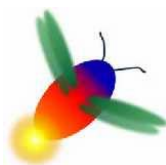
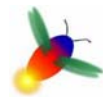


世界罕見疾病組織資料庫建置計畫



委託單位：財團法人罕見疾病基金會

贊助單位：Genzyme corporation-Taiwan

計畫名稱：世界罕見疾病組織資料庫建置

計畫主持人：唐先梅副教授

協同主持人：曾敏傑副教授

計畫期程：94/1/1-94/6/30

世界罕見疾病相關組織資料建置

摘要

爲因應罕見疾病基金會未來國際化的需求，俾將罕見疾病基金會多年來本土化的運作經驗與國際相關社群接軌，及促進罕見疾病基金會未來與國際相關團體聯繫交流之用，有必要建置世界上與罕見疾病相關團體的聯繫資訊。本計畫因此透過網路檢索現有國際罕病相關團體資訊，並加以蒐錄其主要基本資訊如後，合計包括：國際性「罕見疾病跨病類」組織 2 則；主要國家「罕見疾病跨病類」組織含 14 個國家 52 個組織；亞洲主要國家「罕病病友組織」含 7 個國家 128 個組織；罕見疾病相關「網站資料庫」5 類 116 則；世界罕見疾病相關「個人」資料含 247 則；總共合計爲 545 則相關資料。

由於世界罕見相關組織之資訊會不斷變化，未來本資料庫需要繼續定期予以更新，以便隨時掌握國際最新動態，並方便隨時聯繫交流之用。

Information of World Organizations on Rare Diseases

Abstract

In order to prepare the internationalization for Taiwan Foundation for Rare Disorders (TFRD) and to bridge the networking between TFRD and international community on rare diseases, a collection of information on world organizations related with rare diseases will be necessary for TFRD at this stage. Thus, this project focused on collecting the core information of organizations and individuals on rare diseases through the internet searching as comprehensively as possible during the research period.

This report finally collected all the information as the following: including 2 items of “international umbrella organizations ,” 52 items of “national umbrella organizations,” 128 items of “disease-specific patient organizations,” and 116 items of “rare diseases websites,” and 247 items of “individuals.” The researchers suggest that a regular revision for these informational lists will enable TFRD to keep the most up-dated information at hand.

世界罕見疾病相關組織資料建置

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世界罕見疾病相關組織資料庫

壹、國際性「罕見疾病跨病類」組織資料

The Alliances for Rare Diseases in Europe

Support groups of single diseases or groups of diseases have joined together in European countries to form Alliances or Federations: in France, Belgium, Denmark, Spain, Italy... You can find all this information on the [Eurordis Website](#).

Country	The Alliance	Web Site
Denmark	Kontaktudvalget for Mindre Sygdoms- og Handicap-foreninger (KMS)	www.kms-danmark.dk
France	Alliance Maladies Rares	www.alliance-maladies-rares.org
Germany	Bundesarbeitsgemeinschaft Hilfe für Behinderte e.V. (BAGH)	www.bagh.de
Italy	Federazione Italiana Malattie Rare (UNIAMO)	www.uniamo.org
Netherlands	Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP)	www.vsop.nl
Spain	Federación Española de Enfermedades Raras (FEDER)	www.enfermedades-raras.org
Sweden	Sällsynta diagnoser	www.sallsyntadiagnoser.nu

European Organization for Rare Diseases (Eurordis)

**Hôpital Broussais
Plateforme Maladies Rares
Bâtiment Gaudart d'Allaines
102, rue Didot
75014 Paris
France**

Tel: +33 (1) 56.53.52.10

Fax: +33 (1) 56.53.52.15

e-mail: eurordis@eurordis.org

<http://www.eurordis.org>

To provide patients, healthcare personnel and the pharmaceutical industry with an independent global network, specialising in the development, registration, marketing and distribution of orphan medicinal products for the treatment of rare disorders.

Orphan Europe was founded in Paris in 1990 with the objective of developing and providing orphan drugs to patients affected by rare disorders. In 2004, Orphan Europe has subsidiaries or offices in: France, UK, Germany, Spain, Italy, Poland, Nordic countries and Benelux. Further expansion into other European Union member states is planned in the near future.

Through our offices in Europe, our established partnerships with pharmaceutical companies, and collaborations with health authorities and doctors throughout the world, we are able to tailor-make specific marketing and distribution strategies in 50 countries. Orphan Europe has developed a balanced mix between in-licensed products and in-house developed products, as well as therapies developed in collaboration with other pharmaceutical companies or research institutes. In 2004, our portfolio consisted of 14 products and over 4000 people benefited from these therapies. Two new products are currently in development.

貳、主要國家「罕見疾病跨病類」組織資料

Australia

The Association of Genetic Support of Australasia (AGSA)

66 Albion Street, Surry Hills, New South Wales, Australia, 2010

Telephone: +61 2 9211 1462 Fax: +61 2 9211 8077

Reg Charity No. CFN: 15481 ABN: 83 594 113 193

E-mail: agsa@ozemail.com.au

<http://www.agsa-geneticsupport.org.au/>

The Association of Genetic Support of Australasia (AGSA) Inc., a tax-deductible registered charity, was formed in 1988 to provide support and information for individuals and families affected by a genetic condition.

What is a genetic condition?

A gene or chromosome fault can result in a genetic condition. Genes are the instructions that determine physical characteristics such as height, hair and eye colour, strength of our bones and the correct functioning of our bodies. Genes are located on chromosomes inside the cells of our bodies. A genetic condition can run in families, but may occur without a previous family history.

How many families in Australasia are affected by a genetic condition?

- Currently it is estimated one person in ten will be adversely affected, directly or indirectly, by a genetic problem during their lifetime.
- About half of all miscarriages are caused by chromosomal abnormalities.

The completion of the full human genome sequence, in February 2001, refined the estimated number of genes in the human genome to around 30,000. Interestingly, the number of genes needed to make a human being is only double the number needed for apparently much simpler animals, such as fruit fly or a worm!

Around 11,000 genes have been identified to date. Almost 10,000 of these have been mapped to their chromosomal location and of these around 1,500 genes have been associated with human genetic disorders.

The list is increasing every year and includes such disabilities as blindness, cystic fibrosis, muscular dystrophy, haemophilia, breast cancer and problems with intellectual and physical development.

At present genetic testing is available in Australasia for approximately 300 disorders. Some tests are for genes involved in rare congenital disease of childhood. Some are for single gene disorders that manifest in the adult years.

How can AGSA help?

The diagnosis of a genetic condition in a family member, particularly a child, places enormous stress on a family. Families may feel the need for personal support offering a specialised understanding of their particular condition. Whilst there are support groups established for a number of genetic disorders within the Australasian region, AGSA may provide the only contact point for families affected by rare conditions. AGSA will endeavour to facilitate contact with another family/individual affected by the same, or similar conditions, and/or provide information about an overseas support group. AGSA also provides: A Peer Support and Information Officer who deals with enquiries and facilitates ongoing support for individuals, families, health professionals and other interested groups.

- AGSA has a database of over 500 predominantly rare genetic conditions
- Resources relating to education, respite care, medical services, allowances, and other helpful organisations
- Information seminars
- Local and regional contacts
- Regular newsletters

Genetic Support Network Victoria, Australia

10th Floor

Royal Children's Hospital

Flemington Road

Parkville

Victoria 3052

PO Box 1100

Parkville VIC 3052

Tel:(03) 8341-6315

Fax:(03) 8341-6390

E-mail: info@gsnv.org.au

<http://www.gsnv.org.au>

The Genetic Support Network Victoria is a vibrant and active organisation which aims to maintain a thriving network committed to promoting the interests and well-being of people affected by genetic conditions.

It was first established in 1996 as an unfunded, volunteer organisation and gained funding for staff in 1998. Since that time it has grown to include two part time staff, Leah Lonsdale and Lindy Hodgkin and is housed on the tenth floor of the Royal Children's Hospital in Melbourne, Australia.

The Network is proud to be associated with a wide range of support groups throughout Victoria as well as peak professional bodies such as Genetic Health Services Victoria.

The GSNV offers a range of services including information on genetic conditions, contact details for support groups, and even links between families with the same condition. We can point you towards your local community resources or give you links to the latest information on genetic hot topics.

The GSNV can also link up existing support groups to facilitate in the exchange of information and ideas or can even help in the establishment a new support group.

The Network is proud to promote education, encourages communication and support and represents the views of individuals and families. We currently circulate a number of publications including our monthly news update.

We hope that our role in the collaboration between individuals, families, professionals and genetic services, strives to enable all people with a genetic disorder living in Victoria have appropriate and accurate information and support for their disorder that empowers them to manage the challenges to their health and well-being.

Vision: *Overcoming genetic challenges.*

Mission: *To facilitate an information, support and advocacy network that empowers people to overcome genetic challenges.*

Information

- Provide a point of reference, information and referral to support groups and community resources, for families and individuals with a genetic condition.
- Facilitate an exchange of information, resources and assistance in order to support existing genetic support groups and aid in the development of new groups.
- Link groups for the purpose of transferring information.
- Provide information in a variety of formats e.g. website, newsletters, phone contact, being involved with other groups.
- Provide good information on time, in time, from the right people.

Support

- Provide a point of contact for families and individuals affected by a genetic condition to find the most appropriate support group.
- Ensure individuals are supported in all areas including ongoing development.
- Have appropriate support and information available immediately to people with a genetic condition and their parents/carers.
- Support "specific issues/crusades" of support groups - mechanics of lobbying etc.
- Provide support for support groups.
- Assist new groups with set-up, incorporation, finances etc.

Advocacy

- Represent the interests and views of people and their families affected by a genetic condition to the community, State and Federal Government.
- Provide "arms length" representation when needed.
- Empower GSNV members and the general community.

Representation

- Collaborate with professionals, peak bodies and government in order to ensure consumer participation in the quality and development of genetic services in Victoria.
- Have representatives on all relevant committees and be approached for our expertise.

Ethical Debate

- Promote and participate in ethical debate in the community
- Drive member and community awareness of ethical issues

Metabolic Dietary Disorders Association (MDDA)

PO BOX 33

MONTROSE VIC 3765

Aust: 1800 288 460.

