancers as a public health priority within cancer policy and rare diseases policy

### Health policy:

- 5th European Conference on Rare Diseases (ECRD) 2010 Poland
  - Planning of 5th ECRD 2010 Poland<sup>7</sup>: dates, venue, logistics, promotion
  - Programme development
  - Launch of registration
- National Plans on Rare Diseases:
  - Involvement of national rare disease alliances through information, exchange, common agenda<sup>8</sup> through the Council of National Alliances
  - Partner in European Project for Rare Diseases National Plans Development - EuroPlan- 2008-2011<sup>9</sup>: work with patient advisors in WP8 EuroPlan to promote best practices and measures through national conferences on rare diseases
  - Develop European common minimum recommendations for national strategies & action plans
- Centres of Expertise and European Reference Network: A strategy and a tool box to promote policy and good practices at national and EU levels towards better patient access to diagnosis and care
  - Participation in the EU High Level Group on Health Services and Medical Care
  - Contribution to the adoption of the policy on European Reference Networks of Centres of Expertise within the Directive on patients' rights to cross-border healthcare
  - Eurordis Declaration for Centres of Expertise & European Reference Networks: Launch at Rare Disease Day 2009
  - Publication of a Book based on data from EurordisCare 2&3, testimonies and photos<sup>10</sup>
  - Working Group of patient representatives, health care professionals and policy makers on Centres of Expertise & European Reference Network<sup>11</sup>
    - Eurordis Charter for Good Practice Collaboration between Patient Groups and Centres of Expertise & European Reference Networks on Rare Diseases

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<sup>5</sup> Supported by Operating Grant

<sup>6</sup> Supported by Operating Grant

<sup>7</sup> Supported by the POLKA project

<sup>8</sup> Supported by EUROPLAN project

<sup>9</sup> Supported by EUROPLAN project

<sup>10</sup> Supported by Operating Grant

<sup>11</sup> Supported by the POLKA project

- New Eurordis Website section, On Line Resource Centre and On Line Patient Communities on Centres of Expertise
  - EurordisCare 2&3 further analysis by academic research teams
  - Partner in the European Reference Network for Rare Paediatric Neurological Diseases - nEUroped - 2008-2011
  - Advisor to several of the European Reference Networks
- Rare Diseases as a Priority in Commission's Public Health programmes:
  - EU Public Health: promote rare diseases in Work Programme (2008 - 2013) + input in call for proposals + Rare Disease Task Force (RDTF)
  - Advocate for an EU Committee on Rare Diseases (ex-Rare Disease Task Force)
- Contribution to the patient mobility within the Directive on the application of patients' rights to cross-border healthcare and advocacy to avoid pre-payment of care by patients
- Start "Patient Preferred Policy Scenarios for Rare Diseases" project – Polka – 2008-2011<sup>12</sup>
  - To build consensus on preferred policy scenarii for rare diseases (deliberative patients' debates inspired by methods developed by DG Research, Scientific Advice and Governance)
  - To support and guide the implementation of the EU policy for European Reference Networks from the patients' perspective (continuation of the working group on Reference Networks created within the frame of the RAPSODY project)
  - To stimulate dialogue on policies for rare diseases in some of the Member States having recently joined the EU (meetings between EURORDIS, local rare diseases patient organisations, health care professionals and policy makers)
  - To raise awareness on rare diseases in European regions where EU Conferences on rare diseases have not yet taken place (Organisation of the European Conference on Rare Diseases 2010 in Poland)
- Services to patients: further develop networks of services for patients initiated in the framework of "Rare Disease Patient Solidarity" project - Rapsody
  - European Network of Rare Disease Help Lines<sup>13</sup>:
    - Strengthen the European Network of Help lines for Rare Diseases (processing the network memberships, applying membership conditions, installing software and online tools where needed, organising the annual network meeting on 7<sup>th</sup> May in Athens)
    - Maintaining the database with the Caller Profile Analysis, Knowledge base, Tool for Very Isolated Persons, best practices materials
    - Adopting new best practices and disseminate them to members of the network
    - Organising more capacity building sessions on "Where to find validated medical information on the Internet"
  - Therapeutic Recreation Programmes<sup>14</sup>: promote quality of and access to programmes
    - Collaboration with the European Camping Association (application to become a member) to develop new best practices and standards, and exchange of information
    - Maintenance of online information on existing programmes
  - Respite Care Services<sup>15</sup>: promote public policy on and access to respite care
    - Maintenance of online information on existing services

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<sup>12</sup> Supported by the POLKA project

