Structure of PARD 2 Website

Updated 15/3/ 2003

Structure	Content
I. **About Eurordis**	
1. **Presentation**	
2. **Corporate Information**	
	Achievements
	Current Priorities
	Mission Statement
	History
	Objectives
	Bye-Laws
	Annual Activity Report
	Financial Information
	Corporate Sponsorship
	Information
	Organisation
3. **Eurordis**	
	The Rare Disease Platform
	Eurordis Offices
	How to Visit Us (Map and Explanation)
4. **Eurordis People**	
	Board of Directors
	Staff and volunteers
5. **Key Actions and Programmes**	
	PARD I
	PARD II
	PARD III
	EuroBioBank
	EurordisCare
	etc.
6. **Eurordis Membership**	
	Map of European Union
	List of Members
	Become a member of Eurordis
	Rare diseases European network
7. **Main Events**	
	Eurordis General Assembly
	European Rare Disease Conference
	link to Events
8. **Publications**	
	Video (Building a Community)
	Newsletters
	Reports
II. **About Rare Disorders**	
1. **What is a rare disorder?**	
2. **People Living with Rare Disorders**	
3. **Reference Texts**	
	decision n°1295/1999/CE 29 avril
	regulation n° 141/2000 of December 1999 about orphan medicinal products
4. **National websites on rare disorders inside Europe**	

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5. **Pan-European websites on rare disorders**	
	Orphanet
6. **National websites on rare disorders outside Europe**	
	NORD
III. **Patient Organisations**	
1. **Inside Europe**	
	National Alliances
	European Federations/ Disease Specific Groups
	Organisations by disease or group of diseases
2. **Outside Europe**	
	NORD, CORD, TORD,….
3. **Patients with very rare or unknown diseases**	
	What is a very rare disorder?
	What is an unknown disorder?
	How to find someone like you?
IV. **About Orphan Drugs**	
1. **Definition**	
2. **Development of an Orphan Drug**	
3. **Authorisation of an Orphan Drug**	
	How is it evaluated for marketing authorisation?
	What are the obligations of the sponsors?
	How to find information?
	Why to prescribe an orphan drug?
	Pharmacovigilance
4. **The Role of Patient Organisations**	
5. **Ongoing clinical trials**	
6. **Existing Orphan Drugs**	
	European Union registry of designated orphan drugs *(link to DG Enterprise)*
	U.S. registry of designated orphan drugs *(link to FDA)*
	Orphan drugs on the market in the European Union *(link to EMEA/EPAR)*
	Orphan drugs on the market in the U.S. *(link to FDA)*
7. **Search for an orphan drug**	
	in the European Union *(link to EMEA)*
	in the US *(link to FDA)*
	in Japan *(link to Japan)*
8. **The Committee on Orphan Medicinal Products**	
	1. monthly press releases *(link to EMEA)*
	2. final report *(link to EMEA)*
9. **Inventory of European Union and national incentive measures**	
	link to EMEA incentives
	Comment from Eurordis
Link to Legislation and public policies	

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Structure	Content
V. **Legislation and public policies**	
1. **At European level**	
2. **At National level (by country)**	
VI. **Resources**	
1. List of resources	
	Regulatory bodies inside Europe (COMP/EMEA)
	Regulatory bodies outside Europe (FDA)
	National Research institutes (INSERM, NIH…)
	Industrial partners (EPPOSI, EFPIA)
	Medical references
	National Helplines…
2. **Search the Website**	
3. **Search the Internet**	
VII. **News**	
1. **Events**	
	Upcoming (by date or by country)
	Past (by date or by country)
2. **Headlines**	
	latest OMP designations/marketing authorisations
	requests for proposals (European Commission,...)
	various...
3. **Articles and Press Releases**	
4. **Link to Eurordis Newsletter**	
5. **Link to National Alliances Newsletters and news**	
VIII. **Media Centre**	
IX. **Forum**	
	Public areas
	Password-protected areas
Password-protected areas	
X. **Members' Club**	
1. **How to create your website**	
2. **Advocacy and lobbying tools**	
3. **Best practices**	
4. **Information update to members**	
	electronic letter
	update on Eurordis projects
5. **Correspondence Board**	
Link to password-protected forum for members	
XI. **Directors' Section**	
1. **BoO meetings**	
2. **BoD meetings**	
3. **Eurordis Internal Information**	
	Calendar
4. **Reference Documents**	
Through buttons	
XII. **Sitemap**	
XIII. **Customise**	
XIV. **FAQs about Eurordis**	
XV. **Glossary**	
XVI. **Contact Us**	
XVII. **Language switch**	
XVIII. **Search**	