Int: 613 9728 8460

<http://www.mdda-australia.org>

The MDDA is a self-help, not-for-profit, family-support group that was set up in 1996 to assist members and their families with the complex issues in dealing with metabolic dietary disorders. The MDDA is a registered charity, membership is Australia-wide and includes families from countries around the world. This site aims to provide a comprehensive resource for those with an inborn error of metabolism that is partially controlled by medically prescribed diet. The MDDA Committee are not medical professionals. We are Australians from a variety of backgrounds who have had personal experiences in dealing with an inborn error of metabolism.

Canada

Canadian Organization for Rare Disorders

P.O. Box 814

Coaldale, Alberta

Canada T1M 1M7

Phone: (403) 345-4544

Fax: (403) 345-3948

Toll Free: 1-877-302-7273

<http://www.cord.ca/>

Emails: Maureen Gaetz-Faubert

Herve Faubert

Kim Hankey

Mission Statement

"Through an educational and informational support network , CORD is committed to the enhancement of the lives of all persons affected by rare disorders."

Objectives

The world wide collection and distribution of information about rare disorders to all interested parties including health care professionals.

To identify those specific groups living with a rare disorder and to encourage medical research into the causes and effects of rare disorders.

To assist with the implementation of an orphan drug act.

To work in harmony with the media and medical community to increase public awareness about the existence of rare disorders in Canada.

Functions

CORD provides information on over 6,000 rare disorders. The information is available in understandable language.

Through a network system, CORD links individuals/families together with the same rare disorder.

CORD is the only organization of its kind in Canada. Millions of affected individuals and their families - as well as support groups, health care and human service professionals, rely on CORD's services.

Historical Overview

The Lethbridge Society for Rare Disorders (LSRD) was founded in April 1987 by Maureen Gaetz-Faubert. Maureen's then unknown rare disorder defied all the standard medical tests and as such, no proper diagnosis could be made. Maureen continued to suffer with her rare disorder but it was not in vain! With dogged determination she sought answers about her condition and was eventually diagnosed, by a geneticist in Edmonton, as having the rare disorder, Ehlers-Danlos Syndrome.

The profound lack of information and public awareness about rare disorders, along with the physiological and psychological impact these diseases have on those affected, confirmed the need for Maureen to establish a support group. As an essential component of this support group, Maureen also realized that an information network

was desperately needed for Canadians diagnosed with rare disorders. With the assistance of Lethbridge health care professionals, the next few months were spent developing an advisory committee. A name search was initiated and finally in November 1987, the Lethbridge Society for Rare Disorders (LSRD) was incorporated.

From its inception, the primary objective of LSRD was to provide support to individuals and their families affected by rare disorders. As a community information resource centre, educational meetings were held each month which led to the creation of specific rare disorder support groups for sufferers of such diseases as AIDS, Lupus, Chronic Fatigue Syndrome, Fibromyalgia and others.

As part of their commitment to heighten public awareness, LSRD wanted to eliminate some of the mystery and stigma attached to the term "rare disorder" by providing a clear definition.

From 1987 to 1995, LSRD received thousands of requests from Canadians seeking information on rare disorders. As a result, this organization had become a vital informational link between all those affected by rare disorders and the medical community. In its relatively short history, LSRD had evolved into an essential service.

The need for information and networking on rare disorders was bolstered by a story about LSRD which appeared in the April 1995 edition of Readers Digest, "When Your Doctor Doesn't Know." As a result of that magazine article there are now approximately 100 daily requests for information and diagnoses on rare disorders from across Canada. Moreover, as a parent and care giver, Maureen's determination for greater support was further augmented when her second child Andrew, born in 1994, was diagnosed with Imperforate Anus - a rare disorder totally unrelated to her own! To accommodate the growing public awareness of rare disorders, an application for incorporation of a more distinctive name, the Canadian Organization for Rare Disorders (CORD) was made and letters of patent were received in September 1995. As a result of her accomplishments, Maureen was awarded the "Women of Distinction" for Lethbridge, Alberta and area in 1996.

The board of CORD is excited about the tremendous response and enthusiasm from across Canada. With an assiduous effort and strong support from both the public and various profession disciplines, CORD, lead by Maureen is confident that they will be able to further enhance the quality of life of all Canadians suffering or affected by a rare disorder

Denmark

Danish Centre for Rare Diseases and Disabilities

Address:

Bredgade 25

Sct. Annae Passage, Opg. F.

Copenhagen K, DK-1260

Denmark

Phone: 00 -453- 3914020

Fax: 00 -453- 3914019

Email Address: chs@chs.dk

E-mail: csd@csd.dk

Web: <http://www.csd.dk/>

The Danish Centre for Rare Diseases and Disabilities is a nonprofit government organization that is concerned primarily with severe physical or mental disabilities that affect a population of fewer than one person in 10,000. Most of these disorders are congenital or hereditary in nature. Founded in 1990, the centre's objectives are to offer nationwide support to adults and families who have children with rare disabilities or special needs, and to ensure their access to highly qualified information and counseling services; to network affected individuals and family members with other affected families thus promoting mutual support and self-help groups; to network healthcare professionals; and to promote dialogue and research. A wide range of information and counseling services is offered to all who, either as health professionals or as private persons, need information on rare diseases. Target groups are local professionals and authorities involved in the provision and coordination of counseling, treatment, education and support for persons affected by rare diseases.

Danish Alliance for Rare Disorders (KMS)

Address:

Frederiksholms Kanal 2, 3rd Floor

Copenhagen K, 1220

Denmark

Phone: 45 -33 -14 00 10

Fax: 45 -33 -14 55 09

Email Address: kms@kms-danmark.dk

Website: <http://www.kms-danmark.dk>

The Danish Alliance for Rare Disorders (KMS) is an umbrella organization embracing 32 small organizations whose aim is to organize people with serious rare diseases. Some of these organizations have hundreds of members. Others have only a few. Founded in 1985, KMS advocates on behalf of people with rare disorders, working to make sure they have access to relevant care, resources and information.

Israel

Israeli Association for Rare Disorders (Eitan)

C/o Nechama Bar

5 Peki'in St (P.O. Box 6349)

Tel Aviv 61063

Tel: 03-6021055

Fax: 03-6021056

Eitan was established in 1995. President is Yehuda Sivan, and chairman is Yehuda Sivan. Yehuda Sivan suffers from a rare syndrome. He worked for several years in the Defense Ministry in several roles, including in the development of the Merkava tank. Today, he is retired.

Eitan's purposes are: to develop awareness of the difficulties and needs of those who suffer from rare syndromes, to provide information to professionals and parents, to give advice to families and to develop support services. It's major activities include Health, Rehabilitation, and Education.

People with rare syndromes suffer from a wide range of disabilities. Most are not regarded as disabled by the National Insurance Institute. Most require medical intervention at critical times, yet lack of information prevents them from receiving proper medical treatment. The most necessary treatment that rare syndrome sufferers require daily is paramedical. In most cases, this is not given or is given for too short a

time. Many medicines and foods are not listed as part of the Ministry of Health's "basket" of health benefits, forcing families to pay costs ranging from 1,000 to 5,000 shekels monthly.

Eitan's main program involves the operation of regional support centers. Two have begun to operate in Tel Aviv and Haifa, and three more are planned. The support centers provide social workers, an information organizer and volunteers, whose role is to meet each family that requests assistance and to relate individually to each problem. Eitan's other activities include: family meetings and support groups, development of community services such as a club and community housing, promotion of legislation for the rights of rare syndrome sufferers, and provision of information to various professionals with the goal of improving the care and treatment of rare syndrome sufferers.

Eitan's accomplishments include: 1. Establishment of support centers for rare syndrome sufferers in the center and north. 2. Involvement in the work of the Health Ministry: membership in the rare syndrome committee. 3. Provision of information to professionals, members of the Knesset and the public.

Eitan's future objectives: 1. Operation of support centers for sufferers of rare syndromes throughout Israel. 2. Initiation of a law to protect the rights of those suffering from rare syndromes - the law has already passed its first reading. 3. Development of community services: clubs, community housing and support groups.

Addition of at least 200 new members each year. Success of individual members' requests to receive government funding for medical and paramedical services, and recognition of their right to receive social security benefits.

1997 Total Income: \$65,000. Membership is open to anyone who has a rare syndrome, his/her family, and family friends.

Japan

Japan Intractable Diseases Information Center

(日本難病情報資訊中心)

<http://www.nanbyou.or.jp>

Japan Intractable Diseases Research Foundation

(財団法人日本難病医学研究財団)

<http://www.nanbyou.jp>

稀少難病者全国連合会

112-0011 東京都文京区千石 3-18-9-204

Tel: 03(3943)7008

03(3945)2175

Fax: 03(3944)6460

日本各地域難病連団体

☆印は J P C 加盟団体／○印は全難連加盟団体 (2004 年 04 月 09 日現在)

※赤文字は H P にリンクしています

	団体名	〒	住 所	TEL
☆	財団法人北海道難病連	064-8506	札幌市中央区南 4 条西 10 丁目	011-512-3233
☆	山形県難病等団体連絡協議会	990-0832	山形市城西町 4-2-38 山形県腎友会内	023-643-4804
☆	茨城県難病団体連絡協議会	310-0851	水戸市千波町 1918 県総合福祉会館内 4F	029-244-4535
☆	群馬県難病団体連絡協議会	371-0843	前橋市新前橋町 13-12 群馬県福祉総合センター内	027-255-0035
	(社)埼玉県障害難病団体協議会	338-0801	さいたま市大原 3-10-1 県障害者交流センター内	048-831-8005
	東京難病団体連絡協議会	101-0064	千代田区猿樂町 2-2-1 澤田ビル 206 号室	03-3291-6239
☆	長野県難病患者連絡協議会	399-0425	長野県上伊那郡辰野町樋口 463-5	0266-43-2022