<sup>13</sup> Supported by the Operating grant

<sup>14</sup> Supported by the Operating grant

<sup>15</sup> Supported by the Operating grant

- Development of an argumentum in favour of respite care services for rare diseases
- Workshop on respite care services for rare diseases (2S2009)
- Integration at school: establish the base of a future project
  - Strengthening working relation with INS-HEA and Ägrenska
  - Identification of new partners for the creation of working groups with patient organisations and health care professionals to produce new medical and pedagogical materials
  - Work on the translation and European dissemination of available information
- Post-marketing authorisation phase, early access to medicinal products and Health Technology Assessment
  - Explore national regulatory provisions for compassionate use programmes in EU
  - Establish contacts with experts in the field of health technology assessment in collaboration with the Cochrane foundation
  - Create a EURORDIS Task Force on Health Technology Assessment for Rare Diseases Therapies composed of volunteers

### **Therapeutic development:**

- Orphan drugs:
  - Public policy support to the implementation of the EU Regulation on Orphan Medicinal Products
  - Participation in EMEA Committee for Orphan Medicinal Products (COMP) with 2 representatives and 2 permanent observers
  - Common needs, global development: advocate for harmonisation EU/US for designation and parallel procedure toward converging EU/US requirements (joint action with NORD, FDA/EMEA-COM)
  - Patient access to authorised orphan drugs in the EU: advocate for European assessment of therapeutic added value of orphan drugs and conditional pricing and reimbursement (position paper, EU Pharmaceutical Forum + EMEA COMP)
  - Promote Clinical research grant programmes for designated Orphan Drugs within the 7<sup>th</sup> EC Research Framework (position paper + EMEA COMP)
  - Eurordis Task Force on Orphan Drugs<sup>16</sup> composed of volunteers
  - Follow up of products through COMP, Protocol Assistance, marketing authorisations, product information, availability to patients
  - 10<sup>th</sup> EPPOSI Workshop on Innovative Therapies for Rare Diseases in Brussels
- Drug Information and Transparency:
  - Eurordis Task Force on Drug Information, Transparency and Access<sup>17</sup> composed of volunteers
  - Participate in EMEA Patient & Consumer Working Party (PCWP), with particular emphasis on risk communication and pharmacovigilance
  - Participate in review of package leaflets and EPARs for Orphan Drugs
- Paediatric Drugs:
  - Public policy support in the implementation of the EU Regulation on Paediatric Use of Medicines
  - Participates in Paediatric Committee with 2 representatives as members
  - Eurordis Task Force on Paediatric Drugs: contributions on future policies and guidelines<sup>18</sup>

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<sup>16</sup> Supported by the Operating Grant

<sup>17</sup> Supported by the Operating Grant

- Dissemination of information on paediatric drugs to patient groups
- Advanced therapies:
  - Public policy support in the implementation of the EU Regulation on Advanced Therapies
  - Start participation in the EMEA Committee on Advanced Therapies (CAT) with 2 representatives (if appointed by Commission and Parliament)
  - Participate to key meetings, dialogue with research networks e.g. CliniGene, contribution to future guidelines
- Capacity building of Eurordis Volunteers in orphan and paediatric drug development and EU regulatory affairs: combined innovative approaches
  - Eurordis Summer School<sup>19</sup>: 2<sup>nd</sup> session, 40 volunteers, 14<sup>th</sup>-18<sup>th</sup> June, Barcelona
  - Start first Webinars for online capacity building
  - National capacity Building on clinical trials
    - Support national one-day session in local language based on an adapted version of EURORDIS Pedagogic tool on clinical trials and drug development developed in CAPOIRA
    - Develop and maintain the database of trainees
- Off label use of medicines & promotion of clinical research on their potential use for rare disease patients (collection of case studies)
- Eurordis Round Table of Companies (ERTC) Workshops 2009
  - 19<sup>th</sup> June, Barcelona
  - December, Paris
- Clinical Trial Directive: contribution to the revision of the Directive on rare disease clinical research in Europe (participation in the legislative process for the revision of the Directive in 2009/10)
- Improve relationship between POs and sponsors of clinical trials
  - Promote adoption of the Charter by sponsors
  - Support to POs for the implementation of the Charter, including possible first Community Advisory Boards
- Drug Information Association (DIA)::
  - DIA EuroMeeting 23-25<sup>th</sup> March 2009: Patients speakers in most tracks and Patient Fellowship Programme. Proposal of a strategy to DIA Board to involve more patients and creation of a Specific Interest Action Group (SIAC)

