



Searching databases for rare disease information

EURORDIS Online Training

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EURORDIS

Part 1

Characteristics of databases

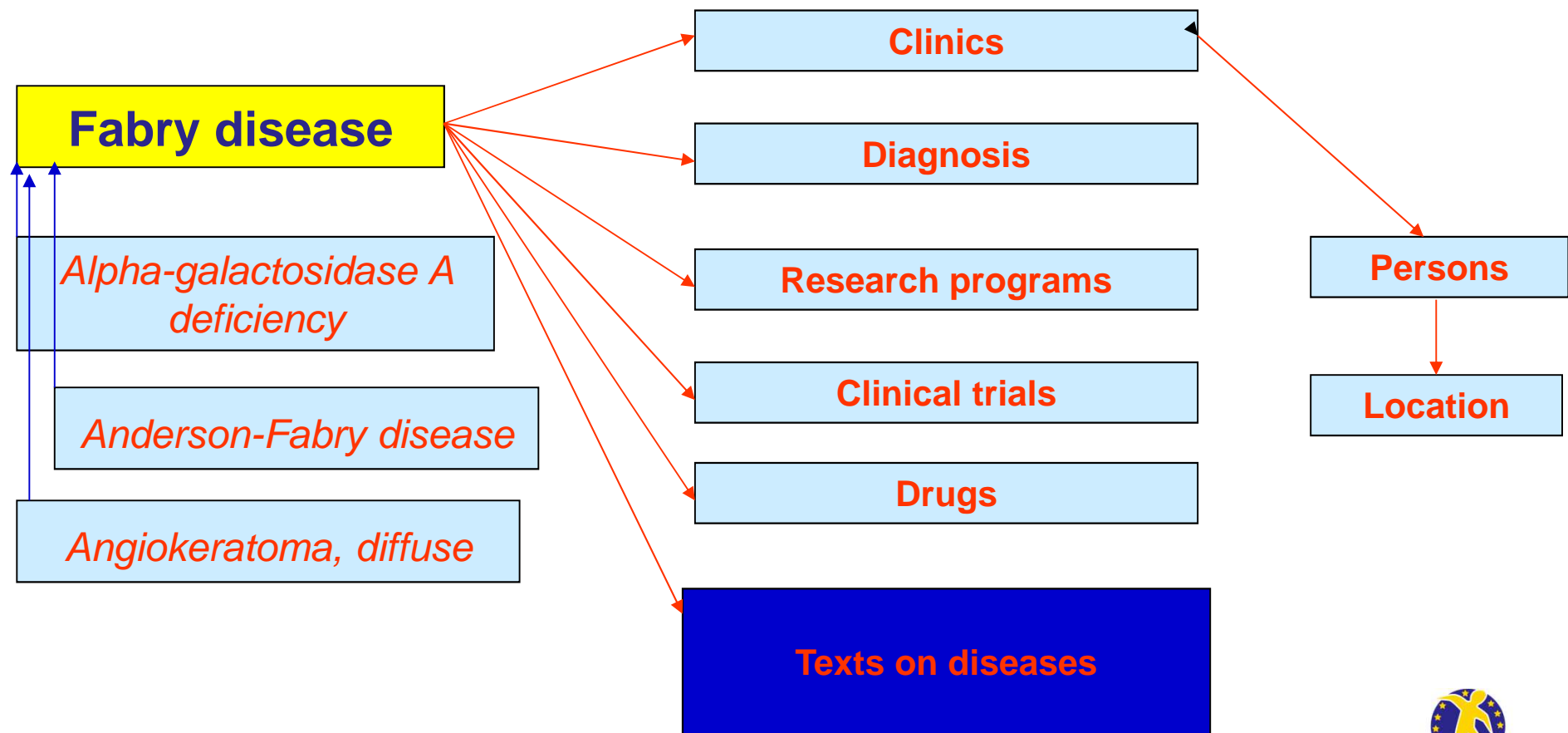
Database definition

**Collection of information,
concerning a defined domain,**

organized,

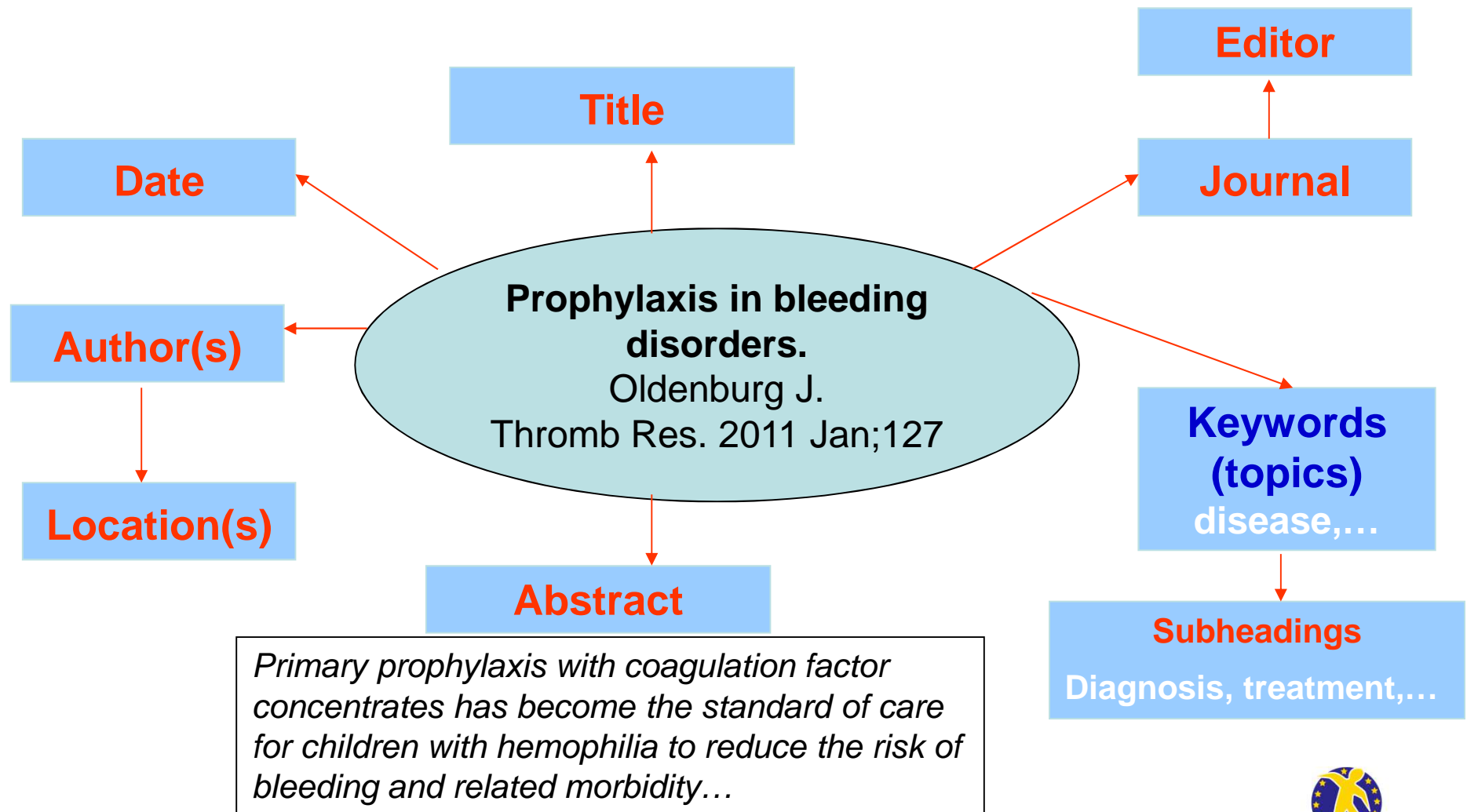
**described with precise and specific
keywords (*indexed*)**

Organisation and indexation of a database Orphanet



Organisation and indexation of a database

Pubmed



Google	Databases
1,000 billion pages collected	Selected resources
Full text	Keywords + Full text
Variable quality	Validated information
Free Ads	Fees

Various types / kinds

Bibliographic databases

Journal,
Date, Title,
Authors

Best Pract Res Clin Rheumatol. 2008 Oct;22(5):863-82.

Hypereosinophilic syndromes.

Kahn JE, Blétry O, Guillevin L.

French Eosinophil Network, Department of Immunology, CHRU de Lille, Université Lille, Lille, France.

Abstract

Hypereosinophilia ($>0.5 \times 10^9/L$) is a common clinical finding that can be secondary to a large variety of diseases (helminth infections allergic diseases, drug reactions, specific organ disease, malignancies, systemic diseases). When a complete evaluation of a chronic hypereosinophilia fails to reveal an underlying disease, the diagnosis of hypereosinophilic syndrome (HES) or Churg-Strauss syndrome (CSS) is suggested.