			有坂 方	
☆	岐阜県難病団体連絡協議会	500-8881	岐阜市青柳町 5-2-4	058-253-6864
☆	愛知県難病団体連合会	462-0828	愛知県名古屋市中区東水切町 2-22	052-915-4121
☆	静岡県難病団体連絡協議会	420-0856	静岡市駿府町 1-70 静岡県総合社会福祉会館内	054-254-5246
☆	滋賀県難病連絡協議会	524-0022	守山市守山 5 丁目 6-15 県立心身障害児総合療育センター内	0775-82-9246
☆	京都難病団体連絡協議会	602-0000	京都市上京区堀川通丸田町南入 京都社会福祉会館 4F	075-822-2691
☆	大阪難病者団体連絡協議会	557-0014	大阪市西成区天下茶屋 2-23-18 サンピア堀江 405	06-6652-1321
☆	兵庫県難病団体連絡協議会	650-0021	神戸市中央区三宮町 1-9-1-903-2	078-322-1878
☆	奈良県難病連絡協議会	630-8144	奈良県奈良市東九条町 1014-29 熊元邦子 方	0742-61-6851
☆	岡山県難病団体連絡協議会	701-0204	岡山市大福 281-5 青木内科小児科医院	086-281-5831
	広島難病団体連絡協議会	730-0013	広島市中区八丁堀 1-23-515	082-227-7834
☆	高知県難病団体連絡協議会	780-0803	高知市弥生町 7-8	088-885-1052
☆	大分県難病患者団体連絡協議会	870-0141	大分市三川新町 1-2-1 ホトオアィス 105 大分県腎協気付	097-558-0010
☆	宮崎県難病団体連絡協議会	880-0925	宮崎市本郷北方 2121-2 谷口紘一方	0985-51-7496
☆	鹿児島難病団体連絡協議会	891-0144	鹿児島市下福元町 5386-3	099-261-4900

Korea

Korean Alliance for Rare Diseases, KARD

Address: 경기도 수원시 영통구 원천동 산 5 번지 아주대학병원
유전학클리닉 내(우: 442-721)

TEL: 031)216-9230

FAX: 031)219-5299

E-Mail: raredisease@hanmail.net

http://www.kard.org/

Korean Organization for Rare Disorders, KORD

New Zealand

New Zealand Organisation for Rare Disorders

P. O. Box 38-538, Wellington Mail Centre.

Phone +64 4 566 7707, Fax +64 4 566 7717,

Email enquiries@nzord.org.nz

http://www.nzord.org.nz/

- Is a Charitable Trust.
- Was set up in September 2000, following a conference of over 30 rare disease support groups.
- Helps people affected by rare disorders and their families to find essential

information.

- Provides resources and information for rare disease support groups.
- Monitors rare disease issues and policy matters.
- Builds partnerships between patients/families, support groups, clinicians, researchers, policy-makers and industry.

Who We Are

- Our People: NZORD is headed by an Executive Director, and steered by a Board of Trustees.
- Support Groups Network : NZORD brings together a large number of New Zealand support groups for people/families affected by rare disorders.

What We Do

- How NZORD Can Help You : how NZORD can help people/families affected by a rare disease, rare disease support groups, clinicians and researchers.
- Our Mission: includes improving information for patients, their family and professionals, and building partnerships to accelerate research towards control and cure of rare disorders.
- NZORD Activities: lists our main activities and achievements since establishment in September 2000.

Northway

National Center for Rare Disorders, Northway

Sandbakkveien 18

N-1404 Siggerud

Northway

Tel: +47-64-85-60-00

Fax: 47-64-85-60-99

E-mail: info@frambu.no

Web: http://www.frambu.no

The Centre for Rare Disorders (Norway) at The National Hospital in Oslo is a project under the Government Action Plan for the Handicapped. The objective of the project is to develop a model for improving the organization and implementation of the

services available for persons with rare disorders in Norway. The Centre is located in The National Hospital since many patients with these disorders visit this hospital concerning diagnosis, treatment, and/or follow-up. Use is made of the medical expertise at the hospital when the Centre works on the disorders. The Centre also establishes close cooperation with other regional hospitals, central hospitals, and rehabilitation services.

Philippine

The Philippine Newborn Screening Program

**Institute of Human Genetics
National Institutes of Health
University of the Philippines Manila
P.O. Box 297 Manila Central Post Office
Manila, Philippines
Tel. (632) 5261710 or (632) 5261725
Fax (632) 5269997**

Spain

Federacion Espanola de Enfermedades Raras (FEDER)

Address:

**Av. Francisco Javier
9 Edificio Sevilla 2 Planta 10 / Mod. 24
Sevilla, 41018
Spain**

Phone: 003-4 9-54989892

Fax: 003-4 9-54989893

Email Address: feder@enfermedades-raras.org

Website: <http://www.enfermedades-raras.org>

The aims of FEDER are to enhance awareness and recognition of rare disorders; improve the medical, social, and financial care that patients receive; call on appropriate authorities to set up nationwide reference, diagnostic, and therapeutic

centers for each disease or group of diseases; promote and support initiatives that encourage prevention, research, and collaboration; develop and implement orphan drug regulations; and defend patient rights and interests.

Sweden

Swedish Information Center for Rare Diseases,

Tel +46 (0)31 773 55 90, fax +46 (0)31 773 55 91,
email smagrupscentrum@sahlgrenska.gu.se

<http://www.sos.se/smkh/indexe.htm>

A knowledge database on rare diseases. The concept of "rare diseases" is defined as: "Disorders or injuries resulting in extensive handicaps and affecting no more than 100 individuals in one million inhabitants". Provides up-to-date information on rare diseases and about the support and services these groups of people require. To date, 180 rare diseases have been described (in Swedish). Additional diagnoses are being drawn up. The alphabetical search list contains both the most common name, in bold print, and other synonyms and abbreviations. (For rare diseases in English, click on the British flag.)

The Swedish government has commissioned the Swedish National Board of Health and Welfare to develop a knowledge database on rare diseases. The work is ongoing. The concept of "rare diseases" is defined as: "Disorders or injuries resulting in extensive handicaps and affecting no more than 100 individuals in one million inhabitants". The ambition of the database is to provide up-to-date information on rare diseases and about the support and services these groups of people require.

To date, 188 rare diseases have been described (in Swedish). Additional diagnoses are being drawn up. The alphabetical search list contains both the most common name, in bold print, and other synonyms and abbreviations.

The Swedish Association of Rare Disorders

Sällsynta diagnoser

Box 1386 172 27 Sundbyberg

Tel 08-764 49 99 |

Fax 08-546 40 494

E-post: dammert@funka.nu

The Swedish Association of Rare Disorders is an organisation for societies organising people with rare disorders and disabilities, and their members. The Swedish Association of Rare Disorders was founded on the 7th of November 1998.

The basis of the Association is to facilitate for people with rare disorders to make themselves heard and improve their situation by co-operating.

A platform for co-ordinated work. The purpose of the Association is to be a common organization for societies of rare disorders and to safeguard the common interests of people with rare disorders. However, the various rare disorders are very different between themselves. Each disorder has its entirely specific problems.

But in spite of the differences, there is a common complex of problems, which is due to the fact that the disorder is:

- rare,
- complicated, and
- that it might be difficult to find information about the disorder, and to spread this information.

The specific difficulties that are consequences of a rare disorder form the basis of the work of the Association.

The official Swedish definition of "rare disorder" According to the Swedish National Board of Health and Welfare, a rare disorder is as follows: "rare illnesses and injuries resulting in extensive disabilities which are found at a maximum of one hundred people per one million inhabitants".

An important goal for us is to increase the knowledge about what it is like to live with a rare disorder.

Feel free to e-mail our information secretary at dammert@funka.nu

Taiwan

Taiwan Foundation for Rare Disorders (TFRD)

10F., No.52, Sec. 2, Jhongshan N. Rd.,
Jhongshan District,
Taipei City 104, Taiwan
Tel: 886-2-25210717
Fax: 886-2-25673560
Email: tfrd@tfrd.org.tw
Web: <http://www.tfrd.org.tw>

Taiwan Organization for Disadvantaged Patients

10F., No.52, Sec. 2, Jhongshan N. Rd.,
Jhongshan District,
Taipei City 104, Taiwan
Tel: 886-2-25604501
Fax: 886-2-25230936
Email: Am06@tfrd.org.tw

United Kingdom

Contact a Family

209-211 City Road, London EC1V 1JN
Tel: 020 7608 8700 Fax: 020 7608 8701
Helpline 0808 808 3555 or Textphone 0808 808 3556
e-mail: info@cafamilly.org.uk

<http://www.cafamily.org.uk/strategy.html>

Contact a Family is a national registered charity, founded in 1979, for families with disabled children.

At our heart is a unique and powerful combination of:

- expert and comprehensive knowledge about rare disorders and all aspects of disability
- a wealth of personal experience and contacts
- an approach driven first and foremost by parents' points of view

Our aim is never to dictate to families but always to enable them to organise their own systems of support and contact. It is this enabling rather than running approach that allows us to deliver social change far beyond our resources and size.

"Contact a Family empowered us"

Group leader

"Now we have hope and a possible future as a family"

Parents

"When I needed someone to talk to you were there for me and it saved my sanity"

Parent

Since January 2003 Contact a Family has achieved further significance in UK-wide policy on disabled children. We have helped to develop the NHS Children's National Service Framework (NSF) in England and Wales, we have helped Scottish parents to directly influence the new Additional Support for Learning legislation in the Edinburgh Parliament, and we have engaged actively with new Government initiatives, in particular the Children's Fund and the new Pathfinder Children's Trusts in England focusing on better coordination of services for disabled children. We have also led the way in helping local authorities across the UK consult more effectively with parent groups.

There have also been difficulties; lack of local funding meant that sadly we had to close our South-West London office. Securing adequate resources continues to be a challenge for our West Midlands office.

We continue to be a unique and highly cost-effective organisation. But given greater resources and funding, we could achieve more far-reaching changes for families and come much closer to our aim of reaching every family with a disabled child in the UK. As ever, one of our greatest challenges remains securing the core funding to underpin our work.

It is thanks to the efforts and commitment of our staff, volunteer Local Area Representatives, funders and supporters that as we near our 25th anniversary we are better placed than ever to take up these exciting opportunities.

Genetic Interest Group

**Unit 4D, Leroy House,
436 Essex Road
London N1 3QP
UK**

Phone +44 (0)20 7704 3141

Fax +44 (0)20 7359 1447

Email: mail@gig.org.uk

<http://www.gig.org.uk>

The Genetic Interest Group (GIG) is a national alliance of organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders.