### Research:

- Contributions to promote rare disease research agenda
- Patient databases, registries and cohorts: promote policy recommendations
- Rare Disease Biological Resource Banks and European Network: promote policy recommendations
- Partner in the European Network of Excellence and projects:
  - Treat-NMD<sup>20</sup>
  - NEUROPED

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<sup>18</sup> Supported by the Operating Grant

<sup>19</sup> Supported by the Operating Grant

<sup>20</sup> Supported by the TREAT-NMD project

- Advisor to European research projects
  - Clinigene
  - Ecrin
  - STEM-HD
  - E-Rare
- Maintain the EuroBioBank network and online service<sup>21</sup>
- Develop (2009-2010) one patient driven pilot health research projects for FP7

**Communication and development:**

**Communication:**

- Rare Disease Day February 28th, 2009: Promotion & Awareness on Access to Diagnosis and Care in conjunction with Health Policy and Public Affairs actions in favour of European Reference Network of Centres of Expertise on Rare Diseases
  - Theme “Rare Diseases – A Public Health Priority” Focus “Patient Care: a Public Affair!”
  - Creation and distribution of poster & other promotional accessories
  - Common features around First Ladies, Member European parliament and Centres of Expertise
  - Dedicated Rare Disease Day 2009 website [www.rarediseaseday.org](http://www.rarediseaseday.org)
- Rare Disease Day February 28th, 2010: launch of preparation
- Communication activities:
  - Printed: leaflets, brochures, fact sheets, press releases, reports, press packs and toolkits<sup>22</sup>
  - Launch of video and photo contest 2009 Launch major photo project 2008-2010 (exhibition and book): “Rare Diseases: Daily Images”<sup>23</sup>
  - Media event (including press conference in Brussels) presenting the publication of the Book “The Voice of 12 000 Patients” from EurordisCare 2 and 3 surveys<sup>24</sup>
- Eurordis Web 2.0 Portal:
  - New technological platform for Eurordis Websites<sup>25</sup>
  - Eurordis Website V4 with Web 2.0 functions
  - On Line Communities<sup>26</sup>: redesign interface, translate in 6 languages, add new tools, launch new communities of rare disease patient & families
  - Social networking

**Development:**

- Start implementation of Strategy & Plan on private funding:
  - Seek and Value In Kind services
  - Private Foundations
  - Corporate financial support from companies other than health

**Finance and office support:**

- Advance Financial Information System & Quality management processes:

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<sup>21</sup> Supported by the TREAT-NMD project

<sup>22</sup> Supported by the Operating Grant

<sup>23</sup> Supported by the Operating Grant

<sup>24</sup> Supported by the Operating Grant

<sup>25</sup> Supported by the Operating Grant

<sup>26</sup> Supported by the Operating Grant

- Budget reporting and forecast cash flow
- Support budgeting project development
- Written procedures
- Advance Information Technology to better support office work and outreach:
  - Eurordis Contact database management: development & procedures finalised, full implementation<sup>27</sup>
  - Convergence: Optimise synergy between Eurordis web sites and project databases & web services, contact management database
  - Virtual office: new IT equipment and servicing for Brussels Office, part sharing intranet with Brussels office, Board and authorised volunteers.

**Governance:**

- Volunteers:
  - Increase number and role of Eurordis Volunteers: individual job descriptions & task forces or steering committees terms of reference; call for volunteer
  - Creation of the Volunteer database, follow up, support, information
  - Time & Economic Worth Value
- Strategy:
  - Perform a Strategic Review for new strategic approach Eurordis 2010-2015 with a comprehensive approach involving the Board, the staff, all members, stakeholders and partners, with Action Plans on each main goals and for each team unit, budget forecast (to be adopted General Assembly 2009)
  - Indicators of activity & results
  - International: sharing & networking & acting beyond EU boundaries
- NGO & Academic partnerships
  - Strengthen NGO partnership: European Patient Forum (EPF), International Council for Orphan Drugs and Rare Diseases (ICORD), International Alliance of Patient Organisations (IAPO), European Platform of Patients Organisations, Science and Industry (EPPOSI), Drug Information Association (DIA)
  - Strengthen Academic partnership on information, clinical research, health technology assessment, social research

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<sup>27</sup> Supported by the Operating Grant

**2009 Budget vs 2008 Actual**

(Profit and Loss including in kind contributions)