PMID: 19028368 [PubMed - indexed for MEDLINE]

Publication Types, MeSH Terms

Publication Types

Review

MeSH Terms

Churg-Strauss Syndrome/complications

Churg-Strauss Syndrome/pathology

Churg-Strauss Syndrome/therapy

Topics

Directory (factual) databases

Disease name → OK

Country ▼

Designated centres of expertise ☐

☒ Medical management only
 ☐ Adult clinic

☐ Genetic counselling
 ☐ Child clinic

☐ All
 ☒ All

:: Reference centre for lysosomal diseases (Coordinator: Dr Nadia BELMATOUG)

Service de médecine interne	Phone	: 33 (0)1 40 87 52 86	Age range	: For Adults and Children
Hôpital Beaujon	Additional Phone	: -	Type(s)	: Medical management
100 Boulevard du Général Leclerc	Fax	: 33 (0)1 40 87 44 34		
92118 CLICHY Cedex	Website [↗]			
FRANCE	Contact secretary	: samira.zebiche@bjn.a-php.fr		
More information	Orpha number	: ORPHA67602		
Head of clinic: Dr Nadia BELMATOUG				

CONSULTANT(S)

[Dr Nadia BELMATOUG](#)

Additional information

Further information on this clinic



EURORDIS
Rare Diseases Europe

Numeric databases


National Cancer Institute
U.S. National Institutes of Health | www.cancer.gov


Surveillance Epidemiology and End Results
providing information on cancer statistics to help reduce the burden of this disease on the U.S. population

[Home](#)
[About SEER](#)
[Cancer Statistics](#)
[Datasets & Software](#)
[Publications](#)
[Information for Cancer Registrars](#)

Search

Cancer Statistics
Available Statistics

- [Cancer Stat Fact Sheets](#)
- [Cancer Statistics Review](#)
- [Fast Stats](#)
- [Cancer Query Systems](#)
- [State Cancer Profiles](#)

Resources

- [Types of Statistics](#)
- [Software Used to Generate Statistics](#)

[Home](#) > [Cancer Statistics](#) > [Cancer Stat Fact Sheets](#) > Cancer of the Urinary Bladder
 [Email](#)
[Print Page](#)
[Glossary](#)

SEER Stat Fact Sheets: Bladder

Cancer:

Mortality data for the current data year is not yet available ([view details](#)). Updated lifetime risk and cancer estimate statistics for the current data year (if applicable) will not be available until the mortality data is released.

It is estimated that 70,530 men and women (52,760 men and 17,770 women) will be diagnosed with and 14,680 men and women will die of **cancer of the urinary bladder** in 2010.¹

The following information is based on NCI's SEER Cancer Statistics Review.² Use the links on this page to learn more about each statistic type:

- [Incidence & Mortality](#)
- [Survival & Stage](#)
- [Lifetime Risk](#)
- [Prevalence](#)
- [References](#)

Incidence & Mortality
SEER Incidence

From 2004-2008, the median age at diagnosis for cancer of the urinary bladder was 73 years of age.³ Approximately 0.1% were diagnosed under age 20; 0.4% between 20 and 34; 1.7% between 35 and 44; 7.4% between 45 and 54; 18.0% between 55 and 64; 27.2% between 65 and 74; 32.0% between 75 and 84; and 13.2% 85+ years of age.

The age-adjusted incidence rate was 21.1 per 100,000 men and women per year. These rates are based on cases diagnosed in 2004-2008 from 17 SEER geographic areas.

Incidence Rates by Race

Race/Ethnicity	Male	Female
All Races	37.5 per 100,000 men	9.2 per 100,000 women
White	40.6 per 100,000 men	9.8 per 100,000 women
Black	21.6 per 100,000 men	7.6 per 100,000 women
Asian/Pacific Islander	16.3 per 100,000 men	4.0 per 100,000 women
American Indian/Alaska Native ^a	14.0 per 100,000 men	3.6 per 100,000 women
Hispanic ^b	16.9 per 100,000 men	4.8 per 100,000 women

Full text databases

La rétinite pigmentaire

Rod-cone dystrophie
Retinitis pigmentosa

[La maladie](#)

[Le diagnostic](#)

[Les aspects génétiques](#)

[Le traitement, la prise en charge, la prévention](#)

[Vivre avec](#)

[En savoir plus](#)

Madame, Monsieur,

Cette fiche est destinée à vous informer sur la rétinite pigmentaire. Elle ne se substitue pas à une consultation médicale. Elle a pour but de favoriser le dialogue avec votre médecin. N'hésitez pas à lui faire préciser les points qui ne vous paraîtraient pas suffisamment clairs et à demander des informations supplémentaires sur votre cas particulier. En effet, certaines informations contenues dans cette fiche peuvent ne pas être adaptées à votre cas : il faut se rappeler que chaque patient est particulier. Seul le médecin peut donner une information individualisée et adaptée.