Its primary goal is to promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them

GIG's primary goals are:

- To promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them.
- GIG seeks to educate and raise awareness amongst opinion formers, people of influence and the public about human genetics and genetic disorders.
- GIG provides a common platform from which effective programmes can be launched to raise awareness, inform the media and influence government, industry and the NHS
- GIG focuses on issues of policy and practice keeping an active watch on developments within the UK and Europe that will influence the effective

transfer of knowledge and understanding into products and services for families that are supported by our member groups.

United States

Genetic Alliance

4301 Connecticut Avenue, NW

Suite 404

Washington, DC 20008-2369

Tel: 202-966-5557 x213

Fax: 202-966-8553

Email: sterry@geneticalliance.org

Web: <http://www.geneticalliance.org>

Genetic Alliance is an international coalition comprised of more than 600 advocacy, research and healthcare organizations that represent millions of individuals with genetic conditions and their interests. As a broad-based coalition of key stakeholders, we leverage the voices of millions of individuals living with genetic conditions.

With an 18-year history as a 501(c)(3) not-for-profit organization, the Alliance identifies solutions to emerging problems and works to reduce obstacles to rapid and effective translation of research into accessible technologies and services that improve human health.

The board and staff of Genetic Alliance empower individuals and families living with genetic conditions by promoting:

- Public participation in informed dialogue
- Access to quality resources essential for informed choices
- Leadership development within advocacy communities
- Involvement of consumers in public policy and healthcare discussions
- Collaboration with diverse, underserved and underrepresented communities

Major Activities

Leveraging the expertise of the genetics community builds capacity in our members through collaborative engagement. Genetic Alliance is at the crossroads of the genetics community — we provide a rich nexus of advocacy and community

organizations, government, industry and private entities. These interactions accelerate translational research, improve the climate for the development of technologies, encourage cohorts for clinical trials, increase the availability of linked, annotated biological resources and ultimately lead to improved human health.

Informed consumers, advocacy groups and community organizations create a demand that is met by genomics technologies, tests and treatments — thus creating a favorable business climate for the early adoption of new products that result from academia, biotechnology and pharmaceutical organizations. In our central position in the genetics community, we are able to empower individuals and advocacy organizations to help better the lives of their constituents: individuals and families living with genetic conditions.

History

The Genetic Alliance was founded in 1986 – four years before the Human Genome Project was launched by scientists and governments world-wide. Landmark meetings of families, support group leaders and health professionals in 1984 and 1985 served as the catalyst for the establishment of the Genetic Alliance (originally named the Alliance of Genetic Support Groups). Parents and professionals shared concerns about medical management and the serious lack in support and information services for families living with genetic conditions. In 1986 founding members created a national coalition of consumers and professionals, a network of genetics organizations, and a strategic road map that would guide the organization's programs and services over the next decade and into the 21st Century. Joan O. Weiss, MSW, LCSW served as Founding Executive Director from 1986 to 1996.

In 1996 the Genetic Alliance celebrated its Tenth Anniversary and welcomed a new Executive Director, Mary Davidson, MSW, to the task of expanding the organization to meet rapidly emerging needs for quality information, support, technical assistance and policy formation. In 1999 the Alliance established a Three-Year Strategic Plan to guide program development. Never straying from the creative vision and foresight of its founders, the Alliance identifies gaps in services and policies that impact health care consumers' access to quality genetic services and creates programs and secures funding to fill these identified needs.

Genetic and Rare Diseases Information Center

The Genetic and Rare Diseases Information Center

P.O. Box 8126

Gaithersburg, MD 20898-8126

(888) 205-2311 (Phone)

(888) 205-3223 (TTY)

(301) 519-3194 (International Telephone Access Number)

gardinfo@nih.gov

(240) 632-9164 (Fax)

Established by the National Human Genome Research Institute (NHGRI) and the Office of Rare Diseases (ORD), the Genetic and Rare Diseases Information Center employs experienced information specialists to answer in English or Spanish questions from the general public, including patients and their families, health care professionals and biomedical researchers.

Note: The Genetic and Rare Diseases Information Center does not give medical advice, provide treatment, or diagnose illness.

March of Dimes Birth Defects Foundation

March of Dimes

1275 Mamaroneck Avenue

White Plains, NY 10605

Fax: (914) 997-4537

E-mail: askus@marchofdimes.com

<http://www.marchofdimes.com>

The first great polio epidemic in the U.S. was in 1916. The disease infected mostly children, killing thousands and leaving many more paralyzed. On a summer day in 1921, Franklin D. Roosevelt became one of its victims and the March of Dimes was born. Through life saving research we beat polio, but we continue our efforts to help children today by working to save babies from the silent crisis of premature birth.

The mission of the March of Dimes is to improve the health of babies by preventing birth defects and infant mortality. We carry out this mission through research, community services, education and advocacy to save babies' lives. March of Dimes researchers, volunteers, educators, outreach workers and advocates work

together to give all babies a fighting chance against the threats to their health: prematurity, birth defects, low birthweight.

The March of Dimes has been dedicated to saving babies from birth defects and other infant health problems for more than 60 years. Our cutting edge research, innovative community services, education and advocacy programs help save babies' lives. You can help, too and be a hero for babies. Join our committed family of 1300 plus employees and more than 3 million volunteers and make a positive impact on the health of babies and on our own future. Work in our national office in White Plains, N.Y. or in any of our 3 regional offices or 55 chapters across the country.

The March of Dimes supports comprehensive newborn screening for all babies in this country, regardless of their place of birth. We urge every state to screen every baby for at least 29 conditions. For each of these conditions, screening has a documented benefit to the child, and a reliable test that enables early detection is available.

Metabolic Disorders National Affiliation/MDNA

c/o Living Faith Church

PO Box 10861

Daytona Beach FL 32120-0861

Tel: 386-4466672

Email:keri@pvns.net

Web:www.livingfaithwm.com

National Coalition for PKU & Allied Disorders

**National Coalition, P. O. Box 1244, Mansfield,
MA 02048**

(877) 996-2723

Web www.pku-allieddisorders.org

National Organization for Rare Disorders,US (NORD)

**55 Kenosia Avenue
PO Box 1968
Danbury, CT 06813-1968**

**Tel:(203) 744-0100
Tollfree: (800) 999-6673 (voicemail only)
TDD Number: (203) 797-9590**

Fax Number: (203)798-2291

**E-mail Contact:
orphan@rarediseases.org**

<http://www.rarediseases.org>

Mission Statement

The National Organization for Rare Disorders (NORD), a 501(c)3 organization, is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

What is A Rare Disorder?

A rare or "orphan" disease affects fewer than 200,000 people in the United States. There are more than 6,000 rare disorders that, taken together, affect approximately 25 million Americans. One in every 10 individuals in this country has received a diagnosis of a rare disease. For almost twenty years, NORD has served as the primary non-governmental clearinghouse for information on rare disorders. NORD also provides referrals support groups and other sources of assistance.

Our Sources of Funding

NORD is not a government agency. It is a non-profit, voluntary health agency that exists to serve rare-disease patients and their families. Our primary sources of funding are contributions, membership fees, and revenues from the sale of our products, such as our books and Rare Disease Database reports. Most of the money donated to NORD

goes directly to programs and services. Copies of our annual report are available upon request.

Founded in 1983

NORD was established in 1983 by patients and families who worked together to get the *Orphan Drug Act* passed. This legislation provides financial incentives to encourage development of new treatments for rare diseases.

NORD Services and Programs

NORD provides information about diseases, referrals to patient organizations, research grants and fellowships, advocacy for the rare-disease community, and Medication Assistance Programs that help needy patients obtain certain drugs they could not otherwise afford.

Sources of Content

NORD's Rare Disease Database reports are written by NORD medical writers and reviewed by physicians. In some cases, the reports are written by physicians. Other content on NORD's Web site is written by NORD staff members.

Office of Rare Diseases, National Institutes of Health

6100 Executive Boulevard, 3B-01

Bethesda, Maryland 20892–7518

Telephone: (301) 402–4336

Fax: (301) 480–9655

Email: ord@od.nih.gov

<http://rarediseases.info.nih.gov/>

The Office of Rare Diseases (ORD) was established in 1993 within the Office of the Director of the National Institutes of Health (NIH). On November 6, 2002, the President established the Office in statute (Public Law 107-280, the [Rare Diseases Act of 2002](#)). A rare disease (also called an orphan disease) is a disease or condition affecting fewer than 200,000 persons in the United States. An estimated 25 million people in the United States have a rare disease.

The goals of ORD are to stimulate and coordinate research on rare diseases and to support research to respond to the needs of patients who have any one of the more than 6,000 rare diseases known today. To leverage its resources, stimulate rare diseases research activities, and foster collaboration, ORD works with NIH Institutes or Centers to support (1) a grants program to establish a network for research on rare diseases,

including the training of rare diseases researchers, (2) an intramural center for patients with undiagnosed rare conditions, and programs to stimulate clinical research on rare diseases including the training of researchers interested in rare diseases, (3) a scientific conferences program to stimulate research where little exists, where research progress may have stalled, or in response to scientific opportunities; (4) regional workshops to assist patient support groups to become partners with the NIH and better understand NIH research programs and gaining better access to NIH research opportunities, (5) an information center and other information dissemination mechanisms to supply reliable and valid information to the public, researchers, and health care providers, including various databases to provide access to information over the web, and the ORD Web site, and (5) a number of ancillary activities that contribute to furthering research on rare diseases.

For information on rare cancers, please contact the National Cancer Institute's Cancer Information Service (CIS) toll free at (800) 4-CANCER.

Organic Acidemia Association

13210 35th Avenue North

Plymouth, MN 55441

Tel: 763-5591797

Fax: 763-6946617

E-mail: OAANews@aol.com

Website: <http://www.oaanews.org/>

Our Mission

The Organic Acidemia Association is a voluntary not-for-profit self-help organization dedicated to providing information and support to families of children with inborn errors of metabolism. Established in the early 1980s, the Organic Acidemia Association provides information to affected families and health care professionals across the country and internationally.