<b>Revenue</b>	<b>2008 Actual</b>	<b>2009 Budget</b>	<b>Ratio</b>	<b>Difference</b>
<b>Patient Organisations</b>	<b>768 151</b>	<b>839 299</b>	<b>29%</b>	<b>71 148</b>
AFM Telethon Grants	588 720	659 820	23%	71 100
In kind contributions (AFM)	179 166	174 479	6%	-4 687
Donations	265	5 000	0%	4 735
Membership fees and grants	23 919	45 000	2%	21 081
<b>Volunteers</b>	<b>262 935</b>	<b>280 000</b>	<b>10%</b>	<b>17 065</b>
Representative and task forces	225 113	210 000	7%	-15 113
Project, office and translators	37 823	70 000	2%	32 177
<b>European Commission</b>	<b>228 775</b>	<b>712 580</b>	<b>24%</b>	<b>483 805</b>
DG Research	108 940	33 000	1%	-75 940
DG Health and consumers	119 835	679 580	23%	559 745
<b>National authorities</b>	<b>87 259</b>	<b>120 610</b>	<b>4%</b>	<b>33 351</b>
<b>Corporate funding</b>	<b>492 000</b>	<b>657 000</b>	<b>23%</b>	<b>165 000</b>
Pharma. and Biotech Cie	492 000	507 000	17%	15 000
Other corporate funding		150 000	5%	150 000
<b>Foundations and NPOs</b>	<b>186 154</b>	<b>222 333</b>	<b>8%</b>	<b>36 180</b>
Pharma. and Biotech Found.	176 154	172 333	6%	-3 820
Other Found. and NPOs	10 000	50 000	2%	40 000
<b>Miscellaneous</b>	<b>57 576</b>	<b>33 280</b>	<b>1%</b>	<b>-24 296</b>
Fees	3 206	3 000	0%	-206
In kind contributions (Others)	25 102	16 080	1%	-9 022
Reimbursement	11 352	14 200	0%	2 848
<b>Sub-total</b>	<b>2 106 769</b>	<b>2 910 102</b>	<b>100%</b>	<b>803 333</b>
<b>Recovery of provisions</b>	<b>46 375</b>			<b>-46 375</b>
<b>Report of non-used income</b>	<b>40 000</b>			<b>-40 000</b>
<b>Total Revenue</b>	<b>2 193 144</b>	<b>2 910 102</b>	<b>100%</b>	<b>716 958</b>