La maladie

● Qu'est-ce que la rétinite pigmentaire ?

La rétinite pigmentaire (RP) est une maladie génétique dégénérative de l'œil qui se caractérise par une perte progressive et graduelle de la vision évoluant généralement vers la cécité. La RP est encore appelée *rod-cone dystrophie* ou *retinitis pigmentosa*. synonymes

Part 2

Rare disease databases

Major resources

- Orphanet
- NORD Rare disease database
- Genetics Home Reference
- *Gene Reviews*
- *OMIM*
- Medscape Reference

Orphanet

- **Portal**
- **6,000 diseases**
- **6 languages**
- **Directory of services**
- **Online encyclopaedia**

*Rare diseases are **rare**, but
rare disease patients are **numerous***



Access our Services

Search a disease

OK

Inventory, classification and encyclopaedia of rare diseases, with genes involved

Assistance-to-diagnosis tool

Emergency guidelines

Inventory of orphan drugs

Directory of medical laboratories providing diagnostic tests

Directory of expert centres

Directory of ongoing research projects, clinical trials, registries and biobanks

Directory of patient organisations

Directory of professionals and institutions

Newsletter

Collection of thematic reports: Orphanet Reports Series


Newsletter

[Read the last newsletter](#)

[Read previous issues](#)

[Sign up to receive the newsletter](#)

Other documents

[Council Recommendation on an action in the field of rare diseases](#) [

[EU Cross-Border Healthcare Directive](#) [

Major resources

- Orphanet
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- **Genetics Home Reference**
- ***Gene Reviews***
- ***OMIM***
- Medscape Reference

Major resources

- Orphanet
- NORD Rare disease database
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- *OMIM*
- **Medscape Reference**

Part 3

Orphan drug information

Designation and Marketing authorization

- **Orphan drugs**
 - Prevalence < 1 / 2,000 people
- **Designation**
 - Criteria
- **EMA (European Medicines Agency)**
 - **COMP (Committee for Orphan Medical Products)**
- **Marketing authorization**
 - Central authorization procedure
- **U.S., Australia, Japan,...**

Orphan drugs

- **List of orphan drugs**
 - European Medicines Agency (EMA)
 - Orphanet
- Orphan drug databases
 - Eudrapharm
 - Orphanet

Orphan drugs

- List of orphan drugs
 - European Medicines Agency (EMA)
 - Orphanet
- Orphan drug databases
 - Eudrapharm
 - Orphanet

- **Eudrapharm (EMA)**
 - **Drugs with marketing authorization**
 - **Europe**
 - **Centralized procedure**
 - **1995**
 - **Summary of Product Characteristics**
 - *European languages*
 - characteristics as agreed during the assessment process
 - for health professionals
 - available for general public.





- Orphanet
 - Orphan designation in Europe
 - Marketing authorization
 - Europe
 - United States
 - Japan, Australia,...

Part 4

Clinical trial databases

Clinical trials

- **Research study**
 - New drug, new indication
 - Medical device
- **Safety**
- **Efficacy**

ClinicalTrials.gov is a registry and [results database](#) of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health care professionals. [Read more...](#)

▶ [Search for Clinical Trials](#)

Find trials for a specific medical condition or other criteria in the ClinicalTrials.gov registry. ClinicalTrials.gov currently has **108,646 trials** with locations in **174 countries**.

▶ [Investigator Instructions](#)

Get instructions for clinical trial investigators/sponsors about how to register trials in ClinicalTrials.gov. Learn about mandatory registration and results reporting requirements and US Public Law 110-85 (FDAAA).

▶ [Background Information](#)

Learn about clinical trials and how to use ClinicalTrials.gov, or access other consumer health information from the US National Institutes of Health.

Resources:

[Understanding Clinical Trials](#)

[What's New](#)

[Glossary](#)

Study Topics:

[List studies by Condition](#)

[List studies by Drug Intervention](#)

[List studies by Sponsor](#)

[List studies by Location](#)



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