What is a Organic Acidemia

Organic Acidemias are a group of inheritable genetic metabolic disorders in which there is a defect in protein metabolism where an essential enzyme is absent or malfunctioning. This defect results in a build up of chemicals, in this case usually acids, on one side of the metabolic blockage and a deficiency of vital chemicals on the other.

This causes an overdosage of one chemical (often toxic) and the shortage of another which is essential to normal body functioning.

The effect of the disorder will depend upon the age at which symptoms occur. Children with less severe forms of the conditions develop symptoms later.

Characteristics of the conditions include general malaise, reluctance to feed, breathing problems, vomiting, hypotonia (floppiness) and/or spasticity (stiffness).

Early detection and treatment can greatly mitigate the effects of the disorder.

Save Babies Through Screening Foundation

4 Manor View Circle

Malvern, PA 19355-1622

Email: email@savebabies.org

Tel: 1-888-454-3383

Web: www.savebabies.org

Save Babies Through Screening Foundation is a national nonprofit public charity run by volunteers. Its mission is to improve the lives of babies by working to prevent disabilities and early death resulting from disorders detectable through newborn screening. Without proper screening affected children will likely suffer mental retardation, physical disability or even death. Most affected children can lead normal, healthy lives when diagnosed and started on treatment early.

Save Babies Through Screening Foundation supports, assists and advocates screening for disorders that are detectable through filter paper newborn screening; are unlikely to be clinically diagnosed without screening; and cause mental retardation, physical disability and/or death in early childhood when left untreated.

參、亞洲主要國家「罕病病友組織」資料

China

廣東省地中海貧血防治協會

Hong-Kong

地中海貧血兒童基金

香港薄扶林道瑪麗醫院護士宿舍 B1 座 201-203 室

電話：(852) 2523-5400

傳真：(852) 2818-0636

<http://www.thalassaemia.org.hk>

背景

爲了改善地中海貧血病童的生活，協助他們的正常成長，一群醫生、病童家長以及一些熱心人仕在一九九三年六月二十三日在香港組成了這基金。

現況

地中海貧血可分兩種。常見的一種是輕型地中海貧血，受影響的人約佔本港人口百分之八。輕型地中海貧血對身體沒有影響，表面上也無蹟可尋。但當父母都帶有輕型地中海貧血的遺傳基因時，他們的幼兒便可能患上重型地中海貧血病，受影響的機會高達四分之一。

重型地中海貧血病是一種嚴重的疾病，患者身體無法製造足夠的紅血球來支持生長及正常的活動。患病的嬰兒出生後不久，便開始感到不適，並且會有進食緩慢、發育遲緩、腹部腫脹及骨骼變形等症狀。他們必需按時輸血以維持生命；從幼兒開始，他們便需要每月住院一至兩天，進行輸血，月復月，年復年。如果這些病童得不到適當的治療，他們的生長會受到嚴重的影響，導致身材矮小、骨骼變形，不能進入青春發育期，甚至一早死亡。

由此可見，患有重型地中海貧血病的兒童身心都受到損害。此外，長期的輸血會造成鐵質沉積，引致心臟衰竭、肝病及發育不良等併發症。因此，患病的兒童還需要接受除鐵靈的注射。他們每晚睡覺時，都要接受皮下注射，讓注射器將藥物徐徐注入體內，歷時八至十二小時。除鐵靈能將身體多餘的鐵質排泄體外，改善了病童的身體健康。然而這些都是治標的方法。一些其他國家現已開始使用一隻名為L1的口服除鐵藥，但香港的醫學界仍有很大爭論，因為該藥可能有對肝臟損害的副作用。

工作目標

- ▣ 提高普羅大眾對地中海貧血病的關注。
- ▣ 向受影響的父母提供諮詢服務。
- ▣ 購置先進的醫學儀器，提高病人的護理。
- ▣ 邀請世界知名的學者來港講學，提高本地醫護人員及病者對此病的認識。
- ▣ 向受影響的病人及其家庭提供心理輔導及社會工作服務。
- ▣ 資助醫學研究。

INDIA

Thalassemics India

A-9, Nizamuddin (West), New Delhi - 110 013 (INDIA)

Tel : +(91)-(11)-24353871

Fax : +(91)-(11)-26183664

E-mail : info@thalassemicsindia.org

<http://www.thalassemicsindia.org/>

Established in 1986, Thalassemics India was conceived to check and help deal with Thalassaemia. A non-governmental organization, Thalassemics India is working zealously across the country, operating in close association with doctors, drug/equipment companies, hospitals, thalassemia associations & centers throughout the country and abroad.

An association which was formed by a few thalassemia parents in 1986, it has now

achieved the status of a State Awardee (1998) Organization with a 1000 strong membership that includes thalassemics, thalassemia parents, associations, doctors & social workers.

Giving Thalassaemia International Federation (Cyprus) its first Vice President, Thalasseemics India works in close association with the TIF; an international non-governmental organization collaborating closely with members of thalassemia associations worldwide.

Among some of the main achievements of the association since its inception are the establishment of a thalassemia center, organization of successful International Conferences & Workshops, holding of free thalassemia clinics, collection of medicines/equipments for free distribution, organization of free thalassemia detection camps, collection of funds from India & abroad to help needy thalassemics towards their treatment & collaborating closely with important offices & departments for achieving the goals.

Japan

	団体名	〒	住 所	TEL
○	全国難病団体連絡協議会	102-0071	東京都千代田区富士見 2-4-9-203	03-3288-8166
☆	日本患者・家族団体協議会(J P C)	170-0002	東京都豊島区巣鴨 1-20-9 巣鴨ファーストビル 3F	03-5940-0182
☆	日本患者同盟	204-0022	東京都清瀬市松山 2-13-12	0424-91-0058
	(社)日本オストミー協会	124-0023	東京都葛飾区東新小岩 1-1-1-901	03-5670-7681
☆	日本肝臓病患者団体協議会	161-0033	東京都新宿区下落合 3-6-21-201	03-5982-2150
☆	スモンの会全国連絡協議会	160-0022	東京都新宿区新宿 2-1-3 サニーシティ新宿御苑 1001 スモン公害センター内	03-3357-6977
☆	全国パーキンソン病友の会	107-0052	東京都港区赤坂 1-9-13 三会堂ビル 8F	03-3560-3355

☆ ○	(社)全国腎臓病協議会	170-0002	東京都豊島区巣鴨 1-20-9 巣鴨ファーストビル 3F	03-5395-2631
○	全国多発性硬化症友の会	175-0083	東京都板橋区徳丸 5-11-5 坂本 方	03-3934-3060
	あせび会	113-0021	東京都文京区本駒込 6-5-19-102	03-3943-7008
	全国脊髄小脳変性症友の会 (全国 SCD 友の会)	170-0004	東京都豊島区北大塚 2-7-2	03-3949-4036
○	全国膠原病友の会	102-0071	東京都千代田区富士見2-4-9 千代田富士見マンション203	03-3288-0721
	日本二分脊椎症協会	173-0037	東京都板橋区小茂根 1-1-10 心身障害児総合医療療育センター内 SB 情報ネットワーク室	03-3974-1800
○	日本 ALS 協会 (筋萎縮性側索硬化症)	162-0837	東京都新宿区納戸町 7-103	03-3267-6942
○ ☆	パーチェット病友の会本部	173-8605	東京都板橋区加賀 2-11-1 帝京大学医学部内	03-3964-3315
	低身長児・者友の会(ボブラの会)	165-0032	東京都中野区鷺宮 2-15-10 星川 方	03-3330-8612
	全国「腎炎・ネフローゼ児」を守る会 (腎ネフ会)	273-0037	千葉県船橋市古作 4-14-10	047-338-1466
	(財)全国精神障害者家族会連合会	110-0004	東京都台東区下谷 1-4-5	03-3845-5084
	(社)日本筋ジストロフィー協会	162-0051	東京都新宿区西早稲田 2-2-8	03-5273-2930
	(社)東京進行性筋萎縮症協会 (東筋協)	143-0025	東京都大田区南馬込 2-9-6 西端 方	03-3773-8331
	(社)日本リウマチ友の会 (リウマチ友の会)	101-0047	東京都千代田区内神田 2-7-7 新内神田ビル 3F	03-3258-6565
	(社)日本てんかん協会	162-0051	東京都新宿区西早稲田 2-2-8 全国心身障害児福祉財団ビル	03-3202-5661
	全国じん肺患者同盟	431-0431	静岡県湖西市鷺津 1544-14	053-576-3184

	森永ひ素ミルク中毒の被害者を守る会	530-0022	大阪府大阪市北区浪花町 13-38 千代田ビル北館 2F (財) ひかり協会気付	06-6371-5304
	すこやか村・喘息館			073-471-5222
	通風友の会	105-0001	東京都港区虎ノ門 1-1-25 虎ノ門一丁目ビル	03-3593-0714
	日本アレルギー友の会	135-0002	東京都江東区住吉 2-6-5 インテグレート村上ビル 3F	03-3634-0865
	胆道閉鎖症の子供を守る会(CBA の会)	170-0002	東京都豊島区巣鴨 3-2-5 豊ビル 202	03-3940-3150
	口唇・口蓋裂友の会(口友会)	140-0001	東京都品川区北品川 2-23-2-202	03-5479-8941
	全国脊髄損傷者連合会	134-0085	東京都江戸川区南葛西 5-13-6	03-5605-0871
	川崎病の子供をもつ親の会	214-0036	神奈川県川崎市多摩区南生田 6-34-16 浅井 満 方	044-977-8451
☆	もやもや病の患者と家族の会	560-0081	大阪府豊中市新千里北町 2-40C56-207	06-6872-3101
☆	日本喘息患者会連絡会	920-0848	石川県金沢市京町 23-2 サン・ヴィンテージ 103	076-252-6746
	・つくしの会 (軟骨無形成症患者・家族の会) ・つくしの会東京支部	791-8031	愛媛県松山市北斎院町 812-7 新山 登 方	089-952-0435
	日本 AS(強直性脊椎炎)友の会 Japan Ankylosing Spondylitis Club(JASC)	181-0004	三鷹市荒川 1-11-5 井上 久 方	0422-45-7985
	つばさの会 (先天性免疫不全症患者と家族の会) (原発性免疫不全症患者と家族の会)	454-0958	愛知県名古屋市中川区東かの町 505-1 永井敬子 方	052-302-9829
	サルコドイシス友の会(ザ友の会)	529-1801	滋賀県甲賀郡信楽町勅旨 599 小林弘幸 方	0748-83-0748
	網膜色素変性症の患者と家族の会	350-1131	埼玉県川越市岸町 1-31-41	0492-48-4834