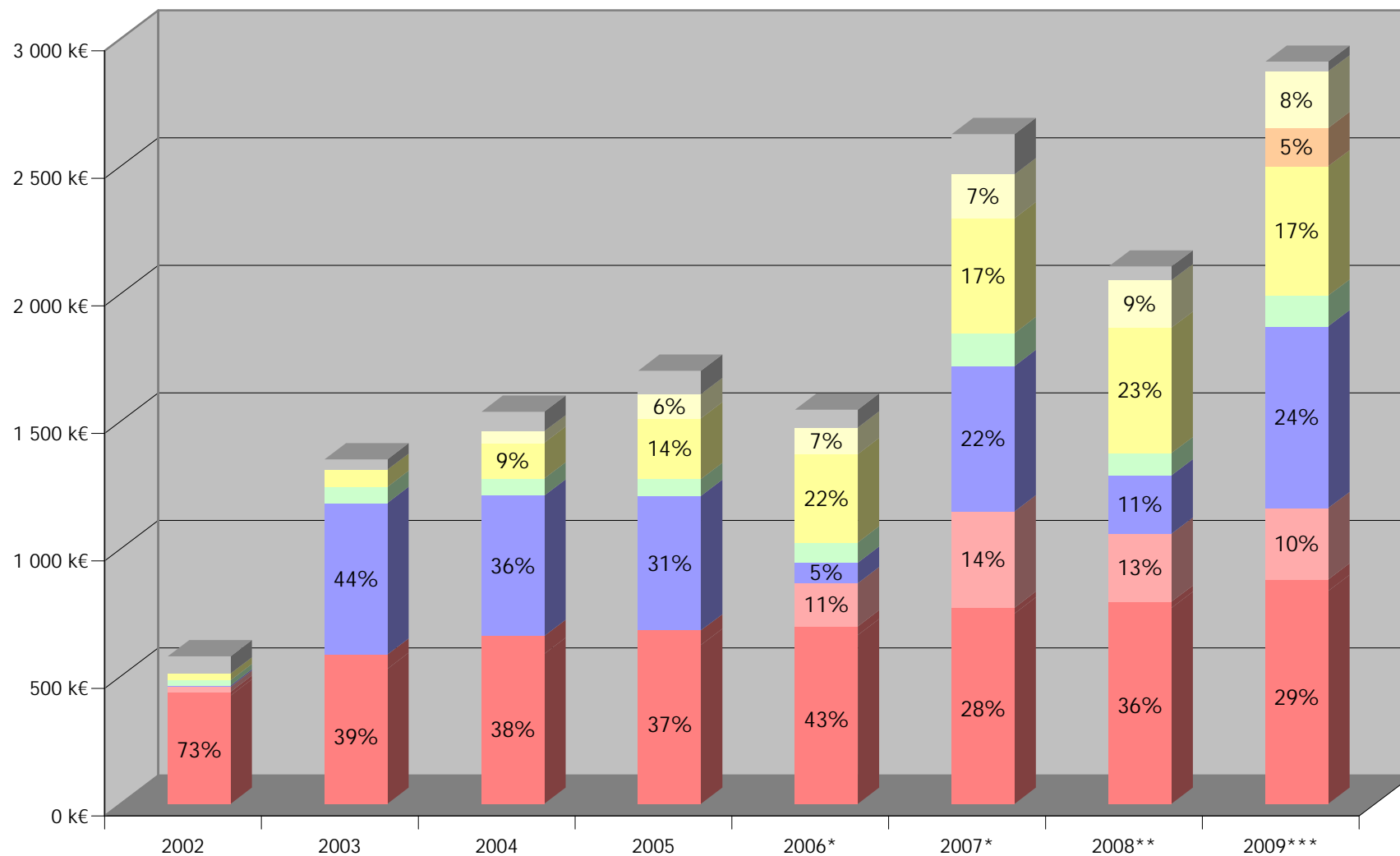
<b>Expenses</b>	<b>2008 Actual</b>	<b>2009 Budget</b>	<b>Ratio</b>	<b>Difference</b>
<b>Staff</b>	<b>1 058 785</b>	<b>1 384 524</b>	<b>48%</b>	<b>325 739</b>
Wages and charges	1 046 704	1 372 524	47%	325 820
Training	2 428	12 000	0%	9 572
<b>Volunteers</b>	<b>262 935</b>	<b>280 000</b>	<b>10%</b>	<b>17 065</b>
Representative and task forces	225 113	210 000	7%	-15 113
Project, office and translators	37 823	70 000	2%	32 177
<b>Travel and subsistence</b>	<b>155 951</b>	<b>342 190</b>	<b>12%</b>	<b>186 239</b>
Travels	140 784	326 110	11%	185 326
In kind contribution	15 167	16 080	1%	913
<b>Services</b>	<b>563 049</b>	<b>781 331</b>	<b>27%</b>	<b>218 283</b>
Honorary	323 034	504 031	17%	180 997
Event logistics and catering	51 655	72 649	2%	20 994
EC projects partners	9 137	40 266	1%	31 129
Telecom and post	45 089	37 610	1%	-7 479
Rent	96 749	97 019	3%	270
Other services	37 384	29 757	1%	-7 627
<b>Purchase</b>	<b>81 498</b>	<b>121 823</b>	<b>4%</b>	<b>40 326</b>
Office furniture	22 310	35 000	1%	12 690
Amortization	14 715	17 492	1%	2 777
Publications	27 571	66 191	2%	38 620
Other purchases	16 902	3 140	0%	-13 762
<b>Financial and insurance expenses</b>	<b>4 580</b>			<b>-4 580</b>
<b>Sub-total</b>	<b>2 126 797</b>	<b>2 909 868</b>	<b>100%</b>	<b>783 071</b>
<b>Contingency and loss provisions</b>	<b>20 306</b>			<b>-20 306</b>
<b>Commitment on assigned income</b>	<b>14 916</b>			<b>-14 916</b>
<b>Total Expenses</b>	<b>2 162 019</b>	<b>2 909 868</b>	<b>100%</b>	<b>747 850</b>
<b>Result</b>	<b>31 126</b>	<b>234</b>		<b>-30 892</b>