			富山 方	
	SSPE 青空の会(亜急性硬化性全脳症)	245-0016	神奈川県横浜市泉区和泉町 2813-8 中村一 方	045-803-6410
	日本ムコ多糖症親の会(MPS 親の会)	323-0016	栃木県小山市扶桑 2-7-15,7-310 田島直秀 方	0285-22-6643
	骨形成不全友の会	232-0066	神奈川県横浜市南区六ッ川 3-80-3 奥田欣也 方	045-711-2102
	ゴーシェ病患者及び親の会(G の会)	274-0063	千葉県船橋市習志野台 8-4-10	047-461-5291
	再生つばさの会(再生不良性貧血)	248-0027	神奈川県鎌倉市笛田 4-1-18-106 関つたえ 方	0467-32-0886
	人工呼吸をつけた子の親の会 (バクバクの会)	553-0002	大阪府大阪市東淀川区北江口 4-13-2 吉岡由美子 方	06-6340-2274
	特定非営利活動法人 全国 IDDM ネットワーク	849-8501	佐賀県佐賀市鍋島 5-1-1 佐賀医科大学小児科内	0952-34-2314
	日本ハンチントン病ネットワーク	116-0003	東京都荒川区南千住 5-29-6 阿久津 方	
	SMA(脊髄性筋萎縮症)家族の会	100-8693	東京中央郵便局私書箱 1377 号 SMA 家族の会事務局	
	東京「腎炎・ネフローゼ」を守る会	154-0012	東京都世田谷区駒沢 2-21-8	03-5481-0483
☆	全国心臓病の子どもを守る会	161-0033	東京都新宿区下落合 3-15-22 ランドール目白	03-5982-4933
	嚢胞性線維症(Cystic Fibrosis) 患者と家族の会	481-0043	愛知県西春日井郡西春町沖村岡 213	0568-22-2562
	家族性アミロイドーシス(FAP) 患者・家族会「道しるべの会」	864-0011	熊本県荒尾市下井手 1068-3 前田憲作 方	0968-65-8383
☆	全国脊柱靱帯骨化症患者家族 連絡協議会(全脊柱連)	245-0016	横浜市泉区和泉町 1503 青沼三郎 方	045-803-4526
	日本網膜色素変性症協会(JRPS)	140-0013	東京都品川区南大井 2-7-9 アミューズKビル	03-5753-5156

	腎性尿崩症友の会	536-0023	大阪市城東区東中浜 3-11-9 神野稜 方	06-6963-4022
	ボンベ病の会	819-0013	福岡県福岡市西区愛宕浜 4-45-17	092-883-3801
	若年性関節リウマチ【JRA】の 子供を持つ親の会「あすなろ会」			
	全国ポルフィリン代謝障害友の会 「さくら友の会」	115-0055	東京都北区赤羽西 4-46-13	03-3907-5800
	シェーグレン症候群患者の会	920-0293	～事務局～ 石川県河北郡内灘町大学 1-1 金沢医科大学血液免疫内科	076-286-2211
	「沖縄クローン友の会」 (クローン病,潰瘍性大腸炎の 患者をサポート)	900-0013	沖縄県那覇市牧志 3-24-29 グレイスハイム喜名 21 階 アンビシャス内	
	「沖縄県難病支援センター NPO 法人アンビシャス」 (118 種類の難病患者をサポート)	900-0013	沖縄県那覇市牧志 3-24-29 グレイスハイム喜名 21 階	098-951-0567
	熊本 IBD	869-0461	熊本県宇土市網津町 1418-4 中山泰男 方	e-mail: hannah@xa2.so-net.ne.jp
	IBD ネットワーク	062-0933	札幌市豊平区平岸 3 条 5 丁目 9-5 平岸 3 条ハウス 203 号室 IBD 会館内 IBD ネットワーク宛	e-mail: info@ibdnetwork.org
	大阪 IBD	663-8183	西宮市里中町 3 丁目 11 番 21 号 布谷嘉浩 方	e-mail: nuno@optstyle.com
	滋賀 IBD	520-0845	滋賀県大津市若葉台 8-13	e-mail: cresta5000@ybb.ne.jp
	ファブリー病/患者と家族の会	277-0825	千葉県柏市布施 547-1 東川隆 方	電話: 080-5013-2409 FAX: 050-1021-7929 e-mail:

				Fabry200412@yahoo.co.jp
	特定非営利活動法人 JAPAN IBD	655-0861	兵庫県神戸市垂水区下畑町字向井 459-1	電話 & FAX 078-752-5266 e-mail : japanibd@ybb.ne.jp
	兵庫県OPLL友の会やまぼうし (後縦靱帯骨化症患者家族会)	665-0876	兵庫県宝塚市中山台 1-13-6	電話 & FAX 0797-88-4043
☆	全国筋無力症友の会 	170-0031	東京都豊島区目白 3-13-18 ウィング目白 205	電話 & FAX 03-5996-5595 e-mail: info@mgjp.org

Korea

Muscular Dystrophy Association

Tel: 82 2 835 4225

E-mail: mda@korea.com

Web: www.mdakorea.org

Multiple Myositis Association

Tel: 82 33 641 7162

E-mail: 9137023@hanmail.net

Takayasu Arteritis Association

Tel: 82 16 759 0669

E-mail: best2940@hanmail.net

Korean Organization of Parkinson Disease

Tel: 82 2 3497 3446

Web: <http://yongdong.yongsei.ac.kr/parkinson/>

CMD Association

Tel: 82 31 298 2263

E-mail: bobae01@hanafos.com

Dystonia Association

Tel: 82 502 823 5154

E-mail: hg981309@hanmail.net

Leprechaunism Association

Tel: 82 2 3486 4535

E-mail: sesjjnhs@yahoo.co.kr

Lupus Association

Tel: 82 2 2285 4546

Fax: 82 2 2285 4585

E-mail: winlupus@hanmir.com

Web: www.luisa.or.kr

ALD Association

Tel: 82 2 956 5151

E-mail: ald2000@kornet.net

Gaucher Association

Tel: 82 2 422 0886

Web: www.kord.or.kr/gaucher

Fabry Association

Tel: 82 2 821 9945

E-mail: fabry@lycos.co.kr

MPS Association

Tel: 82 31 456 6928

E-mail: inhwa0816@hanmail.net

Web: <http://www.mps.or.kr/>

Penylketonuria Association

Tel: 82 2 722 7471

Multiple Sclerosis Association

Tel: 82 2 362 7744

E-mail: kmss@kmss.or.kr

Crohn's Disease Association

Tel: 82 18 370 9927

E-mail: mediasonic@hanmail.net

ALS Association

Tel: 82 2 583 9292

Prader-Willi Syndrome Association

Tel: 82 2 441 3198

E-mail: seongon@naver.com

Web: www.pwskorea.co.kr

Rett Syndrom Association

Tel: 82 2 931 5714

E-mail: master@rett.pe.kr

Web: www.rett.pe.kr

LPK Association

Tel: 82 2 576 3849

E-mail: kwangrhm@dreamwiz.com

Web: www.lpk.or.kr

Korea Ataxia Society

Tel: 82 31 354 0125

Web: <http://home.freechal.com/ataxia>

Chronic Granulomatous Disease Association

Tel: 82 2 2664 5158

E-mail: cyg1228@hanmail.net

Web: www.cgd.co.kr

Wilson's Disease Association

Tel: 82 2 2625 9654

E-mail: youngs0691@hanmail.net

Web: www.wilson.or.kr

Spinal Muscular Atrophy Association

Tel: 82 2 3399 3626

E-mail: whlee@syu.ac.kr

Web: www.koreasma.com

Myelomeningocele Association

Tel: 82 31 574 9309

Web: <http://café.daum.net/lipo>

Cornelia de Lange Syndrome Association

Tel: 82 2 3295 3085

E-mail: skyroom2000@hanmail.net

Web: <http://cdls.com.ne.kr>

Achondroplasia Association

E-mail: kwangrhm@dreamwiz.com

Web: www.lpk.or.kr

Neutropenia Association

Tel: 82 31 705 6988

Web: <http://café.empass.com/neutropenia>

Behcet Patient Association

Tel: 82 2 2652 6636

E-mail: behcet@naver.com

Web: www.behcet.co.kr

Marfan Syndrome Association

Web: <http://café.daum.net/Happyhill>

Osteogenesis Imperfecta Association

Tel: 82 11 386 9899

E-mail: hellohero@hanmail.net

Web: www.koia.org

Glanzmann's thrombasthenia Asso.

Tel: 82 32 212 8259

E-mail: saehim17@netian.com

Web: <http://gt.netian.com>

Penguin Korea Asso.

Tel: 82 2 3672 7220

Fax: 82 2 566 5335

E-mail: penguin@penguinkorea.org

Web: www.penguinkorea.org

Korea Blood Cancer Association

82 2 3432 0807

Fax: 82 2 3432 0609

E-mail: sbnuri@dreamwiz.com

Web: <http://sbnuriallmedicus.co.kr>

Respiratory Disorder Asso.

Tel: 82 31 397 8822

E-mail: c18j921@chollian.net

Fibrinomyalgia Syndrome Asso.

E-mail: fmscfs@fmscfs.co.kr

Web: www.fmscfs.co.kr

Fetal Alcohol Syndrome Asso.

Tel: 82 11 9323 6404

E-mail: njs6350@hanmail.net

Web: <http://café.daum.net/fas2002>

Ehlers Danlos Syndrome Asso.

Tel: 82 2 6294 2252

Web: <http://café.daum.net/Ehlers>

Malaysia

The E-Thalassaemia Community

<http://www.ethal.org.my>

Overview

The E-Thalassaemia project is an electronic community for the blood disorder, Thalassaemia. The aim of this E-Community is to primarily provide a community for the sufferers of this disorder, their families, medical personnel, social workers, voluntary workers and members of the public both, locally and internationally. The project also involved the linking of various hospitals and Thalassaemia Associations to the e-community.