## Risk Analysis 2009 Budget

		Contract 18%	On Going 72%	Challenge 8%	Option 2%
<b>Revenues</b>	<b>2 910 101</b>	<b>527 846</b>	<b>2 087 255</b>	<b>225 000</b>	<b>70 000</b>
<b>AFM</b>	<b>834 299</b>	<b>174 479</b>	<b>659 820</b>	<b>0</b>	<b>0</b>
Core funding	653 100		653 100		
nEUroped co-funding	6 720		6 720		
In Kind	174 479	174 479	0		
<b>Other POs</b>	<b>20 000</b>	<b>0</b>	<b>0</b>	<b>20 000</b>	<b>0</b>
<b>Membership fees</b>	<b>25 000</b>	<b>0</b>	<b>25 000</b>	<b>0</b>	<b>0</b>
<b>Staff volunteers</b>	<b>280 000</b>	<b>0</b>	<b>280 000</b>	<b>0</b>	<b>0</b>
Representative and task forces	210 000		210 000		
Projects, office, translation	70 000		70 000		
<b>European Commission</b>	<b>712 579</b>	<b>56 158</b>	<b>656 421</b>	<b>0</b>	<b>0</b>
Treat-NMD	33 000	33 000			
nEUroped	7 666	7 666			
Europlan	14 766	14 766			
Polka	183 346		183 346		
Opera	473 075		473 075		
Others	726	726			
<b>National authorities</b>	<b>120 610</b>	<b>98 877</b>	<b>21 733</b>	<b>0</b>	<b>0</b>
INSERM (secunded staff)	84 500	84 500			
Polka nat. Officials	13 510	13 510			
Summer School (Spain Med Agency)	20 000		20 000		
French DGS IT funding	2 600	867	1 733		
<b>Eurordis Round Table of Companies</b>	<b>245 000</b>	<b>0</b>	<b>230 000</b>	<b>15 000</b>	<b>0</b>
Renewal Members 2007	230 000		230 000		
Acquisition New Members	15 000			15 000	
<b>Other pharmaceutical companies</b>	<b>262 000</b>	<b>150 000</b>	<b>77 000</b>	<b>35 000</b>	<b>0</b>
Polka (CSL Berhing)	50 000	50 000			
Polka (Sigma-Tau)	50 000	50 000			
Polka (Novartis)	50 000	50 000			
EBB (Sponsors)	2 000		2 000		
Amm (Several)	55 000		55 000		
Web2.0 (Other Pharma Cie)	55 000		20 000	35 000	
<b>Other corporates</b>	<b>150 000</b>	<b>0</b>	<b>0</b>	<b>100 000</b>	<b>50 000</b>
Electronic newsletter	50 000			50 000	
Rare Disease Day	50 000			50 000	
Photo project	50 000				50 000
<b>Non Profit Org. (Pharma &amp; Biothech F.)</b>	<b>172 333</b>	<b>48 333</b>	<b>104 000</b>	<b>0</b>	<b>20 000</b>
Rare! Together (MEDTRONIC)	50 000	25 000	25 000		
Enews (MEDTRONIC)	23 333	23 333			
Web2.0 (LEEM)	55 000		55 000		
Summer School (DIA foundation)	24 000		24 000		
Web2.0 (Nat. Pharma asso. in EU)	20 000				20 000
<b>Other Non Profit Organisations</b>	<b>50 000</b>	<b>0</b>	<b>0</b>	<b>50 000</b>	<b>0</b>
Web2.0 (Other NPOs)	50 000			50 000	
<b>Miscellaneous</b>	<b>38 280</b>	<b>0</b>	<b>33 280</b>	<b>5 000</b>	<b>0</b>
Donations	5 000			5 000	
AMM fees	3 000		3 000		
COMP Travels (in kind)	16 080		16 080		
Reimbursements	14 200		14 200		

### EURORDIS Funding from 2002 to 2009

- AFM
- Membership fees and grants
- Volunteers
- European Commission
- National authorities
- Pharmaceutical companies
- Other corporates
- Non Profit Org. (except members)
- Others