One of its aims is to also reach out to its members, associates, supporters and the general public with view of developing greater interaction between them. It will help in providing support, counselling and assistance to those suffering with Thalassaemia and their families and also contribute in the larger battle against Thalassaemia.

In the past organisations such as Thalassaemia Association of Malaysia (TAM), have had a limited reach in interacting with its members and supporters because of time and staffing constraints, physical availability of experts and geographical / physical boundaries. The setting up of this E-Community has helped to overcome much of these obstacles.

History

The idea of E-Thalassaemia was conceived in 2000. This idea was made a reality with the help of The Government Of Malaysia via its representative MIMOS Bhd. The Thalassaemia Association of Malaysia (TAM) being the initiator and promoter of E-Thalassaemia was awarded a grant under the DAGS scheme to develop and subsequently to administer this E-community.

Together with the MyOpenSource Group and the Living Impact Group, TAM was able to develop this E-community. Without this "smart partnership" the E-Thalassaemia community would not be a reality to day.

Taiwan

Taiwan SCA (Spinocerebellar Ataxia) Association

7F., No.208, Kunming St.,
Wanhua District,
Taipei City 108, Taiwan
Tel: 886-2-23147035
Fax: 886-2-23147041
sca0310@ms65.hinet.net
<http://sca.ym.edu.tw/scaweb/index.php>

Taiwan MPS (Mucopolysaccharidoses) Association

No.357, Jinjhou St.,
Jhongshan District,
Taipei City 104, Taiwan
Tel: 886-2-25032125
Fax: 886-2-25039435
cks47@ms21.url.com.tw
<http://www.tacocity.com.tw/cks49>

Taiwan OI (Osteogenesis Imperfecta) Association

5F.-2, No.12-3, Jilin Rd.,
Jhongshan District,
Taipei City 104, Taiwan
Tel: 886-2-25224036
Fax: 886-2-25224037
Email: oif.taiwan@msa.hinet.net
<http://www.oif.org.tw/>

Taiwan MND (Motor Neurone Disease) Association

1F., No.13, Lane 56, Shihjian St.,
Beitou District,
Taipei City 112, Taiwan
Tel: 886-2-28201357
Fax: 886-2-28201431
Email: mnda2874@ms39.hinet.net
<http://www.mnda.org.tw/>

Taiwan Muscular Dyatrophy Association

3F.-3, No.58, Jiouru 1st Rd.,
Sanmin District,
Kaohsiung City 807, Taiwan
Tel: 886-7-3801000
Fax: 886-7-3800231
Email: tmda168@ms22.hinet.net
<http://www.mda.org.tw/>

Taiwan Thalassemia Association

2F., No.1, Changde St.,
Jhongjheng District,
Taipei City 100, Taiwan
Tel: 886-2-23891250
Fax: 886-2-23891362
Email: thala@ha.mc.ntu.edu.tw
<http://www.thala.org.tw>

Kaohsiung Concerned Ichthyosis Association

No.202, Jianwu Rd.,
Sanmin District,
Kaohsiung City 807, Taiwan
Tel: 886-7-3833641
Fax: 886-7-3941031
Email: khh.home@msa.hinet.net

Taiwan Concerned Ichthyosis Association

10F.-2, No.105, Guangfu N. Rd.,
Songshan District,

Taipei City 105, Taiwan
Tel: 886-2-27482908
Fax: 886-2-27423071
Email: Tai.fish105@msa.hinet.net

Taiwan Concerned Thalassemia Association

No.276, Sec. 3, Zhiyou Rd.,
East District,
Taichung City 401, Taiwan
Tel: 886-4-22121260
Fax: 886-4-25260276
Email: ttag@ms75.hinet.net
<http://www.tta.org.tw>

Taiwan Multiple Sclerosis Association

No.10-2, Lane 290, Jhongnan Rd.,
Douliou City,
Yunlin County 640, Taiwan
Tel: 886-5-5518011*242
Fax: 886-5-5511013
Email: inka@food.com.tw
<http://www.ms.org.tw>

Association of Congenital & Inherited Metabolic Disease, R.O.C.

Room 512, 9F., Jhongjheng Building,
No.201, Sec. 2, Shihpai Rd.,
Beitou District,
Taipei City 112, Taiwan
Tel: 886-2-28767181
Fax: 886-2-28767181
Email: pkuintw@yahoo.com.tw
<http://www.pku.org.tw>

Taiwan Hereditary Epidermolysis Bullosa

2F., No.192-1, Huashan St.,
Fongshan City,
Kaohsiung County 830, Taiwan
Tel: 886-7-7404469

Fax: 886-7-7635924

Email: Liu_mom@msn.com

http://home.kimo.com.tw/liu_mom/

Taiwan Huntington's Disease Association

1F., No.208, Alley 1, Lane 46, Jinjiang St.,

Jhongjheng District,

Taipei City 100, Taiwan

Email: sbb001@ppts7.seednet

Taiwan Prader-Willi Syndrome Association

3F., No.8-2, Lane 465, Songshan Rd.,

Sinyi District,

Taipei City 110, Taiwan

Tel: 886-2-27253701

Fax: 886-2-23457902

Email: twpws@pchome.com.tw

<http://www.taconet.com.tw/twpws>

Taiwan Tuberous Sclerosis Complex Association

4F., No.14, Lane 147, Baosin Rd.,

Baoshan Township,

Hsinchu County 308, Taiwan

Tel: 886-3-5205184

Email: slshieh@yahoo.com.tw

<http://www.tsc.idv.tw/>

Taiwan Wilson Disease Association

4F., No.57, Wuchang St.,

Jhongshan District,

Taipei City 104, Taiwan

Tel: 886-2-25067678

Fax: 886-2-25028116

Email: aaron.nol@msa.hinet.net

Taiwan Achondroplasia Association

7F., No.7, Lane 49, Sec. 2, Chengtai Rd.,

Wugu Shiang,

Taipei County 248, Taiwan

Tel: 886-2-22924411

<http://mylittlebaby.idv.tw/>

Taiwan Primary Pulmonary Hypertension Association

12F., No.396, Jingping Rd.,

Jhonghe City,

Taipei County 235, Taiwan

Tel: 886-2-8941934

肆、罕見疾病相關「網站資料庫」資料

Newborn Screening related websites

NewbornScreening.com

This site posts articles and news stories submitted by members.

Center for Disease Control (CDC)

National Center for Chronic Disease Prevention and Health Promotion Government Information and Research

National Institutes of Health

Provides Government Information, Articles On Health and links to various health organizations.

American Academy of Pediatrics

Provides online access to AAP's recommendations, research findings and policy statements.

The March of Dimes Birth Defects Foundation

A worldwide organization offering information and programs related to birth defects prevention, health statistics, biomedical research, and improved access to health care for mothers and children.

National Birth Defects Prevention Network (NBDPN)

A national organization of individuals working at the local, state and federal level in birth defects surveillance, research, and prevention.

FODSupport.org

An organization promoting supplemental newborn screening specifically for fatty oxidation and metabolic disorders.

National society of Genetic Counselors

The voice, authority and advocate for the genetic counseling profession.



ORPHANET Websites

ORPHANET is a database dedicated to information on rare diseases and orphan drugs. Access to this database is free of charge.

ORPHANET aims to improve management and treatment of genetic, auto-immune or infectious rare diseases, rare cancers, or not yet classified rare diseases.

ORPHANET offers services adapted to the needs of patients and their families, health professionals and researchers, support groups and industry.

Missions

Orphanet is a database of rare diseases and orphan drugs for all publics. Its aim is to contribute to the improvement of the diagnosis, care and treatment of patients with rare diseases.

Orphanet includes a rare diseases encyclopaedia, which is expert-authored and peer-reviewed, and a directory of services. This directory includes information on specialised outpatient clinics, clinical laboratories, research activities and support groups.

► Organisation

Orphanet is run by a consortium of European partners, the French one being the project manager. Currently the following national teams are actively participating :

Country	Coordinator
Orphanet Austria	Dr Till Voigtländer
Orphanet Belgium	Pr Jean-Pierre Fryns
Orphanet Bulgaria	Pr Emil Simeonov
Orphanet Cyprus	Dr Violetta Anastasiadou
Orphanet Denmark	Pr Karen Brondum-Nielsen
Orphanet Estonia	Pr Andres Metspalu
Orphanet Finland	Pr Helena Kaariainen
Orphanet France	Dr Ségolène Aymé (project manager)
Orphanet Germany	Pr Joerg Schmidtke
Orphanet Greece	Dr Lina Florentin-Arar
Orphanet Hungary	Pr Gyorgyi Kosztolanyi
Orphanet Ireland	Pr Andrew Green and Dr Brendan Buckley
Orphanet Italy	Pr Bruno Dallapiccola

Orphanet Lithuania	Pr Vaidutis Kucinskas
Orphanet Netherlands	Pr Martina Cornel
Orphanet Portugal	Dr Margarida Reis-Lima
Orphanet Romania	Pr Mircea Covic
Orphanet Spain	Dr Miguel Del Campo
Orphanet Switzerland	Dr Loredana d'Amato Sizonenko
Orphanet United-Kingdom	Pr Dian Donnai

The national teams are in charge of collecting information about clinical services, research activity and support groups at the country level. All teams adhere to a [quality charter](#). They also manage the Orphanet encyclopaedia translation into their national languages (optional).

In each country a scientific advisory board has been established. It is in charge of advising the local Orphanet team and of validating the information about services provided in the country before their release.

The coordination team is responsible for maintaining the database and the website, for updating the diseases list and classification, for producing the Orphanet encyclopaedia, for coordinating the national teams effort and of implementing a quality control.

► **Orphanet services**

Orphanet is offering services for all stakeholders: patients and their families, healthcare providers, researchers, industry and regulators.

The Orphanet encyclopaedia is a comprehensive collection of review articles on rare diseases. It is an author-based, peer-reviewed online publication. The encyclopaedia is placed under the scientific responsibility of an [editorial Committee](#). The editorial office is in Paris. All articles are written in English. The abstracts are progressively translated to be available in 6 languages: French, Italian, Spanish, German and Portuguese.