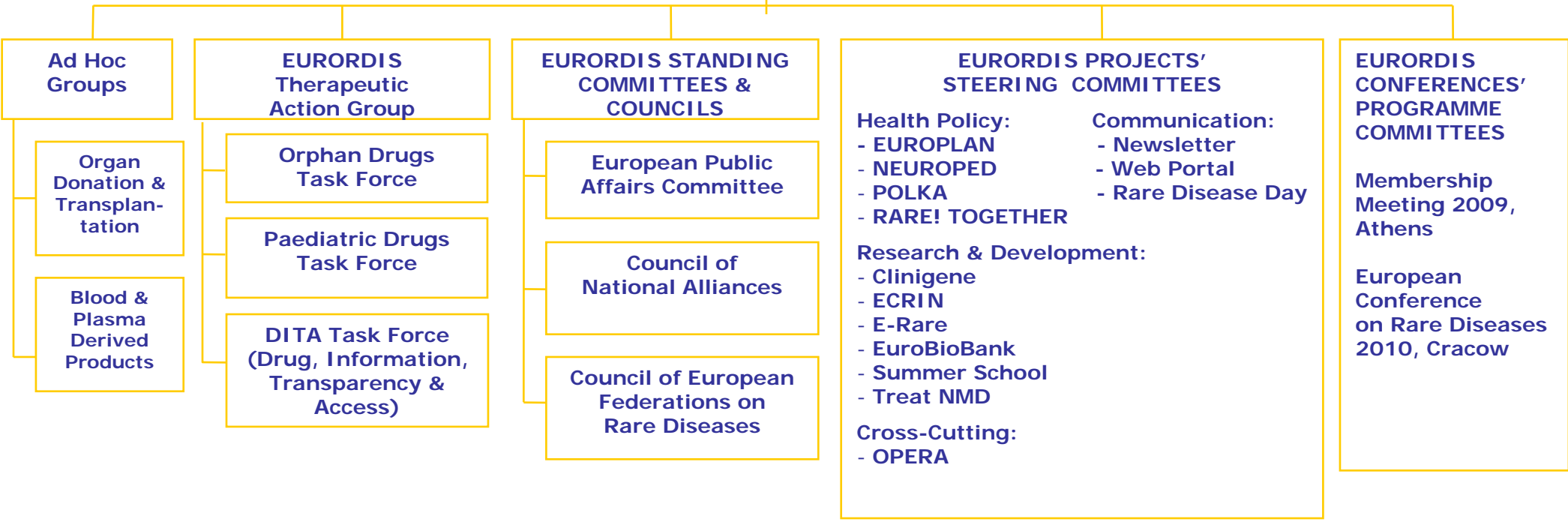
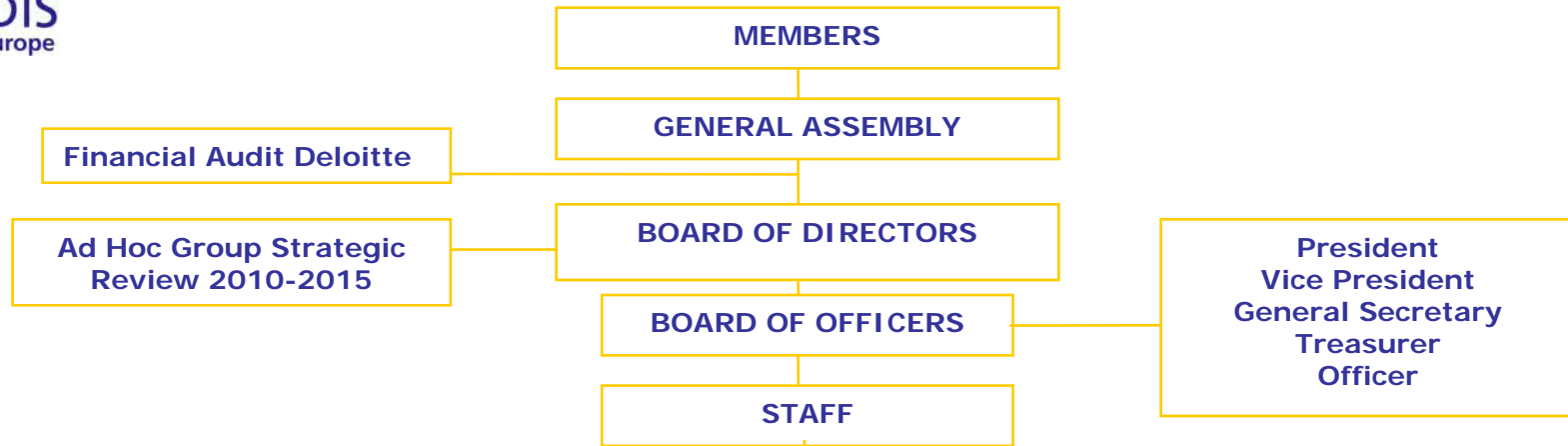
\* Recovery of provisions excluded in accordance with the financial report 2007 validated by the Auditors

\*\* 2008 Financial Statement, adopted by the Board of Directors, validated by the auditor Deloitte, to be adopted by Members

\*\*\* Budget 2009, adopted by the Board of Directors, to be adopted by Members

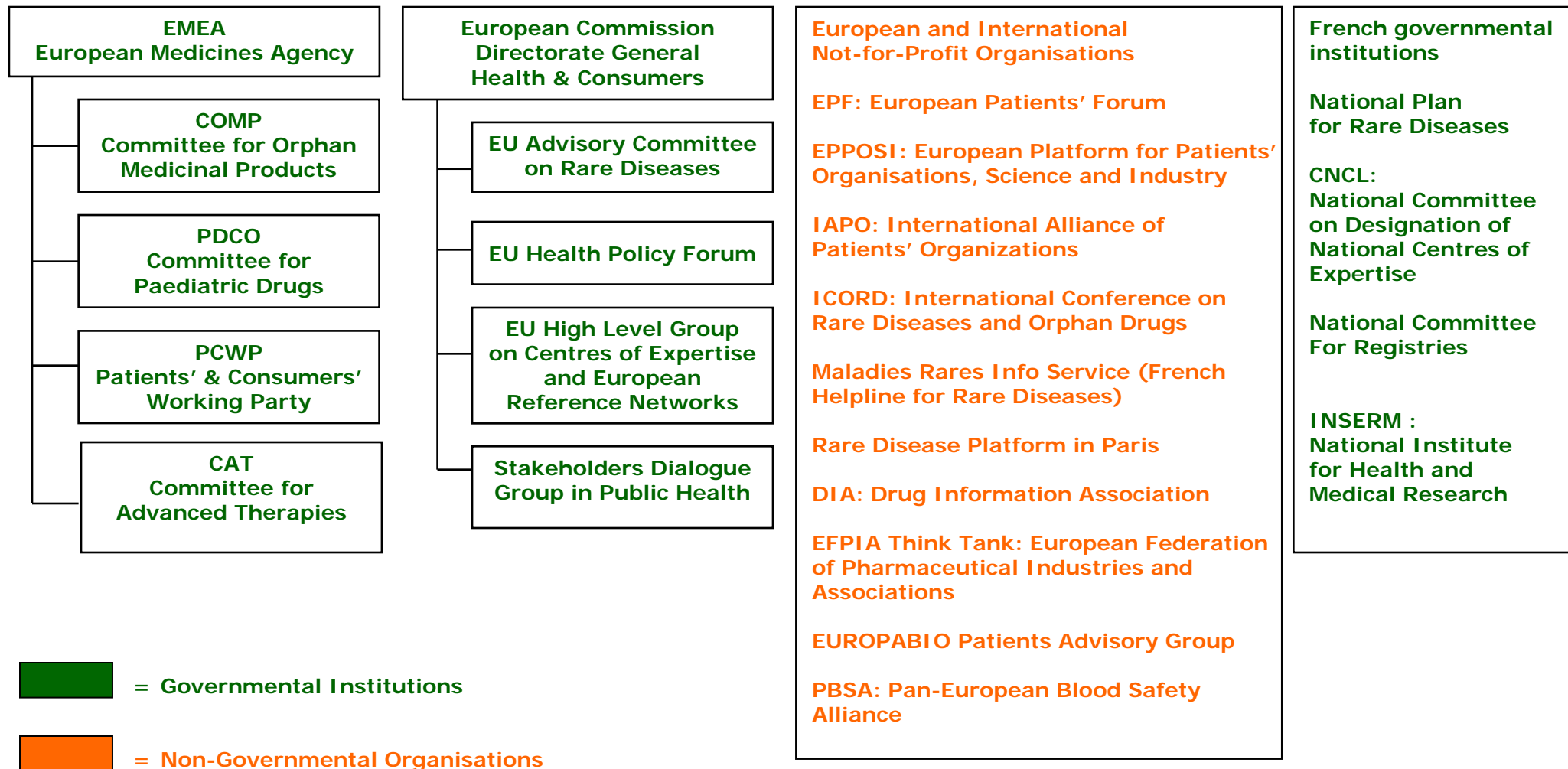


## EURORDIS GOVERNANCE CHART 2009





## EURORDIS' REPRESENTATION IN EXTERNAL INSTITUTIONS AND ORGANISATIONS IN 2009



## PROJECTS' ACRONYMS DEFINITION

- **CliniGene** EU network for the advancement of clinical gene transfer and therapy
- **ECRIN** European Clinical Research Infrastructures Network
- **E-Rare** Develop synergies amongst 8 national research programmes on rare diseases
- **EuroBioBank** European Network of DNA, cell and tissue banks for rare diseases
- **EUROPLAN** European Project for the development of Rare Disease National Plans
- **NEUROPED** European Reference Network for Rare Paediatric Neurological Diseases
- **OPERA** Operating Grant for Rare Disease Associations
- **POLKA** Patient's Consensus on Preferred Policy Scenarios for Rare Diseases
- **Treat-NMD** Translational Research in Europe – Assessment and Treatment of Neuromuscular diseases