The Orphanet Directory of services provides information on specialised clinics, clinical laboratories, research projects, registries, clinical trials and support groups in connection with rare diseases. The data collection is performed by local teams and validated at the country level. It is still in progress in most participating countries.

The [search by clinical signs](#) is designed to facilitate diagnosis. This service is available exclusively for dysmorphic syndromes (about 2300 syndromes) and not for the entire set of rare diseases.

The [Public Database of Orphan Drugs](#) provides information about drugs with an orphan designation and marketing authorisation in Europe, USA, Japan or Australia.

[OrphanXchange](#) is a database of molecules with a potential orphan indication, and of research projects with an identified potential for being developed for the diagnosis or the treatment of rare diseases. It is intended to speed up the development of diagnostic and therapeutic solutions for rare diseases.

[OrphaNews](#) is the Orphanet bimonthly newsletter, which provides scientific and political information about rare diseases and orphan drugs. It is currently electronically distributed exclusively in French. Registration is free of charge and available on the French home page website. The English version, covering news in the field of rare diseases will be available soon.

A facility allowing patients to [register as a volunteer](#) to participate in research projects, including clinical trials has been designed. This service aims at speeding up the enrolment of patients in clinical research.

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► Orphanet funding

Orphanet was established in 1997 by the French Ministry of Health ([Direction Générale de la Santé](#)) and the [INSERM](#) (Institut National de la Santé et de la Recherche Médicale). Both agencies are still funding the core project.

The European Commission is funding the encyclopaedia and the collection of data in European countries (since 2000 [DG Public Health and Consumers Protection](#) grants No S12.305098; S12.324970; SPC.2002269-2003220 and since 2004 [DG Research](#) grant No LSSM-CT-2004-503246).

Others sponsors are also funding Orphanet services :

- The French Muscular Dystrophy Association ([Association Française contre les Myopathies ; AFM](#)) is sponsoring the OrphaNews letter and the collection of support groups data in France.
- The Social Security System ([Union des Caisses d'Assurance Maladie ; UNCAM](#)) is sponsoring Orphanet website developments and the production of the Rare Disease Orphanet Directory.
- The French pharmaceutical companies association ([Les Entreprises du Médicament; LEEM](#)) is sponsoring the development of the OrphanXchange database and the collection of orphan drugs data.
- [The Foundation 'Groupama pour la santé'](#) is sponsoring online tools and services for patient support groups.

► Orphanet partnerships

Orphanet has established a partnership with [EURORDIS](#), which is a European umbrella organisation of patient support groups.

Likewise, a formal collaboration with [EUROCAT](#), which is a network of registries of congenital malformations, has been set up.

In addition, Orphanet has established partnership agreements at national level. They are described on the relevant national web pages.

► Orphanet users

[Statistics](#) on the number of users visiting the website is accessible for the last 12 months.

Several recent surveys have shown that half of the users are health professionals. Patients and their families account for one third of the users, others being teachers, students, journalists, industry managers or interested people.

Genetics legislation and policy related websites

[Genetic Discrimination Legislation Resources, Genetic Alliance](#)

Provides links to passed and pending bills and legislation related to genetic discrimination in USA.

- [Genetic Privacy Act and Commentary, Boston University School of Public Health \(USA\)](#)

This draft bill was written in 1995 by George Annas to assist policy makers and legislators. Proposes that access to information in genetic data banks should be regulated during sample collection, storage, disclosure, and use. Provides introduction to, contents of, and commentary for the Genetics Privacy Act.

- [Genetics laws and legislative activity, National Council of State Legislatures \(USA\)](#)

Provides links to U.S State Genetic Laws and ongoing legislative activity in areas of embryonic and fetal research, employment, genetic counselor licensing, health insurance, health insurance enforcement, human cloning, insurance, newborn screening, privacy, use/storage/disposition of frozen embryos.

- [Policy Briefs: Current Genetics Issues of the Day, National Council of](#)

State Legislatures (USA)

To encourage information exchange between state legislators, health officials and governors' offices on genetics policy issues.

- Genetics privacy and legislation, US Department of Energy

This site offers up-to-date legislative activity in the U.S regarding genetics and issues of privacy, confidentiality and non-discrimination.

- GEMdatabase

The Genetic Education Materials (GEM) Database is a searchable listing of public health genetics policy documents and clinical genetics educational materials. It is a project of the National Newborn Screening and Genetics Resource Center (NNSGRC) USA.

Human Genetics on the Web

1. Human Genome Central links (<http://www.ensembl.org/genome/central/>)

Resource
Ensemble
National Center for Biotechnology Information
Oak Ridge Genome Channel
BLAST (ensemble , ncbi)
The SNP consortium
OMIM
Gene Map '99
Human genome maps
Human Genome Project Working Draft Sequence
Ethical, Legal, & Social Issues(ornl , nhgri)

2. Clinical and public health genetics

Resource
GeneClinics
Online Mendelian Inheritance in Man
Human Genome Epidemiology Network
Office of Rare Diseases, National Institutes of Health
The Genetics Resource Center
National Cancer Institute's CancerNet
National Newborn Screening & Genetics Resource Center

3. Some for-profit organizations offering clinical genetics information and/or services

Resource
GeneSage
Genetic Health
Genomic Health

4. Genetic testing

Resource
GeneTests
Secretary's Advisory Committee on Genetic Testing
A Question of Genes : Inherited Risks
Understanding Gene Testing

5. Support and advocacy group' web sites

Resource
The Genetic Alliance
National Organization for Rare Disorders
Family Village
Rare Genetic Diseases in Children

<u>The Genome Action Coalition</u>
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<u>Coalition for Genetic Fairness</u>

6. Genetics education for health professionals - web sites

Resource

<u>Genetics : Educational Informtion</u>
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<u>National Coalition for Health Professional Education in Genetics</u>

<u>Clinical Genetics : A Self Study for Health Care Providers</u>

<u>HuGem II</u>

<u>Genetics Program for Nursing Faculty</u>

<u>Foundation for Genetic Education and Counseling</u>
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<u>Information for Genetics Professionals</u>

7. Genetics education for the general public-web sites

Resource

<u>Genetic Science Learning Center</u>
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<u>Gene Almanac</u>

<u>The New Genetics: A Resource for Students and Teachers</u>

<u>The Human Genome Project: Exploring Our Molecular Selves</u>

<u>MendelWeb</u>

<u>Genetics Education Centre</u>
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<u>The DNA Files</u>

<u>Foundations of Classical Genetics</u>
--

8. Ethical, legal, and social issues - web sites

Resource

<u>Bioethics Resources on the Web</u>

<u>The Communities of Color & Genetics Policy Project</u>

<u>The Council for Responsible Genetics</u>

<u>The Gene Media Forum</u>
<u>Genetics & Ethics</u>
<u>Genome Technology and Reproduction : Values and Public Policy</u>
<u>HumGen</u>
<u>National Information Resources on Ethics & Human Genetics</u>
<u>Your Genes Your Choice</u>

9. Genetics professional groups' web sites

Resource
<u>American Board of Genetics Counseling</u>
<u>American College of Medical Genetics</u>
<u>American Society for Human Genetics</u>
<u>Genetics Society of America</u>
<u>International Society of Nurses in Genetics</u>
<u>National Society of Genetic Counselors</u>
<u>Society for the Study of Inborn Errors of Metabolism</u>

10. Genetics Journals - web sites

Resource
<u>Nature Genome Gateway</u>
<u>Genetics in Medicine</u>

11. U.S. Government genetics agencies' web sites

Resource
<u>National Human Genome Research Institute</u>
<u>National Institutes of Health</u>
<u>Department of Energy</u>
<u>Center for Disease Control and Prevention Office of Genetics & Disease Prevention</u>

12. Sites that track or report on what's new in genetics

Resource
The Gene Letter (GeneSage, Inc.)
Genetics and Molecular Medicine Front Page (American Medical Association)
Genomics Today (Pharmaceutical Research & Manufacturers of America)

Health, Birth Defect Prevention Related Websites

[Anencephaly Awareness](#) Possible causes and information for future prevention of this disorder.

[March of Dimes](#) Resources for reducing infant mortality and birth defects. Offers a health library, research, programs and a donation form.

[Tyler For Life Foundation, Inc.](#) Organization providing information on newborn screening and related disorders.

[National Birth Defects Prevention Network](#) Information about the organization, news, publications and upcoming meetings. Links to state monitoring programs, national as well as international. Instructions for joining the email list.

[Arkansas Center for Birth Defects Research and Prevention](#) This organization works to reduce the prevalence of birth defects and their economic, social, and psychological impact in Arkansas and the United States.

[California Fetal Alcohol Spectrum Organization, CalFAS.org](#) Working together to eliminate the disability FASD, Fetal Alcohol Spectrum Disorder by offering information, support and advocates. FASD includes FAS, ARND, ARBD and Static Encephalopathy caused by prenatal alcohol exposure.

[Newborn Screening.Com](#) Regularly updated information and news pertaining to testing and screening. Explanation as to what it is, condition profiles, lab profiles and a discussion forum.

[The Pregnancy Risk Network](#) Offers free telephone information about possible effects that medications, alcohol, illness, on children.

[ObGynWorld: What Route for Delivery?](#) Article reviews research findings on whether vaginal delivery or C-section is better in the case of various congenital anomalies. [Requires free registration.]

[Kiss It Make It Better: Vitamin A and Birth Defects](#) Includes information on possible risks pre-formed vitamin A for a pregnant woman.

[How Folate Can Help Prevent Birth Defects](#) Information from the FDA on the importance of folic acid supplementation before pregnancy.

[Birth Defects and Adverse Birth Outcomes](#) Information about the risks of using alcohol, tobacco, and drugs during pregnancy.

[California Teratogen Information Service](#) CTIS provides free, nonjudgemental information on the effects of drugs, medications, and other exposures on the unborn child.

[Effects of Tobacco Use On the Unborn Baby](#) Summary of a study performed by the Indiana State Department of Health.

伍、世界罕見疾病相關「個人」資料

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Biotechnology, neurosciences and their implications for the concept of human dignity.

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